Access to Care for Disabled Children Under Medicaid

Sharon K. Long, Ph.D. and Teresa A. Coughlin, M.P.H.

This article examines differences in access and use of care among children on Medicaid with physical disabilities, mental illness, and mental retardation/development disabilities (MR/DD) in New York City (NYC). We use 1999 and 2000 survey data obtained from the parents of a random sample of disabled children on Medicaid to conduct both descriptive and multivariate analyses. We find that the Medicaid Program has been successful at linking disabled children to health care providers. However, there is evidence of greater access problems for some subgroups of disabled children. Improving access for disabled children under the Medicaid Program will require targeted help to specific groups of children.

INTRODUCTION

Medicaid provides health care to one-third of all disabled children and 7 out of 10 poor disabled children (Bruen and Holahan, 2001). Not surprisingly, disabled children on Medicaid use significantly more health care services than healthy children. They also require services far beyond basic preventive and primary care, needing care from an array of providers including medical specialists, therapists and social service agencies. Consistent with their greater service use, caring for disabled children is much more costly. One recent study estimated that Medicaid costs for children with chronic disabilities were six times greater than other children on Medicaid and accounted for about 75 percent of total Medicaid expenditures on children (Allen and Croke, 2000). If recent trends persist, disabled children will likely account for a bigger share of the Medicaid costs in the future: Over the past decade, the disabled—both adults and children—were the fastest growing enrollment group in Medicaid (Bruen and Holahan, 2001).

While the challenges of accessing care under the Medicaid Program are well-documented for the overall Medicaid population, very little is known about access to care for children with special health care needs, including how access differs for children with mental and physical disabilities (Allen and Croke, 2000; Shalala, 2000). State administrative data provide little or no information on the beneficiary's disabling condition and surveys of Medicaid beneficiaries seldom include large enough samples of disabled children to provide information on their health care experiences. Given the vulnerability of children with special health care needs and their high costs under the Medicaid Program, a better understanding of the needs and experiences of these children is needed. This article uses data from a survey of blind and disabled Medicaid children living in NYC to address that information gap. Specifically, it explores the health care experiences of children who are eligible for Medicaid by virtue of receiving Supplemental Security Income (SSI), the Federal program that provides cash assistance to needy aged, blind, and severely

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The authors are with the Urban Institute. The research in this article was supported by the Centers for Medicare & Medicaid Services (CMS) under Contract Number 500-95-0040 and by the Center for Health Care Strategies, Inc., under Contract Number ML-595,9945. The statements expressed in this article are those of the authors and do not necessarily reflect the views or policies of the Urban Institute, CMS, or the Center for Health Care Strategies, Inc.

disabled individuals. We examine differences in access and use of care among children on Medicaid with physical disabilities, mental illness, and MR/DD. To our knowledge, this is the first article to document access and use within the population of disabled children on Medicaid.

Having some understanding of the health care experiences of disabled children is important. Among other things, this information can help identify gaps in the current Medicaid Program, specifically whether particular groups of children are having problems getting access to particular types of care. Further, knowing more about the population will help Medicaid policymakers as they develop managed care programs for disabled beneficiaries, an idea that is being pursued by a number of States (Regenstein and Anthony, 1998).

METHODOLOGY

Data

New York Survey of Disabled Medicaid Beneficiaries

Our sample of blind and disabled child SSI beneficiaries (hereafter referred to as disabled children) is obtained from the New York Survey of Disabled Medicaid Beneficiaries, which was fielded in NYC in 1999-2000. New York was selected for study because of plans by the State to implement mandatory capitated Medicaid managed care for disabled beneficiaries in the future. The survey will provide a baseline for evaluating the impacts of the planned shift to mandatory managed care on disabled beneficiaries. The randomly selected sample of Medicaid beneficiaries was identified through State enrollment records for the Medicaid Program, with information on the primary disabling condition under SSI obtained through a match with Social Security Administration records for the SSI program. (The primary disabling condition represents the disabling condition that most readily qualified the child for the SSI program.) Child SSI beneficiaries in institutions, those receiving long-term care services in the community under Medicaid waiver programs, the homeless, and those receiving Medicare were excluded from the survey. At the time of the survey, approximately 15 percent of the SSI children were voluntarily enrolled in Medicaid managed care. Most of those were individuals who had entered Medicaid managed care while enrolled in the Temporary Assistance to Needy Families program and continued in managed care after their eligibility for SSI was established.

The survey collected information from the child's parent (or guardian) on the child's access to and use of health care. Information on the child's socioeconomic circumstances, health status, and disability information was also collected. Interviews were conducted by telephone using computer assisted telephone interviewing. In attempt to obtain responses from persons without telephones, a toll-free number was provided in an advance letter asking the parent to call in to complete the survey. Interviews were conducted in English and Spanish, with translation services used for other languages.

