Mental Health Services Use among School-Aged Children with Disabilities: The Role of Sociodemographics, Functional Limitations, Family Burdens, and Care Coordination

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Objective. To examine the use of mental health services and correlates of receiving services among community-dwelling children with disabilities, ages 6 to 17 years. **Study Design.** Data are from the 1994 and 1995 National Health Interview Survey Disability Supplements (NHIS-D), conducted by the National Center for Health Statistics. The study sample is 4,939 children with disabilities, representing an estimated eight million children with disabilities nationwide. Parents of children under 16 years of age reported (17-year-olds self-reported) on health, emotional and behavioral problems, mental health services use, and who, if anyone, coordinated the child's health care.

Principal Findings. Among disabled children with poor psychosocial adjustment (11.5 percent), only 41.8 percent received mental health services in the past year. Multivariate logistic regression analysis showed service use was associated with poor psychosocial adjustment; communication, social, and learning-related functional impairments; public health insurance; and financial family burdens. Younger and black disabled children were less likely to receive mental health services. The odds of service use were greater with the involvement of a health professional in coordinating care, in contrast to no one or family only. Moreover, children with disabilities were more likely to use outpatient mental health services if their care was jointly coordinated by a family member and a health professional, compared to a health professional working alone. In contrast to inpatient and outpatient care, race and family burden were not associated with the likelihood of mental health counseling in special education school settings.

Conclusions. Findings indicate that only two in five disabled children with poor psychosocial adjustment receive mental health services. Differences by age, race, and insurance coverage suggest that inequalities to access exist. However, the school setting may be one in which some barriers to mental health services for disabled children are reduced. The study also shows that the involvement of health professionals in care coordination is associated with greater access to mental health care for disabled children. These findings underscore the importance of engaging both health care professionals and the family in the care process.

Key Words. Children, disabilities, utilization, mental health services, care coordination, family burden

Children with disabilities or chronic illnesses have been shown to be at increased risk for psychological morbidity (Bennett 1994; Bussing et al. 1995; Drotar 1997; Lavigne and Faier-Routman 1992; Noll et al. 1999; Pless, Roghmann, and Haggerty 1972; Roizen et al. 1996; Witt, Riley, and Coiro 2003), and to have an elevated need for mental health care services. Little is known, however, about access to and use of mental health services among children with disabilities. Few children are identified as having mental health problems in the primary care setting (Brandenburg, Friedman, and Silver 1990; Costello 1986; Costello, Angold, Burns, Stangl et al. 1996; Costello et al. 1988; Lavigne et al. 1993); even among disabled children with poor psychosocial adjustment, most are not identified in primary care, and only a small percentage of those identified receive mental health services (Cadman et al. 1987).

The presence of a psychiatric disorder is a determinant of increased use of mental health services among children (Cunningham and Freiman 1996; Koot and Verhulst 1992; Laitinen-Krispijn et al. 1999; Pfeffer, Plutchik, and Mizruchi 1986; Pottick et al. 1995; Roghmann et al. 1982). The sociodemographic factors most often associated with mental health care use are the child's age (Cohen and Hesselbart 1993), gender (Chabra et al. 1999; Laitinen-Krispijn et al. 1999; Zahner and Daskalakis 1997), race/ethnicity (Chabra et al. 1999; Hoberman 1992), residence (Cohen and Hesselbart 1993), and socioeconomic status (Cohen and Hesselbart 1993; Cunningham and Freiman 1996; Lurie 1974). In addition, family factors such as maternal distress (Garralda, Bowman, and Mandalia 1999) and family conflict and burden (Angold et al. 1998; Briggs-Gowan et al. 2000; Lavigne et al. 1998; Zahner and Daskalakis 1997) have been correlated with children's use of mental health care. Some studies also have indicated that disability status and health problems are important determinants (Cadman et al. 1987; Gortmaker et al. 1990; John et al. 1995; Zahner and Daskalakis 1997).

One factor that may play a role in identification, referral, and access to mental health care for children with disabilities is "care coordination." Coordination of medical care plays a pivotal role in obtaining specialty care for children with special health care needs (Smith, Layne, and Garell 1994; Ziring et al. 1999). Health care providers, predominantly physicians, most often coordinate medical services for children with disabilities (Briskin and

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Liptak 1995; Liptak 1995; Liptak and Revell 1989). Lack of coordination between the medical and mental health sectors is thought to restrict access to needed mental health services for all children (Stroul et al. 1998), as well as children with disabilities and chronic conditions (Sabbeth and Stein 1990).

Family involvement in care coordination also may increase use of mental health services. Family members are often the most knowledgeable about children's health care needs, and can be essential in identifying mental health problems and assisting in the process of obtaining mental health services (Glascoe 2000; Glascoe and Dworkin 1995). In fact, Wildman and colleagues found that parental disclosure of a child's psychosocial problems was a better predictor of physician identification of a mental health problem than the presence of the child's symptoms (Wildman, Kizilbash, and Smucker 1999). Clinical studies also suggest that parent–provider interactions (Garrison et al. 1992) and levels of agreement about treatment increase the likelihood of receipt of services, and often determine the type of setting in which care is delivered to children with mental health problems (Gardner et al. 2000).

