Child Health Services

Disparities in Use of and Unmet Need for Therapeutic and Supportive Services among School-Age Children with Functional Limitations: A Comparison across Settings

Ruth E. Benedict

Objectives. To determine whether family resources predict use of therapeutic and supportive services and unmet needs in medical versus educational settings.

Data Source. Children 5–17 years of age with at least one functional limitation ($n = 3,434$) from the 1994 to 1995 Disability Supplement to the U.S. National Health Interview Survey.

Study Design. Family resources included the child's type of health insurance, household education level, and poverty status. Therapeutic services included audiology; social work; occupational, physical, or speech therapy. Supportive services included special equipment, personal care assistance, respite care, transportation, or environmental modifications. Need was controlled by child health status and the severity and type of functional limitation(s). Age, gender, race/ethnicity, family size, and structure were covariates.

Data Analysis Methods. Logistic regression provided estimates of associations between family resources and use of or unmet need for therapeutic and supportive services. Multinomial methods were used to determine therapeutic service outcomes in medical versus educational settings.

Principal Findings. Children with public insurance were two to three times more likely to use services than children with private or no insurance regardless of type of service. Household education and public insurance were associated with supportive and therapeutic service use, but for therapeutic services only among children receiving services beyond the school setting. Household education predicted unmet need for both types of services and therapeutic services across settings. Findings should be interpreted cautiously, given the survey's dependence on respondent report to define the need for services and the potential for overrepresentation of children with more severe needs in the public insurance category.

Conclusions. Disparities in the use of services by household education level and by type of health insurance across service settings suggests inequitable access among the U.S. policies and programs serving children with functional limitations. Family income

and education appear to give families an advantage in obtaining services and in identifying a child's unmet need.

Key Words. Child, disability, therapeutic and supportive services, education versus medical setting

Disparity in access to and use of medical services has plagued the U.S. health care system for decades. Children with chronic conditions are particularly vulnerable, given their extensive needs for health and related services. Although Medicaid and the State Children's Health Insurance Program (SCHIP) have improved the system for many children, inequities persist and some children continue to have unmet needs for services (Davidoff, Yemane, and Lesko 2003; Szilagyi et al. 2003; Mayer, Skinner, and Slifkin 2004). Beyond traditional medical services, disparities in access are also apparent in related service use such as mental health treatment, dental services, and care coordination (Weller, Minkovitz, and Anderson 2003; Witt, Kasper, and Riley 2003). Children obtain related services through education as well as health care systems. However, policies and programs vary across service settings and it is not known what effect the different systems have on the use of services or unmet need.

When needed services are not received, children and their families often suffer consequences including poor health, secondary disabilities, or unnecessary limitations in daily activities. The purpose of the study reported here was to determine the extent to which children with special needs and their families use therapeutic and supportive services, how family resources, specifically the child's type of health insurance, household education level, and poverty status, affect service use and unmet need, and whether disparities in therapeutic service use and unmet need persist across service settings. The 1994–1995 Disability Supplement to the National Health Interview Survey (NHIS-DS) provided an unprecedented opportunity for studying the use of therapeutic and supportive services among children with disability.

An estimated 10–14 percent of all U.S. children have impairments in mobility, communication, learning, or self-care abilities that affect their

Address correspondence to Ruth E. Benedict, Dr.PH., OTR/L, Department of Kinesiology, Program in Occupational Therapy, Waisman Center for the Study of Human Development and Developmental Disabilities, School of Education, University of Wisconsin, 123 Waisman Center, 1500 Highland Avenue, Madison, WI 53705.

participation in the home, school, or community activities (Hogan et al. 1997; Newacheck et al. 1998b; Stein and Silver 1999). Therapeutic and supportive services assist children with functional limitations and their families to maximize basic living skills, increase social participation, and improve the quality of their lives. Eligibility for services varies across programs and service settings and depends on criteria such as the child's diagnosis, location, or family income (Morreale and English 2003). In U.S. public schools, Individuals with Disability Education Act Amendments of 1997 (IDEA'97, P.L. 105-17) mandates provision of related services necessary for a child to be educated in the least restrictive environment. Up to three quarters of the children using therapeutic services obtain at least some services in school (Walker et al. 1988; Palfrey et al. 1990). Services to support the family in caring for the child at home or the child's ability to participate in community activities are not included in the education mandate and must be obtained through other means. Thus, while some children may receive services only through the educational system, many children receive at least some therapeutic or supportive services through out-of-school providers.

Children with special needs consume a disproportionate amount of child health care dollars, and some children regularly use services while others do not (Boyle, Decoufle, and Yeargin-Allsopp 1994; Newacheck et al. 1994, 1998b; Ireys et al. 1997; Ray et al. 2000). Therapeutic services are commonly included in health plans but copayments, or restrictions on the amount of services covered, can be barriers to use, and result in unmet need (Walker et al. 1988; Fox, McManus, and Reichman 2002). Supportive services, such as respite care and transportation, are less commonly included as health insurance benefits. Furthermore, some children who would benefit from therapeutic or supportive services do not fulfill the diagnostic criteria required for health insurance reimbursement and must either pay for services out-of-pocket or forego treatment.