The overall response rate for the survey was 53 percent, a rate similar to other recent surveys of Medicaid beneficiaries (Hill and Wooldridge, 2000; Sisk et al., 1996) and general social science surveys (Kenney, Scheuren, and Wang, 1999; Massey, O'Connor, and Krotki, 1997). Virtually all of the non-response was due to an inability to locate sample members rather than a refusal by those who were located to participate in the survey. Locating information was obtained from

Medicaid Program records, directory assistance, the U.S. Postal Service, online address databases, credit bureau checks, contacts with neighbors, and the use of field locators, who went out in the community in an attempt to find sample members who could not be located through other sources.

Sample weights were developed to reflect the probability of selecting each individual for the survey and to adjust for survey non-response. The adjustments for non-response were based on the administrative data available for both respondents and non-respondents, which included basic demographic information about the child (e.g., age and sex) along with primary disabling condition and ZIP Code. Relative to the administrative data, the children in the survey data were somewhat older (72 versus 68 percent age 7 or over) and more likely to be female (41 versus 36 percent). The availability of the administrative data allow us to develop weights that reduce biases that occur because non-respondents have different characteristics than respondents. Nonetheless, it may well be that some bias remains if the children who could not be located differ from those who could be located in unobserved ways that are correlated with their access to care. For example, if, as we suspect, the children who could not be located are in families with more tenuous ties to the community our sample of children in more stable families is likely to overstate access to care among disabled children on Medicaid in NYC.

Measures of Health Care Access and Use

We focus on key aspects of access to care using a standard framework (Andersen, 1968, 1995; Andersen and Aday, 1978; Andersen et al., 1983). We consider potential access—as measured by the presence of a usual source of care and the parent's report of unmet need for health care over the past year[1]—and realized access—as measured by use of health care services and parent's rating of the ease of accessing health care. The measures of health care use include visits to the emergency room (ER), outpatient visits for physical and mental health, and dental care visits over the past year. Higher levels of ER use indicate potential access problems if that use stems from problems obtaining care in other settings. Since we cannot identify inappropriate ER use from the survey, we interpret higher levels of ER use among the disabled Medicaid children as suggestive of problems with access to primary care, particularly if it is combined with high levels of unmet need and reported difficulties in accessing care.

Finally, we consider the parent's assessment of the ease of finding a doctor who will accept Medicaid and the ease of getting specialist, mental health and/or emergency care for the child. For these measures, the child's parent was asked to rate ease of access as excellent, very good, good, fair, or poor.

METHODS

We conduct both descriptive and multivariate analyses. In the descriptive analyses, we document access to and use of care among child Medicaid beneficiaries and assess the extent to which there are differences between children with a mental disability and those with a physical disability.

Our goal in the multivariate analysis is to identify the characteristics of disabled children that are associated with greater difficulties in obtaining care under Medicaid. We focus on measures of outpatient care

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[1] Questions on unmet need vary greatly across surveys. The question used here was: "Sometimes people have difficulties in getting care when they need it. During the last 12 months, was there any time when you thought [CHILD'S NAME] needed [TYPE OF CARE] but did not get it?"

for physical health, the ease of obtaining care, and unmet need. In the multivariate analysis, we consider outpatient care for physical health, but not mental health since all children require care for physical health, including those with mental illness and MR/DD, while not all children need mental health care. To ensure that the outcome measures reflect a period of Medicaid participation, we limit the analysis to children who were on Medicaid for the full year. This represents 96 percent of our sample of disabled children.

In the analysis, we control for measures of the child's predisposition to use health care services (age, race, and sex), factors that enable or impede use (parent's education), and the need for health care (primary disabling condition, health status and measures of physical, cognitive, and social limitations). Our relatively small sample size (446 children) leads us to estimate a fairly parsimonious model, however, the basic findings are robust to a range of alternative model specifications. Since all of the outcome measures are binary variables we estimate logit regression models (Greene, 2000).

Limitations

Although this study provides information on disabled Medicaid children that is not available elsewhere, there are some limitations of the study that must be acknowledged. One shortcoming is that the study focuses on children on SSI in a single city in a single State and, thus, may not be generalized to all of New York or to other States. However, given that New York has the highest spending per disabled Medicaid beneficiary in the Nation, our results may overstate how SSI beneficiaries are faring under Medicaid in other places. Another shortcoming is that the analysis relies on self-reported data, which reflect the parent's recall and self-assessment of the child's medical needs. As such, these survey data, like all survey data, are susceptible to measurement error and to response and reporting biases. Third, our sample is limited to the children with a parent who responded to the survey. Although we have adjusted for non-response in the survey weights, those adjustments may not capture all of the differences between the children included in our survey and those who are not included. As previously noted, if the children who are not captured in our survey are from more transient families, it is likely that we overstate access to care for disabled children. Fourth, one advance of this study is the availability of information from the Social Security Administration on whether the child's primary disabling condition is a physical disability, mental illness, or MR/DD. However, for disabled children who have multiple disabilities, this measure does not capture all of their disabilities, and so provides only an incomplete measure of disability. In the multivariate analysis, we control for health status and physical, cognitive, and social limitations, as well as primary disabling condition. Finally, in addition to the Medicaid Program, there are many Federal, State, local, and private programs that offer services to children with disabilities. The survey does not allow us to separate the services received through the Medicaid Program from those received via other sources and so will overstate the services provided by the Medicaid Program.