Nearly all recent studies of the use of mental health services among children with disabilities have been conducted on convenience samples of families already actively involved with health or mental health care systems in limited geographic areas. This study draws on a nationally representative population-based sample to investigate the factors that are associated with use of mental health care and variations in use by care settings (inpatient, outpatient, and school-based settings) for school-aged children with disabilities. We expect poor psychosocial adjustment, functioning, sociodemographic, and family characteristics to be correlated with overall use and use in each care setting. We hypothesize that the involvement of health professionals in the care coordination process will be associated with increased use of mental health services.

METHODS

Data Source

Data are from the 1994 and 1995 National Health Interview Survey (NHIS) Disability Supplements (NHIS-D). The NHIS is a household survey conducted by the National Center for Health Statistics. The sample for each year is an independent cross-section of the civilian non-institutionalized U.S. population. The population estimates presented here are based on the averaged weighted data for 1994 and 1995, so as to yield a more accurate annual estimate (National Center for Health Statistics 2000).

Study Population

School-aged (6–17 years old) children with disabilities were selected for this study. The NHIS-D relied on a multi-indicator approach to identifying disabled children. The objective was to be sensitive to a wide range of disabilities in both young children and adolescents, and no single indicator or scale was seen as sufficiently comprehensive for purposes of the survey (Simpson 1994). A combination of indicators was used that collected information on: (1) impairments such as those in vision or hearing or requiring prosthetic devices, (2) limitations in age-appropriate activities of daily living, (3) limitations in school attendance or participation due to a chronic condition or impairment, (4) a "very brief" condition list that included Down syndrome, cerebral palsy, cystic fibrosis, and the like, and (5) questions intended to identify children with special ongoing health needs, for example, special diets or regular medications, or ongoing treatment arrangements at home or school. Use of multiple indicators to define the population of disabled children reduces the possibility of misclassifying a disabled child as nondisabled. It also reduces underidentification of children with emotional and cognitive problems (Simpson 1994). Children meeting criteria for disability in the 1994-1995 NHIS-D were re-interviewed to obtain information about their psychosocial adjustment and service use. This study is based on 4,939 children identified as disabled for whom re-interviews were completed (excludes 385 nonrespondents to the re-interview).

Measures

A knowledgeable adult, most often the mother, provided demographic, health, mental health, and utilization-related information about the sample child aged 6–16 years. Children older than 16 years of age were allowed to answer questions about themselves.

Children's Psychosocial Adjustment

The NHIS-D included the Personal Adjustment and Role/Skills Scale (PARS III; hereafter referred to as "PARS") (Stein and Jessop 1990), to measure psychosocial adjustment of children with disabilities or chronic 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 (CBCL) (Achenbach and Edelbrock 1981, 1991), and PARS and CBCL scores are highly correlated (Harris, Canning, and Kelleher 1996). Although the PARS is not a diagnostic instrument, children who score below

the recommended cutoff are highly likely to meet criteria for an emotional or behavioral disorder (Harris, Canning, and Kelleher 1996).

The 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 four-point scale as: never or rarely = 4; sometimes = 3; often = 2; or always = 1. The internal consistency, Cronbach's alpha, for the PARS was .88 or higher in previous studies (Walker, Stein, Perrin, and Jessop 1990) and .93 in our study. Only subjects with at least 70 percent of PARS items were retained (96.3 percent of all cases). Of these, 97 percent reported on all items. The recommended and commonly used cutoff to indicate poor psychosocial adjustment is one standard deviation below the group mean (Pless et al. 1994). Based on the group mean for the study sample (89.5; SD = 17.0), 88.5 percent of children were classified as well-adjusted (score above 72.5) and 11.5 percent as having poor psychosocial adjustment (at or below 72.5). These cut-points for a community population of chronically ill or disabled youth are likely higher than those found in clinical populations, where children tend to be more psychosocially disturbed (Harris, Canning, and Kelleher 1996; Walker, Stein, Perrin, and Jessop 1990).

Child and Family Sociodemographic and Health Characteristics

These characteristics included the child's gender, age (6–10; 11–14; and 15–17 years), race/ethnicity (white non-Hispanic; black non-Hispanic; other non-Hispanic; and Hispanic), and health insurance status (no health insurance, any publicly funded health insurance such as Medicaid or Medicare, and private health insurance only). The highest level of education in the household was categorized as high school and below, high school graduate, 1–3 years of college, or college graduate/postgraduate. Family incomes were classified as above or below 100 percent of poverty using the 1994 and 1995 federal poverty thresholds, which adjust income for family size.

Functional status was assessed in three areas: self-care or mobility in the last 12 months, communication in the last 12 months, and social/learning in the last 2 weeks. Previous research by Hogan et al. (1997a, 1997b) substantiated these as separate domains of functioning in severely disabled populations (Eyman et al. 1990; Eyman, Grossman et al. 1993; Eyman, Olmstead et al. 1993).

Family Burden

The impact of the child's disability on other family members was assessed in three areas: work status (six questions), sleep patterns (one question), and

financial problems (one question).¹ If the respondent indicated in response to any question that the child's disability had ever interfered with work, then a work-related family burden was indicated. Interference with sleeping patterns or financial problems in the last 12 months related to the child's disability was counted as sleep-related and financial family burdens, respectively.