The Health Behavior Model (Andersen 1995; Aday et al. 1998) suggests that need, predisposing, and enabling characteristics influence access to health care services. Living in a higher income family or having health insurance promotes the use of medical services (Dubay and Kenney 2001; Silver and Stein 2001). However, little is known about factors that facilitate or impede access to therapeutic and supportive services or whether all needs for services are being met. Previous studies using the NHIS-DS provide evidence that service use and unmet need are associated with predisposing and enabling characteristics of the child and family (Maag 2003; Stein and Silver 2003; Weller, Minkovitz, and Anderson 2003; Witt, Kasper, and Riley 2003). Among

children with chronic conditions, public health insurance and family educational attainment predict the rate of health and related service use (Weller, Minkovitz, and Anderson 2003). Child age and ethnicity are associated with use of some types of services such as mental health but others, such as care coordination, have no apparent relationship. There are, however, limitations to this previous work. Most studies do not distinguish between the types of settings providing services. One exception is Stein and Silver's work (2003), which found that the association between family socioeconomic status and service use varied across traditional medical, special education, or mental health settings. Children living in higher income families used traditional medical services at a higher rate than children living in poverty, while lower income children used special education and mental health services at a higher rate. However, therapeutic services, specifically occupational and physical therapies, were grouped with traditional medical services. Thus, it was not possible to distinguish in what ways factors affecting use of therapeutic services might differ from factors affecting use of other types of services either within or across settings.

Another limitation is that previous studies include all children participating in the NHIS-DS in the analysis of service use. Estimates of health service use will vary according to the chosen operational definition of special need. The NHIS-DS included children experiencing at least one consequence of a chronic condition. However, the need for therapeutic and supportive services is likely to be restricted to a subset of these children. An earlier paper discusses the rationale for focusing on children with functional limitations (Benedict and Farel 2003). Briefly, alternative definitions of special health care needs include children for whom the only consequence of the condition is an elevated use of traditional medical services or prescription drugs with no associated functional implications. It is unlikely that these broader definitions will truly capture the population most likely to benefit from therapeutic and supportive services.

Using data from the 1994 to 1995 NHIS-DS, three questions were addressed. First, is there an association between greater family resources, specifically a child's type of health insurance, family income above poverty level, and household educational attainment and use of therapeutic and supportive services among children with functional limitations? It was expected that children in families with greater resources would be more likely to use services than those in families with fewer resources. Second, is any observed association consistent across service settings? Third, what factors predict unmet need for therapeutic and supportive services, and are there disparities across service settings in the level of unmet need?

METHODS

Data Source

The NHIS is an ongoing, government-conducted, household survey of the noninstitutionalized U.S. population. In 1994–1995, the NHIS included a supplement that collected information on disability status of respondents (NHIS-DS) (Adams and Marano 1995). The survey was conducted in two phases. Phase 1 included core items used routinely in the NHIS and a special set of items related to determination of disability such as specific impairments, functional limitations, use of specialized services, and benefits. The Phase 2 follow-back survey targeted children with disability and included more detailed questions on service use and child function. It was administered 12–18 months after Phase 1, with the preferred respondent being the adult in the household with the most knowledge about the child's health. Information was provided on a total of 41,300 children, ages 5–17, during the Phase 1 interview. Ninety-one percent of the 6,342 children flagged in Phase 1 as having a "disability" participated in Phase 2 (National Center for Health Statistics 1998a, b). For the purposes of this analysis, observations were limited to children identified as having a functional limitation ($N = 3,434$). Conditions causing the functional limitations were not consistently identified but among others, they included cerebral palsy, cystic fibrosis, learning disability, mental retardation, muscular dystrophy, and spina bifida.

Children were classified by type of functional limitation using a scale developed by Hogan et al. (1997). Four key dimensions of functional capacity are delineated including: (1) mobility (i.e., getting in/out of bed or chair, getting around the home, uses special equipment, or problem/delay in physical development); (2) self-care (i.e., difficulty with bathing, dressing, eating, toileting, or personal care); (3) communication/sensory skills (i.e., difficulty communicating, understanding others, problem/delay in speech or language development, difficulty getting along with others); and (4) social cognition/learning ability (i.e., difficulty learning what others of their age can learn, understanding materials, paying attention in class, controlling behavior, problem/delay in mental or emotional/behavioral development, learning disability). A distinct scale was constructed for each dimension, validated, and found to predict disability and societal limitations (Hogan et al. 1997).

Measures

Therapeutic and Supportive Services. Use of or unmet need for therapeutic and supportive services during the past 12 months were the outcomes of interest.

Therapeutic services included reimbursed allied health and related professional services typically provided in rehabilitation, home health, or community-based settings, including audiology; occupational, physical, or speech/language therapy; or social work services. Supportive services were reimbursed program services and products that assist families in the care of a child with functional limitations. Specifically, families reported any special equipment, paid personal care assistance, respite care, transportation services, or environmental modifications used to care for the child. Respondents were asked whether their children needed therapeutic or supportive services that were not received, or whether the family had tried to obtain additional special education services. Services not received because of problems with insurance, a provider, transportation, work responsibilities, or other access issues were considered unmet needs.

Child Need. A child's reported health status, the type, and the severity of his or her functional limitation indicated need for services. Types of limitation included mobility, self-care, communication/sensory, and learning problems. Indicator variables were included in models for each type of limitation. Using the NHIS-DS survey, Hogan et al. (1997) created an ordinal scale to rank the reported difficulty that a child experienced in completing functional tasks (0 = no difficulty to 3 = completely unable). For each type of limitation, the scores were summed to provide a measure of the severity of the functional limitation. Children were categorized according to their most severe limitation.

Family Resources. Children depend on adult family members to determine the need for and to provide the material resources that enable access to services. The highest level of education of family members, in most cases a parent, was categorized as less than, equal to, or greater than 12 years. Family income was coded as "below" or "at or above" the federal poverty level (FPL). Family resources included whether or not the target child had health insurance and, among those having insurance, whether the payment source was a public source or a private plan. Other covariates included family size (4 or fewer versus greater than 4) and family structure (living with two parents, one parent and other adult, one parent only, or other).