RESULTS

Overview of Disabled Children on Medicaid

In keeping with the national distribution of primary diagnosis among SSI children, the single largest subgroup in our sample

Table 1

Demographic and Socioeconomic Characteristics of Disabled Children on Medicaid, by Primary Disabling Condition: 1999-2000

Characteristic	Total Sample	Primary Disabling Condition Mental	 Physical
		Percent	
Demographic			
Age (Mean)	10.1	**10.5	8.9
Female	33.8	**34.6	49.3
Race/Ethnicity			
Hispanic	53.4	53.0	54.3
White, Non-Hispanic	6.7	7.4	5.0
Other, Non-Hispanic	39.9	39.6	40.7
Caregiver			
First Language Is Not English	41.1	40.1	43.4
Has Not Completed High School	49.1	*52.3	41.2
Annual Family Income < $20,000	85.2	85.1	85.3
Problems with Age Appropriate Activities			
Crawling, Walking, and/or Running [1]	40.9	**33.2	60.9
Delays in Cognitive/Mental Development [1]	62.2	**70.7	40.1
Getting Along with Other Children [2]	54.7	**59.7	41.5
Needs Assistance with Activities of Daily Living[3]			
None	55.9	55.1	58.3
1 to 2	24.6	26.2	20.0
3 or More	19.5	18.7	21.7
Health Status			
Very Good/Excellent	28.5	**33.2	16.8
Good	34.7	34.4	35.4
Fair/Poor	36.8	**32.4	47.8
Sample Size	446	318	128

*(**) Indicates value for children with a mental disability is significantly different from that for children with a physical disability at the 0.05 (0.01) level, two-tailed test.

[1] Limited to children age 1 or over.

[2] Limited to children age 2 or over.

[3] Limited to children age 5 or over. Includes bathing, dressing, eating, transferring, toileting, and getting around the house.

SOURCE: New York Survey of Disabled Medicaid Beneficiaries, 1999-2000.

was children with MR/DD, who account for nearly 60 percent of the sample (Pickett, 1999). Physically disabled children was the second largest group and represented about 30 percent of the population. Children with mental illness comprised the balance of the population (12 percent). Because of the small number of children with mental illness in our sample, we combine them with the MR/DD children for the descriptive analysis.

Demographic Characteristics and Family Circumstances

There are relatively few differences in the demographic and socioeconomic characteristics of children with physical and mental disabilities (Table 1). However, we do find that children with physical disabilities are somewhat younger (9 versus 10.5 years) and more likely to be female (49 versus 35 percent) than those with mental disabilities. The greater share of males on SSI with mental disabilities may be due to males being overidentified as disabled (U.S. Department of Education, 1998) and real differences in the prevalence of some types of disability between males and females (e.g., hemophilia, autism, Fragile X syndrome). The age difference between the two groups may in part reflect the difficulties of diagnosing mental retardation/developmental disabilities and mental illnesses among very young children (National Academy of Social Insurance, 1996).

Although similar across the subgroups of disabled children, family income and parent characteristics are cause for concern as both have implications for the family's ability to meet the needs of the disabled child (Stein, 1997; Halfon, Inkelas and Wood, 1995). As would be expected for a population of children on SSI, nearly all (85 percent) of the disabled children live in families with incomes less than $20,000 per year. About 40 percent of the parents do not speak English as their first language, raising the possibility of language barriers in obtaining care. Further, many parents had limited formal education: More than one-half of the parents of children with mental disabilities and 41 percent of the parents of children with physical disabilities have not completed high school. A lack of a high school education is much less common among the parents of the full population of children on Medicaid (37 percent) and of all children nationwide (16 percent) (Urban Institute, 2003).

Health and Disability Status

We find a variety of health and disability conditions as well as substantial variation in need among the SSI children on Medicaid. A key element in establishing disability under SSI for children is that their impairment reduces their ability to function independently and engage in age-appropriate activities. Thus, it is not surprising that many children with both physical and mental disabilities have difficulties with day-to-day activities. Consistent with their primary disabling condition, physically disabled children are significantly more likely to have mobility problems, such as difficulties crawling, walking, or running (61 versus 33 percent). Children with mental disabilities, by contrast, are more likely to have delays in cognitive development (71 versus 40 percent) and problems getting along with other children (60 versus 42 percent).