Coordination of Care

Respondents were asked whether a particular doctor, or anyone who is not a doctor, coordinates overall medical care by keeping in touch with the child's doctors or therapists, knowing the results of all tests and treatments, and being aware of the child's prescription medicines. If yes, respondents were asked who does this. Multiple responses were accepted (e.g., doctor, parent, therapist). A second question asked whether a physician or anyone else arranged nonmedical care, like social services and personal care services. Again multiple types could be named as helpers. Based on these questions, care coordination was categorized as: (1) no one coordinates the child's care; (2) family (includes friends) without health professional participation; (3) health professional (doctor, therapist, nurse social worker, case manager, hospital discharge planner) only, with no family participation; and (4) both family and health professional involved in the coordination of care.

Dependent Variables

Inpatient psychiatric or substance abuse care was based on report of an overnight stay in a hospital or other place to receive services for mental health or substance abuse. Outpatient mental health or substance abuse services included services in ambulatory care settings, other than school. For school-based services, parents were first asked about whether their child had received special education services; then, which types of services or benefits their child received, including mental health or counseling services. A summary variable of any mental health care use over the last 12 months was constructed from these three indicators.

Data Analysis

Analyses were conducted using *SUDAAN* (Research Triangle Institute 2001) to correct for the effect on tests of statistical significance of the complex sample design of the NHIS (National Center for Health Statistics 1998). Generalized logit models were fit in two-stages using Generalized Estimating Equations (GEE) (Liang and Zeger 1993; Zeger and Liang 1986) to adjust for the

clustering within the year of administration, strata, primary sampling unit, and children within a household.

Propensity Score

For some sociodemographic and health characteristics, there were significant differences in receipt of any care coordination, and in involvement in care coordination by a health professional (reported below in Results). To adjust for potential confounding of these characteristics on the relationship between care coordination and mental health service use (Rosenbaum 1991), a logistic regression model was used to predict the probability of reporting receipt of care coordination involving a health professional (Little and Rubin 2000; Rubin 1997; Rubin and Thomas 1996). The dependent variable in this model was "no health professional involvement" (no care coordination or family only) versus "any" (health professional alone or with family). Covariates included in the model were those of interest in the utilization model plus additional variables thought to be associated with involvement of a health professional in care coordination.² Estimated propensity scores for each child were developed; these ranged from <.01 to .94.

The difference between children with and without a health professional involved in care coordination was evaluated using receiver-operating-characteristic (ROC) analysis (Zou, Hall, and Shapiro 1997; Zweig and Campbell 1993). The ROC was .65, which indicates "fair" discrimination between the groups. The Hosmer and Lemeshow goodness-of-fit-test p-value equaled .45, indicating the model was a reasonable fit of the observed data (Hosmer and Lemeshow 2000).

Tertiles of "propensity for involvement of a health professional in care coordination"—representing low, medium, and high—were created from the predicted probabilities and entered into the utilization regression models as covariates. Low propensity for care coordination involving a health professional served as the reference category for testing the association of propensity level to mental health care utilization.

Although the sociodemographic, health, and family burden measures were included in the propensity score model, it is appropriate to retain them in the multivariate model to test for associations between these characteristics and mental health service use that are independent of their relationship to involvement of a health professional in care coordination. (The highest level of education in the household was excluded in multivariate models due to multicollinearity.) To test the full models, the Wald, the likelihood ratio test, and the Hosmer and Lemeshow (Lemeshow and Hosmer 1982) goodness-offit measures were used.

RESULTS

Sociodemographics, Health, and Psychosocial Adjustment of Disabled Children

A higher percentage of children with disabilities were male, white, between 6 to 10 years of age, privately insured, and in households with incomes above poverty (Table 1). Social/learning limitations were most common (53.8 percent), followed by communication limitations (27.5 percent); about 10 percent had self-care or mobility limitations. For one in five of these children, a family member indicated the child's disability resulted in a work-related burden. Sleep-related and financial burdens were less common. (Higher prevalence of work-related family burdens may be related to measurement, more items were used to construct this measure, providing more "opportunities" to endorse a work-related burden. Sleep-related and financial burdens were based on single-item indicators.)

There were significant differences in psychosocial adjustment by child and family characteristics as well. Average PARS scores were lower for disabled children who were male, black, and Hispanic, 6 to 10 years of age, with public insurance coverage, poor, and in families with lower educational attainment. Mean PARS scores also were lower for disabled children with functional limitations and children in families where burdens related to the child's disability were reported.

Relationship of Psychosocial Adjustment and Patterns of Care Coordination to Use of Mental Health Services by Children with Disabilities

Across all care settings, 14.3 percent of disabled children received some type of mental health service in the past year (Table 2), most commonly in outpatient settings (10.9 percent). As expected, PARS scores were associated with use of mental health care. Only 1.3 percent of children with PARS scores above the mean by two or more standard deviations used services compared to 39.3 percent and 54.6 percent of those with scores one and two or more standard deviations below the mean, respectively. Children with poor psychosocial adjustment (at least one standard deviation below the overall mean PARS score) represented 11.5 percent of children with disabilities and 41.8 percent of these received some type of mental health treatment.