Predisposing Characteristics. Disparities in access to health services based on age, gender, and race suggest the need to control for these variables (Newacheck, Hung, and Wright 2002; Smedley, Stith, and Nelson 2002;

Zuvekas and Taliaferro 2003). Access to services is also affected by the availability of providers, the location of training facilities, or reimbursement mechanisms. The NHIS-DS did not include specific measures of these geographically dependent variables. Type of residence (rural versus urban) and region of the country were included as proxy measures of service availability but were determined not to be significant contributors.

Analysis

Records from Phase 1 and Phase 2 of the NHIS-DS for children 5–17 years of age and the corresponding Phase 1 respondent were merged to create a dataset linking child and family information (National Center for Health Statistics 1998a, b). Analyses were completed using *Stata* 7.0, which includes a Taylor-series linearization adjustment procedure for variance estimation to account for the complex survey design (StataCorp 2002). In the final models, sample data were weighted to reflect the age–sex–race distribution of the U.S. child population.

To address the first research question, two separate regression equations provided likelihood estimates of the association between family resources, and (1) use of therapeutic services and (2) use of supportive services. Next, an outcome variable was created for therapeutic services that identified children as having received therapeutic services in the school environment only or at least some services outside of the educational system. It was not possible to create a similar outcome variable for supportive services as some services such as respite care are not typically provided by the schools or the survey did not provide information on use within the school system. Models were fit using multinomial logistic regression to estimate the relative effect of family resources on: (1) use of and (2) unmet need for therapeutic services within and outside of the school setting. Similar models were fit for supportive services, disregarding setting. Independent variables were evaluated for interactions but none were identified or retained in the final models.

RESULTS

Descriptive

Children with functional limitations differed from those without limitations both in terms of service use and demographic characteristics (Table 1). Children with limitations used therapeutic and supportive services and reported unmet needs for services more frequently than children without

Table 1: Estimates of Selected Characteristics of Children with Disability in the U.S. School-Age Population (5–17 years) by Functional Limitation Status, from 1994 to 1995 NHIS-DS Phase 2, Weighted

<i>Weighted N</i>	<i>Children with Functional Limitations (n = 3,464) 4,204,335</i>		<i>Children without Functional Limitations (n = 2,323) 2,865,931</i>	
	<i>%</i>	<i>SE</i>	<i>%</i>	<i>SE</i>
<i>Outcomes</i>				
Use of services				
Therapeutic	32.7	1.0	14.0	0.9
Schools only	5.5		1.8	
Beyond schools	27.1		12.3	
Supportive services	10.1	0.5	6.5	0.5
Unmet need for services				
Therapeutic	14.7	0.7	4.1	0.4
Schools only	7.9	0.6	1.9	0.3
Beyond schools	6.8	0.5	2.2	0.3
Supportive	11.1	0.6	3.2	0.3
<i>Need characteristics</i>				
Child health status				
Excellent–very good	62.2	1.0	62.7	0.3
Good–fair–poor	36.6		36.3	
Severity of limitation				
Moderate–severe	51.9	1.0		
Mild	48.4			
Type of limitation				
Mobility	11.3	0.6		
Self-care	6.5	0.4		
Communication	46.5	0.9		
Learning	89.4	0.6		
<i>Enabling characteristics</i>				
Household education (years)				
< 12	16.6	0.9	11.4	0.8
= 12	38.8	1.0	32.8	1.2
> 12	44.5	1.2	55.6	1.2
Family income				
Below poverty threshold	28.4	1.0	18.8	1.0
At or above threshold	71.6	1.0	81.2	1.0
Child's health insurance				
None	11.9	0.6	9.0	0.6
Private/other	56.0	1.1	73.2	1.1
Public	32.1	1.1	17.8	0.9

continued

Table 1: *Continued*

<i>Weighted N</i>	<i>Children with Functional Limitations (n = 3,464) 4,204,335</i>		<i>Children without Functional Limitations (n = 2,323) 2,865,931</i>	
	<i>%</i>	<i>SE</i>	<i>%</i>	<i>SE</i>
<i>Predisposing characteristics</i>				
<i>Age*(years)</i>				
5–7	20.5	0.7	20.1	0.9
8–10	27.3	0.8	22.9	1.0
11–13	26.0	0.7	22.7	0.9
14–17	26.2	0.9	34.2	1.1
<i>Gender</i>				
Girl	34.2	0.9	47.6	1.1
Boy	65.8		52.4	
<i>Race</i>				
Black, non-Hispanic	17.9	1.0	13.4	0.9
White, non-Hispanic	67.6	1.2	73.7	1.2
Hispanic	11.2	0.7	10.0	0.7
Other	2.9	0.4	2.5	0.4

*Age groupings were based on typical developmental stages (i.e., early elementary school, late elementary school, middle school, and high school).

SE, standard error.

limitations. The two groups varied in terms of gender, race/ethnicity, and age, with a higher percentage of boys, children of non-Hispanic African-American descent, and in the 8–13-year age range among the group with functional limitations. Children with functional limitations more frequently reported enrollment in public health insurance, having family incomes below the poverty threshold, and living in households achieving less than 12 years of education than children without limitations. Larger family size and living in a single-parent household were also more frequently reported among children with limitations (41 and 27 percent, respectively) than among children without limitations (36 and 21 percent, respectively). Among children with functional limitations, an estimated 15 percent have an unmet need for therapeutic services and 11 percent have an unmet need for supportive services. Families of 8 percent of the children with functional limitations reported only trying to obtain additional special education services for their child while an additional 7 percent of families indicated an unmet need for therapeutic services, at least some of which was beyond the school setting.