Despite these differences in development and functioning, the children with physical and mental disabilities are equally likely to need assistance beyond that normally required of children of the same age with activities of daily living (ADLs), i.e., bathing, dressing, eating, transferring, toileting, and getting around their home. Somewhat less than one-half of both groups needed special help with one or more ADLs. In general, the patterns of ADL needs were the same across both disability groups, with the greatest shares of both groups needing special help with bathing and dressing (data available from author upon request).

Somewhat surprisingly, using a global measure of health, the majority of the disabled children (63 percent) are reported to be in good, very good, or excellent health. This compares to 95 percent of all children nationwide and 90 percent of all Medicaid children (Urban Institute, 2003). One possible explanation for the general good health reported for the disabled children is that the assessment of the child's health status is a subjective measure based on the parent's point of reference. Within the limitations imposed by the child's long-term functional disability, the parent may report that their child is in otherwise good health.

Table 2
Health Care Access and Use for Disabled Children on Medicaid, by Primary Disabling Condition: 1999-2000

Characteristic	Total Sample	Primary Disabling Condition Mental	 Physical
		Percent	
Access to a Usual Source of Care			
Has a Usual Source of Care, Other than ER for Physical Health	95.5	96.0	94.4
Sees Same Provider at All or Most Visits	82.1	*80.0	87.1
Service Use in Last 12 Months			
Hospital Stay	18.5	**14.3	28.5
Multiple	7.5	**4.2	15.6
ER Visit	45.3	**42.1	53.0
Fall or Accident	10.4	10.5	10.3
Mental or Emotional Health[1]	5.1	5.9	2.9
Multiple to ER	30.6	**26.0	42.1
Outpatient for Physical Health Care	91.7	**89.0	98.5
Outpatient Preventative Care	87.3	**83.8	95.5
Mental Health Care	35.6	**40.9	22.4
Dental Care	84.8	*82.6	90.7
Ease of Access to Care			
Travel Time to Provider of 30 Minutes or More	33.9	**28.5	46.1
Wait in Office is 30 Minutes or More	56.4	**61.6	44.5
Problems Communicating with Providers Due to Language Differences	14.1	14.5	13.3
Parent Rates Ease of Access as Fair or Poor for:			
Finding a Doctor Who Accepts Medicaid	21.1	21.6	20.1
Getting Specialist Medical Care[2]	23.7	*26.2	18.1
Getting Emergency Medical Care[2]	21.0	22.9	17.0
Getting Mental Health Care[2]	22.5	21.7	26.0
One or More of the Above	37.8	38.1	36.8
Reported Unmet Need for Health Care			
Medical Care or Surgery (Including Doctor Care)	10.4	10.8	9.6
Mental Health Care	8.6	**10.7	2.9
Dental Care[1]	12.9	12.2	14.8
Physical, Occupational, or Speech Therapy	10.3	11.2	8.1
Prescription Drugs	6.0	7.0	3.5
Special Medical Equipment	8.2	7.8	9.3
One or More of the Above	31.2	31.7	30.0
Sample Size	446	318	128

*(**) Indicates value for children with a mental disability is significantly different from that for children with a physical disability at the 0.05 (0.01) level, two-tailed test.

[1] Limited to children age 2 or over.

[2] Limited to children who needed that particular type of care.

NOTE: ER is emergency room.

SOURCE: New York Survey of Disabled Medicaid Beneficiaries, 1999-2000.

Access and Use for MR/DD Children

Having a usual source of care (other than the ER) is an important component of access to care. As shown in Table 2, nearly all (96 percent) of the disabled children have a usual source of care for physical health, a level in keeping with the Healthy People 2000 goal for the general population (U.S. Department of Health and Human Services, 1991). Further, over 80 percent of the children see the same provider at all or most visits. This suggests that the Medicaid Program in NYC is successful in connecting most disabled children to health care providers.

As would be expected given their health status, the SSI children are also frequent users of health care. Over the course of a year, 92 percent had an outpatient visit for physical health, 87 percent had a visit for preventive care, and 85 percent had a dental care visit. There are, however, some indications of gaps in care, including differences in access between the subgroups of disabled children. For example, children with mental disabilities are significantly less likely than those with physical disabilities to have an outpatient visit for physical health (89 versus 99 percent), a preventive care visit (83 versus 96 percent) and to see the same provider at all or most visits (80 percent versus 87 percent). Although large shares of both groups are obtaining care, these differences raise concerns about potentially greater difficulty in accessing care among children with mental disabilities. As a further indicator of potential problems among children with mental illness (a subset of those with mental disabilities), nearly 35 percent do not have a usual source of care for mental health (data not shown).