Patterns of care coordination were related to mental health service use among children. Among those with poor psychosocial adjustment, a lower

		Children with Disabilities (Column %)	Mean PARS Score
TOTAL: Weighted N [in thousands] ¹ (unweighted N)	7,495(4,939)	
TOTAL: Mean PARS (standard dev	viation)		89.5 (17.0)
Child's Sociodemographic Characteristic	\$		
Gender	Male	59.8	88.5
	Female	40.2	90.9*
Race/ethnicity ^a	White (Non-Hispanic)	72.3	90.3
	Black (Non-Hispanic)	14.9	86.4*
	Other (Non-Hispanic)	2.6	90.8
	Hispanic	10.2	87.5*
Age ^b	6-10 years	42.3	88.1
0	11–14 years	35.1	89.2*
	15–17 years	22.7	92.3*
Health insurance status ^c	None	13.7	87.7
	Publicly-funded	27.0	85.2*
	Private	59.3	91.8*
Poverty threshold	100% below	24.1	85.8
,	100% or above	75.9	90.7*
Highest level of education in household ^d			
	College graduate/ postgraduate	25.1	93.1*
	1-3 years of college	25.5	89.7*
	High school graduate	35.9	88.2*
	High school and	13.4	85.6
	below		
Children's Functional Status			
Self-care or mobility limitation	Yes	9.2	82.2*
	No	90.8	90.2
Communication limitation	Yes	27.5	82.8*
	No	72.5	92.0
Social/learning limitation	Yes	53.8	85.0*
0	No	46.2	94.7
Burden of Child's Disability on Family			
Work-related burden	Yes	20.4	82.5*
	No	79.6	91.3
Sleep-related burden	Yes	5.3	77.7*
-	No	94.7	90.1
Financial burden	Yes	4.1	77.9*
	No	95.9	90.0

Table 1:Sociodemographic and Health-Related Characteristics of Childrenwith Disabilities Ages 6 to 17 by Psychosocial Adjustment Status

*Differences in PARS score significant at p < .05. ^aReference category = white (non-Hispanic); ^bReference category = 6–10 years; ^cReference category = uninsured; ^dReference category = High school and below; ¹Annual estimates for U.S. based on averaged weighted data for 1994 and 1995. Excludes 208 disabled children who had fewer than 70% of the items completed on the PARS, and 270 disabled children for whom income was unknown. Table 2: Psychosocial Adjustment Status, Patterns of Care Coordination, and Use of Mental Health Services among Children with Disabilities Ages 6 to 17 Years Overall and by Setting

	Children with Disabilities Ages		Percent Us Health Rela	ring Mental ated Services	
	6–17 (Weighted N in thousands)	All Settings	Inpatient	Outpatient	Special Education
TOTAL: Weighted N					
[in thousands] (unweighted N) Frequency Distribution of PARS	[7,885] (4,939)	14.3	2.3	10.9	5.6
2 SD or more above the	6.7% [498] (316)	1.3	0.0	1.3	0.0
mean					
1 SD above the mean	50.0% [3,748] (2,421)	6.4	0.7	5.1	1.5
Within 1 SD of mean	31.8% [2,385] (1,628)	19.4	2.7	14.9	6.9
1 SD below the mean	9.6% [723] (478)	39.3	8.7	28.8	21.8
2 SD or more below the mean	1.9% [141] (96)	54.6	10.4	40.2	32.0
Coordination of Care by					
Psychosocial Adjustment Status ^{**,b}					
Poor Psychosocial Adjustment*	11.5% [864] (574)	41.8	9.0	30.7	23.5
Coordination of Care***	ι ,				
None	30.7% [265] (173)	34.8	8.0	20.5	17.6
Family only	15.4% [133] (83)	33.0	4.0	21.2	13.7
Physician or health professional only	27.0% [233] (157)	41.6	13.2	32.3	27.3
Both family and physician/ health professional	26.9% [232] (161)	54.9	8.7	46.2	31.9
All Other Coordination of Care***	88.5% [6,631] (4,365)	10.7	1.4	8.3	3.3
None	36.1% [2.391] (1.566)	7.3	1.6	5.8	1.7
Family only	13.5% [894] (598)	10.4	0.8	7.4	3.3
Physician or health professional only	27.0% [1,790] (1,176)	12.0	1.3	9.9	3.7
Both family and physician/ health professional	23.5% [1,556] (1,025)	14.5	1.5	11.1	5.4

^aHigher scores indicate better adjustment. ^bPoor psychosocial adjustment = 1 or more SD below the mean; All other = within 1 SD of the mean or higher.

*Differences in service use by PARS score were statistically significant at p < .05 overall and for each specific type of setting. **Differences in use between children with poor psychosocial adjustment and all others were statistically significant at p < .05 overall and for each specific type of setting. ***Differences in use by patterns of care coordination were statistically significant at p < .05 in all settings except for inpatient services, for children with poor psychosocial adjustment and all others.

percentage used mental health services if they received no care coordination or care coordination from family only, and a higher percentage used services when a physician/health professional was involved. These patterns held for outpatient care and mental health care in special education. Inpatient hospitalization was relatively rare, even among children with poor psychosocial adjustment. Hospitalization was most likely with a physician/health professional only coordinating care (13.2 percent).