Determinants of Service Use

Therapeutic Services. The availability of family resources, specifically household education level, having public insurance, and living in a family with more than four members, predicted a child's use of therapeutic services after adjusting for need and predisposing factors (Table 2). Among children obtaining services only at school, none of the enabling factors predicted use of therapeutic services. In contrast, household education, family income, public insurance, and family size predicted use among children obtaining services beyond the school setting. Having a family member educated beyond 12 years doubled the odds of a child with functional limitations using therapeutic services relative to having a household education level of less than 12 years. Children in families living at or above FPL were 40 percent more likely to be using therapeutic services than those whose family income was below FPL. Children with public insurance were 2.4 times more likely to use therapeutic services beyond the school setting than children having no insurance.

As expected, need factors were associated with use of services (Table 2). The severity of the child's functional limitation was associated with therapeutic service use within and outside the school setting. Children with moderate to severe limitations were more likely to be using therapeutic services than children with mild limitations. Communication limitations were predictive of service use in the school setting. Beyond school, children with mobility, self-care, or communication limitations were more likely to use therapeutic services than children without such limitations. A learning limitation was associated with a decreased likelihood of using therapeutic services beyond the school setting. Child health status was related to therapeutic service use beyond but not within the school setting.

Child age was also associated with service use. Younger children were twice as likely to be using services as their older counterparts beyond the school setting. Gender and race/ethnicity were not determinants of therapeutic service use either within or out of school.

Supportive Services. The availability of family resources was associated with use of supportive services (Table 2). Children enrolled in public health insurance were nearly three times as likely to use at least one supportive service as children without health insurance. The odds of using supportive services were increased by 92 percent if a parent had at least 12 years of education. However, poverty level appears not to be a factor in supportive service use. As with therapeutic services, health status and severity of

Table 2: Factors Associated with Service Use for Therapeutic and Supportive Services by Type of Setting among Children with Functional Limitations 5–17 years of age, from 1994 to 1995 NHIS-DS, Weighted

	Service Use			
	Odds Ratio (95% Confidence Interval)			
	Therapeutic Services			
Weighted N	All	School Only (n = 198) 232,028	Out-of-School (n = 944) 1,140,829	Supportive Services (n = 357) 425,934
Need factors				
Child health				
Excellent–very good	—	—	—	—
Good–fair–poor	1.10 (1.02–1.19)	1.05 (0.74–1.51)	1.49 (1.24–1.80)	1.87 (1.37–2.54)
Severity of limitation				
Mild	—	—	—	—
Moderate–severe	1.39 (1.11–1.76)	1.53 (1.05–2.22)	1.35 (1.05–1.74)	1.96 (1.30–2.95)
Type of limitation*				
Mobility	1.69 (1.28–2.23)	1.07 (0.59–1.92)	1.77 (1.32–2.37)	1.43 (0.99–2.07)
Self-care	3.80 (2.47–5.85)	2.14 (1.00–4.58)	3.92 (2.50–6.14)	9.56 (6.31–14.47)
Communication	2.49 (2.01–3.07)	1.86 (1.32–2.62)	2.69 (2.13–3.39)	1.25 (0.93–1.68)
Learning	0.73 (0.54–0.99)	1.72 (0.93–3.21)	0.67 (0.49–0.92)	0.50 (0.31–0.82)
Enabling factors				
Household education (years)				
< 12	—	—	—	—
= 12	1.48 (1.09–2.00)	1.26 (0.92–2.01)	1.59 (1.14–2.23)	1.92 (1.17–3.16)
> 12	1.61 (1.17–2.21)	0.67 (0.41–1.11)	2.11 (1.48–2.99)	2.20 (1.38–3.51)

continued

Table 2: *Continued*

	Service Use			
	Odds Ratio (95% Confidence Interval)			Supportive Services (n = 357) 425,934
	Therapeutic Services			
Weighted N	All	School Only (n = 198) 232,028	Out-of-School (n = 944) 1,140,829	
Family income				
Below poverty threshold	—	—	—	—
At or above poverty threshold	1.33 (1.00–1.78)	1.19 (0.69–2.03)	1.41 (1.03–1.95)	1.39 (0.89–2.16)
Child's insurance				
None	—	—	—	—
Private	1.05 (0.72–1.54)	1.12 (0.60–2.13)	1.08 (0.72–1.62)	1.24 (0.66–2.33)
Public	2.19 (1.57–3.06)	1.70 (0.96–3.03)	2.42 (1.66–3.52)	3.30 (1.70–6.41)
Family structure				
Both parents	—	—	—	—
Single parent	1.14 (0.88–1.48)	1.21 (0.78–1.87)	1.14 (0.86–1.52)	1.05 (0.70–1.56)
Other	1.20 (0.86–1.66)	1.25 (0.70–2.21)	1.13 (0.78–1.63)	1.01 (0.56–1.82)
Family size (members)				
1–4	—	—	—	—
> 4	1.47 (1.19–1.82)	1.36 (0.92–2.01)	1.50 (1.18–1.90)	1.05 (0.74–1.49)
Predisposing factors				
Age (years)				
14–17	—	—	—	—
11–13	1.21 (0.94–1.58)	1.24 (0.78–1.99)	1.20 (0.90–1.62)	0.93 (0.60–1.44)
8–10	1.89 (1.46–2.45)	1.69 (1.10–2.61)	1.97 (1.46–2.66)	0.71 (0.46–1.12)

5-7					
Race/ethnicity	2.13 (1.63-2.78)	0.93 (0.55-1.58)	2.48 (1.84-3.36)	1.07 (0.70-1.64)	
Black, non-Hispanic	—	—	—	—	
White, non-Hispanic	1.13 (0.83-1.55)	0.91 (0.52-1.58)	1.24 (0.89-1.72)	1.30 (0.79-2.13)	
Hispanic	1.04 (0.73-1.50)	1.21 (0.69-2.13)	1.01 (0.69-1.48)	1.15 (0.65-2.02)	
Other	0.98 (0.53-1.78)	1.01 (0.33-3.04)	0.98 (0.53-1.81)	2.48 (0.95-6.52)	
Gender					
Girl	—	—	—	—	
Boy	1.04 (0.87-1.24)	1.04 (0.72-1.49)	1.05 (0.87-1.26)	1.07 (0.79-1.43)	

*Comparison group for each category is children whose functional limitation is of a different type.