The differences in access to care between the subgroups of children do not appear to be related to differences in the ease of obtaining care. Both children with mental and physical disabilities often report significant barriers to care, including long travel times, long office waits, language barriers, difficulties finding a doctor who accepts Medicaid, and difficulties accessing specific types of care. The parents of nearly 40 percent of both groups of children rate the ease of obtaining specialist care, emergency and/or mental health care as fair or poor (data not shown). Altogether, almost 80 percent of children are reported to face one or more of the access problems included in the table (data not shown).

In addition to outpatient visits, ER visits were also common for disabled children, with 45 percent having at least one visit over the course of a year. Across the two subgroups of children, ER visits were reported for over 50 percent of the children with physical disabilities, compared to about 40 percent of children with mental disabilities. Of particular concern, over 40 percent of children with physical disabilities and 26 percent of those with mental disabilities had multiple ER visits during the last year. Although these visits may represent appropriate care, the barriers to care previously outlined and unmet need outlined next raise the possibility that at least some visits could be avoided.

Unmet Need

Despite having a usual source of care and being frequent users of health care services, unmet need is reported for a substantial minority of the disabled children on Medicaid. Unmet need is an indicator of potential access problems and, given their vulnerable health status, is of particular concern for disabled children. In the survey sample, the parents of 30 percent of children with physical and mental disabilities report that their child did not get all the care they believed was needed in the past year.

Parents who reported that the child had an unmet need were asked the main reason for the unmet need. Although the reasons varied by type of unmet need, there were some common patterns (data not shown). For medical care/surgery, mental health, dental care, and therapy services, limited availability of providers was cited as the principal reason for unmet need. By contrast, cost, coverage, and administrative issues were reported as the main reason for unmet need for medical equipment, prescription drugs, and therapy services.

Barriers to Care

As previously noted, 80 percent of the disabled children were reported to face one or more difficulties in obtaining care. Table 3 focuses on the characteristics of the child associated with the reported ease of obtaining health care. As shown in the table, there are very few differences across disabling conditions in ease of obtaining care. The two exceptions are in travel time to providers and office wait times. Travel times of greater than 30 minutes are more common for children with physical disabilities (the omitted category) relative to those with mental illness and MR/DD, while office waits of 30 minutes or more are more common for children with MR/DD. The longer travel times for children with physical disabilities may reflect physical barriers within the transportation system, a need to wait for specialized transportation services, or a more limited set of providers treating this group of Medicaid patients, making accessibility more of a problem. Beyond disabling condition, some other characteristics of the child do appear to be associated with greater barriers to care. In particular, the parents of children in fair or poor health are more likely to report long travel times and more likely to rate as fair or poor the ease of the child's access to specialist care and mental health care. Similarly, the parents of children who have problems getting along with others are significantly more likely to rate as fair or poor the ease of finding a doctor who accepts Medicaid and the ease of getting specialist care, emergency care, and mental health care.

Despite differences in travel times and office waits across the sample, the patterns of unmet need are very similar across children with different disabling conditions (Table 4). We find only one significant difference between children with mental illness and MR/DD, and those with physical disabilities in reported levels of unmet need: The parents of children with mental illness are significantly more likely to report unmet need for mental health care for their child.

We also find that very few characteristics of the child are associated with unmet need. However, the parents of children with mobility problems are more likely to report unmet need for physical, occupational, or speech therapy, and unmet need for special medical equipment, while the parents of children who have problems getting along with others are more likely to report unmet need for mental health care and therapy.

Finally, Table 5 focuses on the factors associated with outpatient care for physical health, preventive care, and dental care by disabled children. Despite the similarities in the ease of access and reported unmet need for care across the children, we find large and significant differences in outpatient care for children with different disabling conditions, after controlling for other factors. Children with mental illness are less likely than those with physical disabilities to have had a preventive care or a dental visit in the last year, all else equal. Similarly, children with MR/DD were significantly less likely than physically disabled children to have had an outpatient visit for physical health or a preventive care visit in the last year.