Patterns of Coordination of Care

Overall, for 35.4 percent of disabled children, no one was seen as coordinating overall medical care or nonmedical care, such as social services and personal care services (Table 3), and for 13.7 percent, a family member was coordinating care without the involvement of health professionals. In all, half of all disabled children had a physician or other health professional involved in coordinating their care—27.0 percent with a health professional only, and 23.9 percent with both a family member and a health professional involved.

Patterns of care, and in particular receiving no care coordination, or coordination from family only, varied by sociodemographic and health-related characteristics. Unadjusted for other characteristics, no care coordination was more common for disabled children who were black (43.5 percent) and Hispanic (38.8 percent); uninsured (42.4 percent); poor (43.9 percent); and in households with low educational attainment (43.3 percent). Generally these same characteristics were associated with greater reliance on family only. Disabled children with self-care/mobility limitations or communication limitations were more likely to receive care coordination, but children with social/learning limitations were more likely to be without care coordination. Children in families acknowledging burdens related to the child's disability were more likely to receive care coordination than others, but relying on family only for care coordination did not differ significantly by the presence of family burdens or functional status (although children with self-care/mobility limitations were less likely to rely on family only than others).

The associations between patterns of care coordination and sociodemographic characteristics suggest there may be differences in access to care coordination involving health professionals, since no care coordination (or family only) was more common among children who were low-income, without insurance coverage, and in low-education households. At the same time, care coordination patterns also were related to severity of disability—as measured by functional limitations and family burden. The relationship to

Related Characteristics					
				Care Coordination Patterns	
		None	Family Only	Physician or Health Professional Only	Both Family and Physician/Health Professional
TOTAL: Percent (unweighted N)' TOTAL: Mean PARS ^a		$35.4\ (1,739)$ 90.5	$\frac{13.7}{88.5*}$	27.0 (1,333) 89.4	$23.9\ (1,186)\ 88.5^*$
				% Distribution	
Child's Sociodemographic Characteristics					
Gender	Male	35.5	14.7	26.2	23.5
	Female	35.3	12.2	28.2	24.4
Race/Ethnicity ^{b,*}	White (Non-Hispanic)	33.2	12.8	28.3	25.7
~	Black (Non-Hispanic)	43.5	13.8	25.5	17.2
	Other (Non-Hispanic)	37.5	18.7	20.7	23.2
	Hispanic	38.8	18.8	21.9	20.5
Age^c	6-10 years	33.7	14.8	27.8	23.8
)	11-14 years	35.9	13.4	26.4	24.3
	15-17 years	38.0	12.1	26.5	23.4
Health Insurance Status ^{d,*}	None	42.4	15.7	23.0	18.9
	Publicly-funded	37.5	15.2	26.9	20.5
	Private	32.9	12.6	28.0	26.5
Poverty Threshold*	Below 100%	43.9	13.2	25.4	17.6
	100% or above	32.8	13.9	27.5	25.9
Highest Level of Education in	College graduate/	30.5	12.7	28.1	29.8
Household ^{e,*}	post-graduate				
	1–3 years of college	33.7	11.1	29.0	26.1
	High school graduate	37.2	15.3	26.2	21.3

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Table 3: Patterns of Care Coordination among Children with Disabilities Ages 6 to 17 by Sociodemographic and Health-

				Care Coordination Patterns	
		None	Family Only	Physician or Health Professional Only	Both Family and Physician/Health Professional
	High school and below	43.3	16.3	23.3	17.2
Children's Functional Status	D				
Self-care or mobility limitation*	Yes	26.8	10.1	25.9	37.2
×	No	36.3	14.1	27.1	22.5
Communication limitation*	Y_{es}	33.0	14.6	25.9	26.5
	No	36.4	13.4	27.4	22.9
Social/learning limitation*	Y_{es}	36.6	14.6	24.9	23.9
)	No	34.1	12.7	29.4	23.8
Burden of Child's Disability on Family					
Work-related burden*	Y_{es}	22.5	13.8	29.8	33.9
	No	38.8	13.7	26.3	21.3
Sleep-related burden*	Yes	17.9	13.4	33.5	35.2
4	No	36.4	13.7	26.6	23.2
Financial burden*	Yes	15.6	15.1	30.8	38.5
	No	36.3	13.7	26.8	23.2
*All p -values <.05 for differences in *None was used as the reference catege cReference category = 6–10 years. ^d R	care coordination pattern by gory for testing significance o eference category = uninsure	values of soci of PARS by car ed. ^e Reference	odemographic an re coordination p category = High	nd health-related character batterns. ^b Reference catego school and below.	istics. ory = white (non-Hispanic).

Table 3: Continued

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psychosocial adjustment is less clear. The average PARS score for children with no care coordination was higher than for children with care coordination (except for those with only health professional involvement). Even when differences in average PARS scores reached statistical significance, however, the differences were quite small (e.g. 90.5 for no care coordination versus 88.5 for family only). In light of these relationships, it seemed necessary to take into account the potential confounding effects of these and other characteristics on the relationship of care coordination patterns to use of mental health services (use of propensity scores to reflect predicted probabilities of involvement by a health professional in care coordination was described earlier).