Bold type denotes significant predictor of outcome.

—, referent category having risk = 1.

limitations were significant determinants of service use. Children with self-care limitations were 9.5 times as likely to use supportive services as those without. Having a learning limitation was associated with a decreased likelihood of using these services. Predisposing factors, including age, gender, and ethnicity, did not predict use of supportive services.

Determinants of Unmet Need

Household education level predicted unmet need for supportive and therapeutic services, regardless of setting (Table 3). Families with at least one member educated beyond 12 years were twice as likely to report unmet needs for supportive and therapeutic services, as families with members having less than 12 years of education. For therapeutic services, an unmet need was associated with a child's health status and with the severity of the child's condition among children whose need was restricted to the school setting. An unmet need for supportive services was associated with the severity of the child's condition and poor health. Mobility and self-care limitations predicted an unmet need for supportive and for therapeutic services beyond, but not within, the school setting. Race and ethnicity, although not associated with use of services, were associated with unmet need.

DISCUSSION

Studies of disparities in medical care access have typically focused on traditional measures of health service use such as hospitalizations, physician, or emergency room visits and have not captured the range of health and related services required by children with special needs and their families (Newacheck et al. 1998a, 2000b, 2001). The findings of the study reported here suggest that disparities exist in the use of therapeutic and supportive services but that patterns of disparity are not consistent across medical and educational settings. Public health insurance predicted greater use of supportive services and therapeutic services outside of the school setting, a finding that may be attributable to the commitment of public programs to serve vulnerable populations such as children with special needs (Davidoff, Yemane, and Lesko 2003). However, as need was determined based on respondent report, the accuracy of the measure is unknown. Children with more severe functional limitations may be overrepresented in the public insurance category, thus resulting in greater need among this population. Further research is needed to shed light on the association between public insurance, need, and service use.

Table 3: Factors Associated with Unmet Need for Therapeutic and Supportive Services among Children with Functional Limitations 5–17 years of age, from 1994 to 1995 NHIS-DS, Weighted

<i>Weighted N</i>	<i>Unmet Needs</i> <i>Odds Ratio (95% Confidence Interval)</i>		
	<i>Therapeutic Services</i>		
	<i>School Only</i> <i>(n = 264)</i>	<i>Out-of-School</i> <i>(n = 248)</i>	<i>Supportive Services</i> <i>(n = 377)</i>
	331,348	284,835	465,962
<i>Need factors</i>			
Child health			
Excellent–very good	—	—	—
Good–fair–poor	1.51 (1.11–2.06)	1.30 (0.93–1.82)	1.55 (1.14–2.10)
Severity of limitation			
Mild	—	—	—
Moderate–severe	1.49 (1.06–2.08)	1.04 (0.74–1.47)	2.27 (1.54–3.35)
Type of limitation*			
Mobility	0.91 (0.58–1.42)	1.60 (1.03–2.50)	1.73 (1.21–2.48)
Self-care	1.08 (0.60–1.95)	1.92 (1.16–3.17)	5.94 (4.01–8.80)
Communication	1.37 (0.99–1.89)	1.88 (1.11–3.20)	1.37 (0.99–1.88)
Learning	1.60 (0.89–2.87)	0.95 (0.58–1.55)	0.79 (0.47–1.33)
<i>Enabling factors</i>			
Household education (years)			
< 12	—	—	—
= 12	1.20 (0.74–1.96)	1.62 (0.99–2.67)	1.53 (0.95–2.48)
> 12	2.02 (1.18–3.47)	1.92 (1.14–3.23)	2.19 (1.33–3.62)
Family income			
Below poverty threshold	—	—	—
At or above poverty threshold	1.07 (0.73–1.57)	1.30 (0.83–2.04)	1.58 (1.06–2.34)
Child's insurance			
None	—	—	—
Private	0.75 (0.47–1.19)	0.81 (0.47–1.40)	0.62 (0.39–0.99)
Public	1.07 (0.67–1.70)	1.05 (0.59–1.87)	1.43 (0.87–2.34)
Family structure			
Both parents	—	—	—
Single parent	1.02 (0.69–1.50)	1.04 (0.71–1.53)	0.98 (0.68–1.44)
Other	1.26 (0.74–2.14)	0.80 (0.45–1.41)	0.77 (0.47–1.26)
Family size (members)			
1–4	—	—	—
> 4	0.99 (0.71–1.39)	0.90 (0.63–1.28)	0.81 (0.62–1.05)
<i>Predisposing factors</i>			
Age (years)			
14–17	—	—	—
11–13	0.74 (0.50–1.08)	1.06 (0.71–1.59)	1.03 (0.71–1.51)
8–10	0.84 (0.57–1.23)	1.05 (0.69–1.59)	1.26 (0.86–1.86)
5–7	1.05 (0.69–1.60)	1.17 (0.73–1.88)	1.27 (0.84–1.93)

continued

Table 3: *Continued*

<i>Weighted N</i>	<i>Unmet Needs Odds Ratio (95% Confidence Interval)</i>		
	<i>Therapeutic Services</i>		
	<i>School Only (n = 264) 331,348</i>	<i>Out-of-School (n = 248) 284,835</i>	<i>Supportive Services (n = 377) 465,962</i>
Race/ethnicity			
Black, non-Hispanic	—	—	—
White, non-Hispanic	1.17 (0.78–1.75)	0.69 (0.44–1.08)	0.72 (0.48–1.07)
Hispanic	1.08 (0.65–1.82)	0.81 (0.45–1.45)	0.49 (0.28–0.86)
Other	1.09 (0.43–3.12)	0.22 (0.06–0.87)	0.91 (0.36–2.30)
Gender			
Girl	—	—	—
Boy	1.26 (0.93–1.69)	1.19 (0.87–1.63)	1.21 (0.91–1.61)

*Comparison group for each category is children whose functional limitation is of a different type.
 Bold type denotes significant predictor of outcome.