Discussion

This article uses recent survey data for an indepth look at disabled children with mental and physical disabilities who are on Medicaid. Information on this population has not been available before because of the limitations of both administrative and survey data. We find that SSI children are a highly diverse population, with many having

Table 3

Odds Ratios from Logit Regressions of Ease of Access to Care for Disabled Children on Medicaid: 1999-2000

Explanatory Variable	Barriers to Obtaining Care: Travel Time to Provider of 30 Minutes or More	Barriers to Obtaining Care: Wait in Office is 30 Minutes or More	Barriers to Obtaining Care: Problems Communicating with Providers Due to Language Differences	Parent Rates Ease of Access as Fair or Poor for: Finding a Doctor Who Accepts Medicaid	Parent Rates Ease of Access as Fair or Poor for: Getting Specialist Medical Care[1]	Parent Rates Ease of Access as Fair or Poor for: Getting Emergency Medical Care[1]	Parent Rates Ease of Access as Fair or Poor for: Getting Mental Health Care[1]
Disabling Condition is Mental Illness	**0.197	1.365	0.152	1.027	1.695	0.921	0.745
Disabling Condition is MR/DD	*0.551	*1.873	1.174	0.872	1.346	1.477	0.565
Predisposing Factors							
Age	0.997	0.986	1.021	1.002	1.031	0.965	1.063
Female	0.863	1.002	0.886	1.013	0.694	1.338	1.703
Black, Non-Hispanic	0.953	1.433	0.644	*0.427	0.915	0.930	1.402
Hispanic	1.317	1.155	0.484	0.585	0.974	0.969	1.562
Enabling Factors							
Parent is a High School Graduate	1.189	1.068	*0.519	1.564	**2.525	1.057	1.714
Need Factors							
Fair or Poor Health	*1.725	0.756	1.245	1.516	*1.848	1.574	*2.047
Problems with Crawling, Walking, and/or Running	0.870	0.927	0.920	0.765	0.763	0.816	0.613
Problems and/or Delays in Cognitivie/Mental Development	1.147	1.367	0.979	1.026	1.155	1.035	0.978
Problems Gettting Along with Other Children	0.822	1.023	1.248	**2.376	*2.002	1.857*	**2.835
Sample Size	401	389	397	378	365	374	245

* (**) Significant at the 0.05 (0.01) level, two-tailed test.

[1] Limited to children who needed that particular type of care.

NOTES: Omitted categories are male; white/non-Hispanic; parent is not a high school graduate; disabling condition is a physical disability; health status is good, very good, or excellent health; no problems with crawling, walking, and/or running; no problems/delays in cognitive/mental development; and no problems getting along with other children. MR/DD is mentally retarded/developmentally disabled.

SOURCE: New York Survey of Disabled Medicaid Beneficiaries, 1999-2000.

Table 4

Odds Ratios from Logit Regressions of Unmet Need for Care for Disabled Children on Medicaid: 1999-2000

	Parent Reports Unmet Need for Health Care for:					
Explanatory Variable	Medical Care or Surgery (Including Doctor Care)	Mental Health Care	Dental Care[1]	Physical, Occupational, or Speech Therapy	Prescription Drugs	Special Medical Equipment
Disabling Condition is Mental Illness	1.745	*4.248	0.653	1.265	0.752	1.011
Disabling Condition is MR/DD	1.102	2.019	0.814	1.922	2.430	1.370
Predisposing Factors						
Age	1.015	1.090	1.040	0.951	1.098	0.953
Female	0.747	0.738	1.573	0.537	0.644	0.715
Black, Non-Hispanic	0.904	1.507	1.179	0.612	1.890	0.697
Hispanic	1.487	2.002	1.237	0.664	1.878	0.875
Enabling Factors						
Parent Is a High School Graduate	1.035	0.675	1.538	1.706	1.687	1.219
Need Factors						
Fair or Poor Health	1.658	1.861	1.296	1.092	1.325	0.784
Problems with Crawling, Walking, and/or Running	1.886	0.550	1.103	*2.107	0.881	**4.782
Problems and/or Delays in Cognitive/Mental Development	0.994	1.658	1.463	0.723	0.713	0.649
Problems Gettting Along with Other Children	1.899	*2.629	1.379	**3.068	1.488	1.455
Sample Size	424	421	386	418	424	423

* (**) Significant at the 0.05 (0.01) level, two-tailed test.

[1] Limited to children age 2 or over.

NOTES: Omitted categories are male; white/non-Hispanic; parent is not a high school graduate; disabling condition is a physical disability; health status is good, very good, or excellent health; no problems with crawling, walking and/or running; no problems/delays in cognitive/mental development; and no problems getting along with other children. MR/DD is mentally retarded/developmentally disabled.

SOURCE: New York Survey of Disabled Medicaid Beneficiaries, 1999-2000.

Table 5

Odds Ratios from Logit Regressions of Outpatient Care Over the Last 12 Months for Disabled Children on Medicaid: 1999-2000

Explanatory Variable	Outpatient Care Physical Health	 Preventive	 Dental[1]
Disabling Condition is Mental Illness	0.164	**0.186	*0.292
Disabling Condition is MR/DD	*0.136	**0.218	0.453
Predisposing Factors			
Age	0.917	0.953	0.979
Female	0.945	0.971	1.071
Black, Non-Hispanic	3.006	2.108	0.659
Hispanic	0.881	1.359	1.009
Enabling Factors			
Parent is a High School Graduate	1.948	1.301	0.987
Need Factors			
Fair or Poor Health	*3.846	2.063	1.142
Problems with Crawling, Walking, and/or Running	0.901	0.847	0.681
Problems and/or Delays in Cognitive/Mental Development	1.563	*1.927	1.060
Problems Gettting Along with Other Children	1.531	1.503	1.381
Sample Size	425	415	369

* (**) Significant at the 0.05 (0.01) level, two-tailed test.