Overall Use of Mental Health Services

Disabled children with poor psychosocial adjustment were over three-and-ahalf times more likely to use mental health services taking other factors into account (Table 4). Older disabled children (11 to 15 years) were more likely to receive services, and black (non-Hispanic) children were less likely to have used care in any setting compared to their white (non-Hispanic) counterparts. There were no differences by poverty status controlling for other variables, but children with public insurance coverage were twice as likely to use services as the uninsured. Children with private insurance coverage were at no advantage over uninsured children, however. Controlling for psychosocial adjustment and sociodemographic factors, use of mental health care was associated with communication, social, or learning-related functional limitations and financial burdens related to the child's poor health.

Disabled children with a medium or high, relative to low, propensity for care coordination involving a health professional were at greater odds of service use. Coordination by a health professional alone, or with the involvement of family, also was associated with an increased likelihood that children received mental health services. Coordination by family members alone provided no advantage over no one coordinating care. In addition, the involvement of both family and health professionals was associated with a 26 percent increase in likelihood of use over coordination by a physician/health professional only and a 64 percent increase over coordination by family alone.

Inpatient Hospitalization for Mental Health Treatment

Aside from poor psychosocial adjustment, older age (11 to 17 years) was most strongly associated with inpatient care. Children with publicly funded health insurance were 2.7 times more likely than uninsured disabled children to have

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				Se	tting of Mento	ıl Health C	are		
		V	h	Įnl	atient	Out_{j}	patient	Special	Education
		OR	CI	OR	CI	OR	CI	OR	CI
Psychosocial Adjustment Child Sociodemoeraphics	Poor^a	3.7*	2.9, 4.7	5.3*	3.1, 9.0	3.1*	2.4, 4.1	4.1^{*}	2.9, 5.8
Gender	(male = 1)	1.1	0.9, 1.3	0.8	0.5, 1.3	1.1	0.9, 1.4	1.3^{*}	1.0, 1.8
Child age ^b	15-17	2.1^{*}	1.6, 2.8	11.3*	6.0, 21.5	2.1^{*}	1.5, 2.8	1.5^{*}	1.0, 2.3
0	11–14 TT:	1.5*	1.2, 1.8	4.3*	2.3, 8.0	1.5*	1.1, 1.9	1.3	0.9, 1.8
Child's race/eumcity	ruspanıc Other (non-Hispanic)	0.5 [§]	0.0, 1.2 0.3, 1.0	0.5	0.4, 1.9 0.1, 2.3	0.5	0.2, 1.1 0.2, 1.1	6.0 6.0	0.0, 1.0 0.4, 2.1
	Black (non-Hispanic)	0.7^{*}	0.4, 1.0	1.0	0.5, 2.0	0.5^{*}	0.3, 0.9	1.0	0.6, 1.5
Below 100% of poverty threshold		0.0	0.7, 1.3	0.7	0.3, 1.4	0.9	0.6, 1.3	1.2	0.8, 1.8
Health insurance ^d	Public	2.2^{*}	1.5, 3.3	2.7^{*}	1.1, 6.3	2.4^{*}	1.5, 3.8	1.9^{*}	1.2, 3.1
	Private	1.0	0.7, 1.4	1.1	0.5, 2.2	1.0	0.7, 1.5	0.9	0.6, 1.6
Child Functional Status	Limited functioning in self-care or mobility	0.9	0.7, 1.3	1.0	0.4, 2.4	0.9	0.6, 1.3	1.1	0.7, 1.6
	Limited functioning in communication	1.3^{*}	1.0, 1.7	1.2	0.7, 2.0	I.I	0.8, 1.4	1.9^{*}	1.4, 2.6
	Limited functioning in social/learning	2.7^{*}	2.1, 3.6	1.5	0.9, 2.6	2.4^{*}	1.8, 3.3	4.5^{*}	2.6, 7.8
Burden of Child's Disability on Family	Work-related burden	1.1	0.8, 1.4	1.0	0.5, 1.8	1.0	0.7, 1.4	$1.5^{\$}$	1.0, 2.2
	Sleep-related burden	1.4^{8}	1.0, 2.0	1.8°	1.0, 3.3	1.3	0.9, 2.0	1.1	0.7, 1.9
	Financial burden	2.0^{*}	1.2, 3.3	4.2^{*}	2.1, 8.1	2.5^{*}	1.5, 4.1	1.2	0.7, 2.3
Care Coordination									
Propensity for care coordination in-									
volving a health professional ^e	Medium	1.5^{*}	1.1, 2.0	0.8	0.4, 1.4	1.6^{*}	1.1, 2.2	1.2	0.7, 1.8
, , ,	High	1.9°	1.3, 2.7	0.8	0.4, 1.8	2.1*	1.4, 3.2	L.U	0.8, 2.3
Patterns of care coordination ¹	Family only	1.2	0.8, 1.8	0.4	0.1, 1.1	1.1	0.7, 1.7	1.2	0.7, 1.9
	Physician or health professional only	1.6^{*}	1.1, 2.1	1.1	0.7, 1.8	$1.7^{*,*}$	1.2, 2.4	$1.9^{*^{+}}$	1.2, 2.9
	Both family and physician/health	$2.0^{*,\ddagger,f}$	1.5, 2.6	0.9	0.5, 1.7	$2.0^{*,t}$	1.4, 2.8	$2.5^{*.E}$	1.6, 3.8
	professional								
OR = odds ratio, CI = confidence	e interval.								
^a PARS score >1 SD below the me	ean. ^b Reference category = $6-10$ years. ^c Re	eference ca	tegory = w	hite (no	n-Hispanie	c). ^d Refer	ence categ	ory = un	insured.