—, referent category having risk = 1.

In contrast to public insurance, private insurance provided children no advantage in accessing therapeutic and supportive services relative to their uninsured counterparts. Children with private insurance were less likely than those with public coverage to use therapeutic services if their need extended beyond the school setting. The type and extent of services covered by Medicaid are known to exceed private plans (Newacheck et al. 1994; Shatin et al. 1998; Ray et al. 2000; Dubay and Kenney 2001; Fox and McManus 2001). Private plans differ widely in the degree to which they provide access to therapeutic and supportive services. Many managed care plans do not cover supportive services or impose restrictions on access to therapeutic services by requiring preauthorization, limiting definitions of medical necessity, or placing caps on the frequency and duration of services (Fox and McManus 2001). Managed care had just begun to penetrate state Medicaid programs at the time of the NHIS-DS and, in many cases, children with special needs were covered through “carve-out” arrangements in which needed services are reimbursed through alternative arrangements, thus providing added protection for publicly insured children (Deal and Shiono 1998; Szilagyi 1998). Given the disadvantage that children covered by private insurance appear to have in access to therapeutic and supportive services, it seems important to explore models of coverage or an expansion of public programs that will ensure access to needed services.

Children having no insurance are at a distinct disadvantage in accessing therapeutic and supportive services. In an attempt to provide health insurance to a significant proportion of the nation's uninsured children, Congress implemented the SCHIP in 1997. SCHIP appears to promote access to at least some therapeutic and supportive services in many, but not all, states (Fox, McManus, and Limb 2000; Hill, Lutzky, and Schwalberg 2001; Fox, Levtoy, and McManus 2003). However, benefits are primarily aimed at services provided after acute illness or injury, and coverage of longer-term conditions such as those experienced by children with functional limitations is not common. Further research is needed to determine whether children are actually using therapeutic and supportive services at a higher rate as a result of enrollment in SCHIP. The National Survey of Children with Special Health Care Needs (NSCSHCN) includes information on enrollment in SCHIP for 750 children with special needs in each state. Using the NSCSHCN, Mayer, Skinner, and Slifkin (2004) examined the prevalence of unmet need for routine and specialty physician care. Some of the findings are consistent with those of studies based on NHIS-DS data, namely that income is associated with disparities in service use. Another study by Dusing, Skinner, and Mayer (2004) found that children from low-income families are more likely to report unmet needs for eyeglasses, hearing aids, or communication aids and devices than children from higher income families. Lack of insurance was associated with unmet need for therapy services or mobility devices, a result consistent with the findings presented here. The NSCSHCN may shed some light on the relationship between lack of insurance, SCHIP, and use of therapeutic and supportive services. However, there are several limitations that prevent an analysis comparable with the one reported here. The NSCSHCN is less comprehensive than the NHIS-DS with regard to: (1) type and severity of functional limitation, (2) inclusion of the breadth of therapeutic and supportive services, or (3) access to special education resources.

Household income was associated with use of therapeutic services beyond school but not among children who were only using school services. Public schools mandate that children identified as having a special educational need to receive related services, a policy that appears to eliminate or reduce inequities in access to and use of therapeutic services. Beyond the school setting, however, therapeutic and supportive services are generally accessed through a combination of health insurance plans, out-of-pocket expenses, or community-based service programs with varying financial arrangements. As noted above, insurance plans frequently place limits on reimbursement for services. Families must pay for uncovered services out of pocket or find other

alternatives. This is particularly problematic for families with limited financial resources or for children requiring long-term or ongoing therapies to maintain or improve their functional status. Thus, gaining access to services beyond the school setting may be dependent on having a higher income, or at least, knowing more about the service system and how to access resources.

A high level of education in the household increased the likelihood that a child would be reported to be using supportive services and therapeutic services beyond the school setting. Having an unmet need for supportive or therapeutic services was also associated with a high level of education, regardless of setting, a finding consistent with the findings of Newacheck et al. (2000a) of more traditional medical services. In their paper, they argue that the family must first recognize a problem and then make an effort to seek help in order for a need to be met. Education may contribute to greater knowledge of health conditions, their consequences, and the availability of services. Parents of children with functional limitations, particularly those related to communication, behavior, or learning, often must advocate for services when the child does not meet traditional categorical eligibility criteria. The success of these advocacy efforts is dependent on having knowledge of the interventions or supports available for managing the child's condition and what must be done to gain access. Families that are knowledgeable about a child's condition, the signs and symptoms requiring intervention, and how the service system works may be more likely to recognize a need and advocate for services to be provided. However, further investigation is needed to clarify the nature of the association observed here. It is also possible that reports of unmet need are biased by recall or parent willingness to report.

Using data from the NHIS-DS, Maag (2003) concluded that for the population of children needing supportive services, health insurance alone does not ensure access. As with service use, overrepresentation of children with more severe functional limitations or poorer health status in the population of publicly insured may explain some of the increase in unmet need. For example, results of the study reported here suggest that children with self-care limitations, usually associated with more severe disabilities, were two to 10 times more likely to both use services and have an unmet need than children with other types of limitations.

The NHIS-DS provides an insight into the use of and unmet need for therapeutic and supportive services. Nevertheless, the cross-sectional nature of the data prevents determination of causal relationships between the various predictors and service use. Questions on the survey regarding service use and limitations of function were not exhaustive, which may contribute to either

selection bias or inaccurate representation of outcomes. Some variables having the potential to affect service use, such as the amount of informal social support provided to a family, were not measured. Future research would benefit from data collection methods that include direct measures of child health and function and documented service provision.