[1] Limited to children age 2 or over.

NOTES: Omitted categories are male; white/non-Hispanic; parent is not a high school graduate; disabling condition is a physical disability; health status is good, very good, or excellent health; no problems with crawling, walking, and/or running; no problems/delays in cognitive/mental development; and no problems getting along with other children. MR/DD is mentally retarded, developmentally disabled.

SOURCE: New York Survey of Disabled Medicaid Beneficiaries, 1999-2000.

marked and severe functional limitations. Further, many SSI children face access barriers beyond health and disability-related challenges. Among other things, the children's parents had limited formal education, face potential language barriers, and have limited financial resources. In addition, most of the SSI children in NYC are from racial and ethnic minorities and, thus, may have difficulties obtaining culturally sensitive care.[2]

Despite these potential barriers, we found evidence that the Medicaid Program in NYC has been successful at linking SSI children to health care providers. For example, nearly all children on SSI have a usual source of care, most have seen a provider in the past year, and many see the same provider at all or most visits. However, there is also evidence of gaps in care under the Medicaid Program: Although the use of care is relatively high, children with mental disabilities are less likely than those with physical disabilities to have had an outpatient visit for physical health, a preventive care visit, or a dental visit over the past year. Further, nearly 35 percent of children with a disabling condition of mental illness do not have a usual source of care for mental health.

Our analysis of the factors associated with ease of access to care and unmet need suggest that many of the barriers to care faced by disabled children on Medicaid are systemwide: We find little association between the characteristics of the children and the measures of access to care and unmet need. However, the differences we do find suggest that children who have problems getting along with others, those in fair or poor health, and those with mobility impairments may have greater difficulty navigating the health care system.

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[2] Culturally sensitive care implies an ability by health care providers and organizations to understand and respond effectively to the cultural and linguistic needs brought by patients to the health care setting.

These differences in access may reflect the presence of specific barriers to care for some groups of disabled children under Medicaid or general access problems faced by all Medicaid beneficiaries that become a problem for those attempting to obtain care. We know that many (80 percent) of the disabled children were reported to face some type of barrier to care, including long travel times, long office waits, difficulties finding a doctor who accepts Medicaid, or difficulties getting specialist, emergency, and/or mental health care. Moreover, the disabled children have relatively high levels of unmet health care needs: The parents of 30 percent of the children report one or more types of unmet need for their child.

Program and Policy Implications

These findings have important Medicaid Program and policy implications. A key one is the need to provide targeted help to specific subgroups of disabled children. Such efforts could include providing increased assistance obtaining care for children with mental disabilities, those in fair or poor health, and those with mobility limitations.

The study also revealed a need to improve access to providers for Medicaid beneficiaries, as many parents reported the following difficulties: finding a doctor who accepts Medicaid; getting specialist care; and getting mental health care. Getting providers to participate in Medicaid has been a longstanding problem for the Medicaid Program. Expanding the network of providers and/or improving the accessibility of the existing network of providers could potentially solve many of the access problems and general dissatisfaction with the health care system reported by survey respondents. In addition, it could also potentially reduce Medicaid Program costs. For example, nearly one-half of children had gone to an ER at least once during the past year and many had had multiple visits. Although we cannot identify inappropriate ER use, the high level of ER use, combined with high levels of unmet need, low ratings of the ease of obtaining care, and long travel times, suggest that by improving access to the network of Medicaid providers at least some of the costly ER use could be avoided.

Although changes to the Medicaid Program to better serve the SSI population could be done under either the fee-for-service system or managed care, it may well be that managed care, with its emphasis on a medical home, preventive care, and care management through an established network of providers, could provide a better structure for introducing such changes for disabled populations. This would particularly be true for managed care models that cover the full array of care needed by the disabled, including physical health, mental health, and dental care. Indeed, part of the motivation for New York's planned transition of the SSI population into managed care is to address the persistent access problems faced by disabled beneficiaries under fee-for-service Medicaid.

As policymakers in New York and other States implement changes in the Medicaid delivery system, such as managed care, it is important that they bear in mind the diversity of needs and circumstances of Medicaid beneficiaries who have disabilities. For example, the considerable variation in both the health status and functional levels reported here highlight the need to view SSI children as a heterogeneous population. In addition, policymakers need to be mindful that the SSI population is distinct from the general Medicaid population, which to date has been the focus of most States' managed care programs. Among other things, SSI children tend to be older, poorer, and have parents with more limited education when compared to the general population of children on Medicaid. Further, as expected, SSI children's health status is lower. In sum, both the health and social circumstances of SSI children will need to be accounted for in the design and implementation of a managed care program.