Table 4: Odds of Mental Health Services Use in Any Setting among Children with Disabilities Ages 6 to 17 Years

Mental Health Services Use among School-Aged Children

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 $^{\circ}$ Reference category = low propensity. ^fReference category = no one coordinates care. [‡]Family and physician/health professional significantly different from family only care from physician/health professional only. ⁸Borderline significance. [£]Family and physician/health professional significant from family only care coordination. *Physician/health professional only significantly different from family only care cocordination. received inpatient care, but other sociodemographic characteristics were not associated. Financial burdens in the family were associated with a four-fold increase in the likelihood of children's use of inpatient care. Neither levels of propensity for care coordination, nor patterns of coordination, were related to inpatient hospitalization for mental health care.

Outpatient Mental Health Care Use

Besides psychosocial adjustment, use of outpatient services was associated with older age (11–14 and 15–17 years) and coverage by publicly funded health insurance. Black (non-Hispanic) children were half as likely to have used outpatient mental health services as their white (non-Hispanic) counterparts. Having a social or learning-related functional limitation was associated with use of outpatient care, but self-care/mobility and communication functioning were not. Family financial burden, but not sleep or work-related burden, doubled the odds of outpatient service use.

Greater propensity for care coordination (medium or high) increased the likelihood of outpatient service use relative to low propensity. Involvement of a health professional alone, or with family, in care coordination also was correlated with increased use relative to no one coordinating the child's care (and increased use relative to family only care coordination).

Mental Health Counseling in Special Education

Disabled children with poor psychosocial adjustment were four times as likely to receive mental health counseling in the special education setting. Older age (15–17 years), male gender, and public insurance also increased the odds of mental health service use in this setting. Social or learning limitations increased the odds of mental health counseling for disabled children four-fold. Coordination of care by a health professional alone, or by both a family member and health professional, was correlated with the increased likelihood of use, relative to children with no one coordinating care.

Unlike for inpatient and outpatient service use, race/ethnicity was not associated with use of mental health counseling services in special education by disabled children controlling for other factors. Nor was family burden related to use (although work-related burden was borderline).

DISCUSSION

Nationally, among disabled children not living in institutional settings, approximately 11.5 percent had poor psychosocial adjustment, based on a

scale developed to assess emotional and behavioral disorders in children with disabilities (Stein and Jessop 1990). Although the percentage of children with disabilities who used mental health services (14.3 percent) was one-and-a-half times higher than for all children (Shaffer et al. 1996), only about two in five disabled children with poor psychosocial adjustment received mental health care.

There was a strong gradient between PARS scores and use of mental health services, indicating that poor psychosocial adjustment, which reflects emotional and behavioral disorders, exerts a strong influence on likelihood of mental health treatment among disabled children. Even after controlling for psychosocial adjustment, however, a number of other characteristics were associated with mental health service use. Disabled children with functional impairments in communication and social/learning behaviors (but not self-care/ mobility) were more likely to use mental health care. This relationship has been observed in other studies (Cadman et al. 1987; Costello, Angold, Burns, Erklani et al. 1996; Leaf et al. 1996), and may reflect the fact that disabled children with some types of impairments are more likely to interface with the health care system (Newacheck and Halfon 1998) and therefore have greater opportunities for referral to mental health treatment. It is also possible that limitations in communication or social/learning behaviors result in mental health treatment in some children, even if psychosocial adjustment is not in the poor range.

Publicly funded insurance coverage, primarily through Medicaid, was associated with the increased likelihood of inpatient, outpatient, and schoolbased care, compared to being uninsured. Privately insured disabled children were not more likely to use mental health services, however. In a national study in the 1980s of the utilization of medical care by children with special health care needs, children on Medicaid were three times more likely to have seen a physician than their uninsured counterparts, but children with private insurance were no more likely than the uninsured (Aday et al. 1993).

These findings contrast with studies of access to physician care, which typically find both public coverage and private insurance improve access relative to being uninsured (Newacheck et al. 1998; Simpson et al. 1997; Weinick, Weigers, and Cohen 1998). One possible explanation for no increased use of mental health services by privately insured disabled children is that, in contrast to physical health problems where private insurance benefits may be the equivalent of, or more generous than, public coverage, publicly funded coverage of mental health care is subject to fewer limitations or restrictions than in many private plans (Mechanic and McAlpine 1999; Meyers 1994).

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Black disabled children were half as likely to receive outpatient mental health care as white disabled children, as previous studies of children have found (Lavigne et al. 1998; Verhulst and van der Ende 1997). (The absence of findings for Hispanic and other non-Hispanic children relative to white children is likely due to small numbers since the direction of the relationships were consistent and suggested lower likelihood of use as well.) Reasons for this disparity offered by others include financial disadvantage (Cunningham and Freiman 1996), cultural differences in the perception of the value or need for mental health care (Garrison, Roy, and Azar 1999; Padgett et al. 1994), use of alternative informal support services such as family or clergy (Frison, Wallander, and Browne 1998; Neighbors, Musick, and Williams 1998), and active or institutionalized discrimination (Garrison, Roy, and Azar 1999; Martin and Grubb 1990; Padgett et al. 1994). Racial disparities in use of mental health counseling in the special education school setting were not present, however. This is important since it suggests that within the school setting some of the disadvantages that may contribute to racial disparities in receiving mental health care are mitigated.