The findings presented here clearly demonstrate the need for greater access to therapeutic and supportive services among children with functional limitations. Further, disparities in use of services are apparent across type of health insurance, level of family income, and household educational attainment. Particularly evident among children using therapeutic services are disparities in access to services in the health care arena as opposed to that in an educational setting. The findings have implications for policies that will protect children whose full participation in society is compromised by limitations in functional ability. Policies that promote access to therapeutic and supportive services have the potential to benefit some of our most vulnerable children and their families. Current initiatives, such as SCHIP or the Family Opportunity Act of 2005 (Senate Bill 183), are intended to help families of disabled children access needed health and related services. What remains to be seen is whether such initiatives provide all children and families equitable access to therapeutic and supportive services and eliminate unmet needs.

ACKNOWLEDGMENTS

The author is grateful to Anita M. Farel, Dr.PH., for mentoring and support during the early stages of this work. The author also thanks colleagues at the University of Wisconsin, two anonymous reviewers, and the editors for their comments and suggestions, which improved the paper. This work was supported in part by the Graduate School and the Waisman Center for Human Development and Developmental Disabilities at the University of Wisconsin.

The author reports no financial or other conflicts of interest, nor any disclaimers related to this study and paper.

REFERENCES

- Adams, P. F., and M. A. Marano. 1995. *Current Estimates from the National Health Interview Survey, 1994*. Hyattsville, MD: National Center for Health Statistics.
- Aday, L. A., C. E. Begley, D. R. Lairson, and C. H. Slater. 1998. *Evaluating the Healthcare System: Effectiveness, Efficiency, and Equity*. Chicago: Health Administration Press.

- Andersen, R. M. 1995. "Revisiting the Behavioral Model and Access to Medical Care: Does It Matter?" *Journal of Health and Social Behavior* 36 (1): 1–10.
- Benedict, R. E., and A. M. Farel. 2003. "Identifying Children in Need of Ancillary and Enabling Services: A Population Approach." *Social Science and Medicine* 57 (11): 2035–47.
- Boyle, C. A., P. Decoufle, and M. Yeargin-Allsopp. 1994. "Prevalence and Health Impact of Developmental Disabilities in U.S. Children." *Pediatrics* 93 (3): 399–403.
- Davidoff, A. J., A. Yemane, and J. Lesko. 2003. "Insurance Coverage for Children with Special Health Care Needs." Proceedings of the AcademyHealth Annual Research Meeting, June 27–29, 2003. Nashville, TN.
- Deal, L. W., and P. H. Shiono. 1998. "Medicaid Managed Care and Children: An Overview." *Future of Children* 8 (2): 93–104.
- Dubay, L., and G. M. Kenney. 2001. "Health Care Access and Use among Low-Income Children: Who Fares Best?" *Health Affairs* 20 (1): 112–21.
- Dusing, S. C., A. C. Skinner, and M. L. Mayer. 2004. "Unmet Need for Therapy Services, Assistive Devices, and Related Services: Data from the National Survey of Children with Special Health Care Needs." *Ambulatory Pediatrics* 4 (5): 448–54.
- Fox, H. B., R. Levto, and M. A. McManus. 2003. *Eligibility, Benefits, and Cost Sharing in Separate SCHIP Programs*. Washington, DC: Maternal and Child Health Policy Research Center, Fox Health Policy Consultants.
- Fox, H. B., and M. A. McManus. 2001. "A National Study of Commercial Health Insurance and Medicaid Definitions of Medical Necessity: What Do They Mean for Children?" *Ambulatory Pediatrics* 1 (1): 16–22.
- Fox, H. B., M. A. McManus, and S. J. Limb. 2000. *Access to Care for S-CHIP Children with Special Health Needs*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured.
- Fox, H. B., M. A. McManus, and M. B. Reichman. 2002. *The Strengths and Weaknesses of Private Health Insurance Coverage for Children with Special Health Care Needs*. Washington, DC: Maternal and Child Health Policy Research Center.
- Hill, I., A. W. Lutzky, and R. Schwalberg. 2001. *Are We Responding to Their Needs? States' Early Experiences Serving Children with Special Health Care Needs under SCHIP*. Washington, DC: The Urban Institute.
- Hogan, D. P., M. E. Msall, M. L. Rogers, and R. C. Avery. 1997. "Improved Disability Population Estimates of Functional Limitation among American Children Aged 5–17." *Maternal and Child Health Journal* 1 (4): 203–13.
- Ireys, H. T., G. F. Anderson, T. J. Shaffer, and J. M. Neff. 1997. "Expenditures for Care of Children with Chronic Illnesses Enrolled in the Washington State Medicaid Program, Fiscal Year 1993." *Pediatrics* 100 (2, part 1 of 2): 197–204.
- Maag, E. 2003. "Unmet Supportive Service Needs of Children with Disabilities." In *Using Survey Data to Study Disability: Results from the National Health Interview Survey on Disability*, edited by B. M. Altman, S. N. Barnartt, G. E. Hendershot, and S. A. Larson, pp. 157–83. Oxford, UK: Elsevier Ltd.
- Mayer, M. L., A. C. Skinner, and R. T. Slifkin. 2004. "Unmet Need for Routine and Specialty Care: Data from the National Survey of Children with Special Health Care Needs." *Pediatrics* 113 (2): e109–15.