States will also need to incorporate these health and social circumstances in how they pay health plans. While in recent years some States have moved to health-based capitation payments, most continue to rely on fairly limited risk adjusters (age, sex, and location) (Allen and Croke, 2000; Regenstein and Anthony, 1998; Kronick et al., 2000). However, given the SSI population's broad diversity, it is important that capitation rates expressly account for this variation. States may also consider developing risk-sharing and stop-loss options for health plans serving disabled populations.

REFERENCES

Allen, S.M. and Croke, A.L.: *The Faces of Medicaid: The Complexities of Caring for People with Chronic Illnesses and Disabilities*. Center for Health Care Strategies. Princeton, NJ. 2000.

Andersen, R.: *A Behavioral Model of Families' Use of Health Services*. Center for Health Administration Studies. University of Chicago. Chicago, IL. 1968.

Andersen, R.: Revisiting the Behavior Model and Access to Care: Does it Matter? *Journal of Health and Social Behavior* 36(1):1-10, 1995.

Andersen, R. and Aday, L.A.: Access to Medical Care in the U.S.: Realized and Potential. *Medical Care* 16(7):533-545, July1978.

Andersen, R., McCutcheon, A., Aday, L.A., et al.: Exploring Dimensions of Access to Medical Care. *Health Services Research* 18(1):49-74, Spring 1983.

Bruen, B. and Holahan, J.: *Medicaid Spending Growth Remained Modest in 1998, But Likely Headed Upward*. The Kaiser Commission on Medicaid and the Uninsured. Washington, DC. February 2001.

Greene, W.H.: *Econometric Analysis*. Prentice-Hall, Inc. Upper Saddle River, NJ. 2000.

Halfon N., Inkelas, M., and Wood, D.: Nonfinancial Barriers to Care for Children and Youth. *Annual Review of Public Health* 16: 447-472, 1995.

Hill, S. and Wooldridge, J.: SSI Enrollees in TennCare: Room for Improvement. Mathematica Policy Research, Inc. Princeton, NJ. 2000.

Kenney, G., Scheuren, F., and Wang, K.: *National Survey of America's Families: Survey Method and Data Reliability*. NSAF Methodology Series, No. 1. Urban Institute. Washington, DC. 1999.

Kronick, R., Gilmer, T., Dreyfus, T., and Lee, L.: Improving Health-Based Payment for Medicaid Beneficiaries: CDPS. *Health Care Financing Review* 21(3):29-63, Spring 2000.

Massey, J.T., O'Connor, D., and Krotki, K.: Response Rates in Random Digit Dial Telephone Surveys. *Proceedings of the Survey Research Methods Section of the American Statistical Association*. 707-712, 1997.

National Academy of Social Insurance: *Restructuring the SSI Disability Program for Children and Adolescents*. National Academy of Social Insurance. Washington, DC. 1996.

Urban Institute: Unpublished tabulations from the National Survey of America's Families. Washington, DC. 2003.

Pickett, C.: *Children Receiving SSI*. Office of Research, Evaluation and Statistics. Social Security Administration. Baltimore, MD. June 1999.

Regenstein, M. and Anthony, S.E.: *Medicaid Managed Care for Persons with Disabilities, Assessing the New Federalism*. Urban Institute. Working Paper Number 11. Washington, DC. 1998.

Shalala, D. E.: *Safeguards for Individuals with Special Health Care Needs Enrolled in Medicaid Managed Care: Report to Congress*. U.S. Department of Health and Human Services. Washington, DC. November 6, 2000.

Sisk, J., Gorman, S.A., Resinger, A.L., et al.: Evaluation of Medicaid Managed Care: Satisfaction, Access, and Use. *Journal of the American Medical Association* 276(1):50-55, 1996.

Stein, R.E.K.: Changing the Lens: Why Focus on Children's Health? In Stein, R.E.K. (ed.): *Health Care for Children: What's Right, What's Wrong, What's Next*. United Hospital Fund. New York, NY. 1997.

U.S. Department of Education: *To Assure the Free Appropriate Public Education of all Children with Disabilities*. Twentieth Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act. U.S. Government Printing Office. Washington, DC. 1998.

U.S. Department of Health and Human Services: *Healthy People 2000*. Public Health Service. U.S. Department of Health and Human Services. DHHS Publication No. (PHS) 91-50213. 1991.

Reprint Requests: Sharon K. Long, Urban Institute, 2100 M Street NW, Washington, DC 20037. E-mail: slong@ui.urban.org