A financial family burden resulting from a child's disability was associated with a greater likelihood of mental health care use overall, and for inpatient and outpatient care, but not school-based care. Work-related family burdens due to the child's disability, although much more prevalent (20.4 percent versus 4.1 percent for financial burden), were not associated with service use. The relationship of mental health and general health services use to family-related distress has been observed in other studies (Briggs-Gowan et al. 2000; Zahner and Daskalakis 1997). However, the reason for the association of financial burden, but not work or sleep-related burdens, to mental health care use by disabled children is not clear. It is possible that family financial burden is associated with use as a consequence of trying to meet the needs of a disabled child with mental health problems.

Coordination of Care

The findings regarding coordination of care, and the involvement of a health professional in coordination of care, are particularly important and not previously studied. Coordination of care for children with disabilities or chronic conditions, who interact in frequent and complex ways with the health care system, is viewed by many (Brewer et al. 1989; Sabbeth and Stein 1990) as a key factor in timely, effective treatment. Among these disabled children, more than one-third had no one who could be identified as fulfilling the

multiple functions involved in care coordination—keeping in touch with different doctors or therapists, knowing the results of tests and treatments, aware of different prescription medicines, and helping arrange nonmedical care such as social services and personal care services. For an additional 14 percent, a family member without the involvement of a health professional assumed these responsibilities. Children with some types of functional limitation and in families that felt the child's disability created burdens were more likely to have a health professional involved in coordinating care. However, children who were poor, uninsured, black, and in families with low educational attainment were at a disadvantage in this regard.

In gaining access to mental health care, the involvement of a health professional meant disabled children were more likely to obtain services. Involvement of both a family member and a health professional appeared to offer some additional advantage over a health professional alone in likelihood of obtaining outpatient care. Care coordination for a disabled child by the family alone made no difference in use compared to no one coordinating care.

Research indicates that most parents do not discuss their children's behavioral problems with a physician (Briggs-Gowan et al. 2000). Parental reports also indicate that physicians, while helpful with issues directly related to the child's medical condition, typically do not address the impact of the child's condition on his or her emotional or behavioral development or on the needs of the family (O'Sullivan, Mahoney, and Robinson 1992). This has been attributed both to lack of knowledge by medical practitioners about child and adolescent mental health assessment (Stiffman et al. 1997), and to fear of ostracizing the family by raising concerns about a child's mental health (Sabbeth and Stein 1990). Several approaches to fostering care coordination for children with disabilities have been proposed. These include: the training of family members and physicians; building collaborations between the family, medical, psychological, and educational systems of care; supporting family-oriented care; and ensuring adequate reimbursement for providers who actively coordinate the care of children with disabilities. Little is known about the effectiveness of these various approaches, but the results of this study indicate that the involvement of a health professional in care coordination of disabled children has a meaningful impact on access to mental health services, and at least for outpatient care, involvement of both family and a health professional may have added benefits.

Limitations

This study has several limitations in addressing mental health treatment for children with disabilities. These analyses were conducted using cross-sectional data. We have used analytic techniques that reduce confounding of the relationship between care coordination and service use, but the nature of the data necessarily limits causal inferences about the relationships of child characteristics, family burden, and care coordination to mental health service use. In addition, although access to mental health services is a critical issue, equally important is the quality of care for children who are in treatment. Prospective studies are needed, and future research should evaluate both the roles of child and family characteristics and of care coordination patterns on quality of care.

CONCLUSION

Nationally, only about 4 in 10 disabled children with poor psychosocial adjustment received treatment in the mid-1990s. Differences by age, race/ ethnicity, and insurance coverage indicate inequalities in access to treatment. Family burden also plays a role in access to needed care. These findings suggest there is underidentification of need and considerable variability in mental health treatment for children with disabilities. This study also demonstrates, for the first time, that the involvement of a health professional in care coordination may play an important role in improving access to mental health care for this vulnerable group of children with disabilities.

NOTES

- Specifically, work status burden includes: a job not taken in order to care for a child, quitting work, changing jobs or work hours, or turning down a better job or promotion. A sleep-related burden is one where anyone in the family changed sleeping patterns for more than a few nights. Financial burden is indicated by a report of severe financial problems because of the child's health.
- 2. The propensity score model included: child's age, gender, race/ethnicity, health insurance status, functional status, whether they were born in the United States, and the number of acute and chronic conditions. We also included variables on any hospitalization in the past 12 months, the interim between doctor visits (greater than one year or never), respondent perception that the child was disabled, family burdens related to the child's disability, family poverty status, parent education, family size, telephone in the household, region of residence, and residence in a metropolitan statistical area (MSA). Interaction terms were also tested. Included in

the model were interactions between (a) health insurance and region and (b) MSA and region. The propensity score model is not shown in the paper, but is available on request.

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