- Morreale, M. C., and A. English. 2003. "Eligibility and Enrollment of Adolescents in Medicaid and SCHIP: Recent Progress, Current Challenges." *Journal of Adolescent Health* 32 (6, suppl): 25-39.
- National Center for Health Statistics. 1998a. *Data File Documentation, National Health Interview Survey on Disability, Phase 1 and Phase 2, 1994 (Machine Readable Data File and Documentation, CD-ROM Series 10, No. 8a)*. Hyattsville, MD: National Center for Health Statistics.
- . 1998b. *Data File Documentation, National Health Interview Survey on Disability, Phase 1 and Phase 2, 1995 (Machine Readable Data File and Documentation, CD-ROM Series 10, No. 10a)*. Hyattsville, MD: National Center for Health Statistics.
- Newacheck, P. W., D. C. Hughes, Y.-Y. Hung, S. Wong, and J. J. Stoddard. 2000a. "The Unmet Health Needs of America's Children." *Pediatrics* 105 (4, part 2 of 2): 989-97.
- Newacheck, P. W., Y.-Y. Hung, K. S. Marchi, D. C. Hughes, C. Pitter, and J. J. Stoddard. 2001. "The Impact of Managed Care on Children's Access, Satisfaction, Use, and Quality of Care." *Health Services Research* 36 (2): 315-34.
- Newacheck, P. W., D. C. Hughes, J. J. Stoddard, and N. Halfon. 1994. "Children with Chronic Illness and Medicaid Managed Care." *Pediatrics* 93 (3): 497-500.
- Newacheck, P. W., Y. Y. Hung, and K. K. Wright. 2002. "Racial and Ethnic Disparities in Access to Care for Children with Special Health Care Needs." *Ambulatory Pediatrics* 2 (4): 247-54.
- Newacheck, P. W., M. McManus, H. B. Fox, Y.-Y. Hung, and N. Halfon. 2000b. "Access to Health Care for Children with Special Health Care Needs." *Pediatrics* 105: 760-6.
- Newacheck, P. W., J. J. Stoddard, D. C. Hughes, and M. Pearl. 1998a. "Health Insurance and Access to Primary Care for Children." *New England Journal of Medicine* 338 (8): 513-9.
- Newacheck, P. W., B. Strickland, J. P. Shonkoff, J. M. Perrin, M. McPherson, M. McManus, C. Lauver, H. Fox, and P. Arango. 1998b. "An Epidemiologic Profile of Children with Special Health Care Needs." *Pediatrics* 102 (1): 117-23.
- Palfrey, J. S., J. D. Singer, E. S. Raphael, and D. K. Walker. 1990. "Providing Therapeutic Services to Children in Special Educational Placements: An Analysis of the Related Services Provisions of Public Law 94-142 in Five Urban School Districts." *Pediatrics* 85 (4): 518-25.
- Ray, G. T., T. Lieu, R. M. Weinick, J. W. Cohen, B. Fireman, and P. Newacheck. 2000. "Comparing the Medical Expenses of Children with Medicaid and Commercial Insurance in an HMO." *American Journal of Managed Care* 6 (7): 753-60.
- Shatin, D., R. Levin, H. T. Ireys, and V. Haller. 1998. "Health Care Utilization by Children with Chronic Illnesses: A Comparison of Medicaid and Employer-Insured Managed Care." *Pediatrics* 102 (4): E44.
- Silver, E. J., and R. E. Stein. 2001. "Access to Care, Unmet Health Needs, and Poverty Status among Children with and without Chronic Conditions." *Ambulatory Pediatrics* 1 (6): 314-20.

- Smedley, B. D., A. Y. Stith, and A. R. Nelson. 2002. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: Institute of Medicine, National Academies Press.
- StataCorp. 2002. *Stata Statistical Software: Release 7.0*. College Station, TX: Stata Corporation.
- Stein, R. E., and E. J. Silver. 2003. "Patterns of Medical, Educational, and Mental Health Service Use in a National Sample of U.S. Children." *Ambulatory Pediatrics* 3 (2): 87-92.
- Stein, R. E. K., and E. J. Silver. 1999. "Operationalizing a Conceptually Based Non-categorical Definition: A First Look at U.S. Children with Chronic Conditions." *Archives of Pediatric and Adolescent Medicine* 153: 68-74.
- Szilagyi, P. G. 1998. "Managed Care for Children: Effect on Access to Care and Utilization of Health Services." *Future of Children* 8 (2): 39-59.
- Szilagyi, P. G., E. Shenkman, C. Brach, B. J. LaClair, N. Swigonski, A. Dick, L. P. Shone, V. A. Schaffer, J. F. Col, G. Eckert, J. D. Klein, and E. M. Lewit. 2003. "Children with Special Health Care Needs Enrolled in the State Children's Health Insurance Program (SCHIP): Patient Characteristics and Health Care Needs." *Pediatrics* 112: e508-20.
- Walker, D. K., J. S. Palfrey, J. A. Butler, and J. Singer. 1988. "Use and Sources of Payment for Health and Community Services for Children with Impaired Mobility." *Public Health Reports* 103 (4): 411-5.
- Weller, W. E., C. S. Minkovitz, and G. F. Anderson. 2003. "Utilization of Medical and Health-Related Services among School-Age Children and Adolescents with Special Health Care Needs (1994 National Health Interview Survey on Disability [NHIS-D] Baseline Data)." *Pediatrics* 112 (3): 593.
- Witt, W. P., J. D. Kasper, and A. W. Riley. 2003. "Mental Health Services Use among School-Aged Children with Disabilities: The Role of Sociodemographics, Functional Limitations, Family Burdens, and Care Coordination." *Health Services Research* 38 (6, part 1): 1441-66.
- Zuvekas, S. H., and G. S. Taliaferro. 2003. "Pathways to Access: Health Insurance, the Health Care Delivery System, and Racial/Ethnic Disparities, 1996-1999." *Health Affairs* 22 (2): 139-53.