

Access to Specialty Medical Care for Children With Mental Retardation, Autism, and Other Special Health Care Needs

Marty Wyngaarden Krauss, Stephen Gulley, Mark Sciegaj, and Nora Wells

Abstract

Access to specialty medical care among children with mental retardation, autism, or other types of special health care needs was examined. Results from a national survey indicate that over a third of the children with autism, over a fifth with mental retardation, and over a fifth with other types of special health care needs had problems obtaining needed care from specialty doctors in the preceding year. The most common problems included getting referrals and finding providers with appropriate training. Children with unstable health conditions, autism, or those whose parent was in poor health were at greater risk for problems. Primary Medicaid coverage and public secondary health coverage were associated with fewer access problems. Implications for health services for children with special health care needs are discussed.

During the 1990s, rapid changes in the organization, financing, and delivery of health care in the United States raised concerns among providers, advocates, families, and policymakers that children with special health care needs might experience barriers to needed health and rehabilitative services (Ferris et al., 2001; Kuhlthau et al., 1998; Newacheck, McManus, Fox, Hung, & Halfon, 2000). Across the nation, over 12 million children with special health care needs live with chronic physical, developmental, behavioral, or emotional conditions requiring them to use more health care and related services than children of the same age (Newacheck et al., 1998). These children present challenges to both health insurers and providers because of their need for more specialized medical care, a wider range of therapeutic services, and greater care coordination services between providers than do other children (Fox, McManus, Almeida, & Lesser, 1997). As both public and private insurers have moved to contain costs, a particular concern is whether access to care from specialty medical doctors has been restricted (Fox, Wicks, & Newacheck, 1993; Horowitz & Stein, 1990; Ireys, Grason, & Guyer, 1996; Perrin, 2002).

In this study we have three goals. The first is to introduce a multidimensional approach to mea-

asuring access to specialty care from medical doctors for children with special health care needs. Most empirical health services studies on such children tend to be focused on service utilization data, with the assumption that lower utilization rates may signal access problems (Aday et al., 1993; Newacheck et al., 2000; Simpson & Frasier, 1999). Although such an outcome-based focus is valuable for many purposes, it masks aspects of the process of accessing care that may enhance or impede obtaining care, which are likely to be complex for many parents of children with special health care needs (Krauss, Wells, Gulley, & Anderson, 2001). We contend that researchers examining access to specialty medical care need to include measures of “hassles” in the process of obtaining timely, appropriate, and coordinated care that are the hallmarks of best practices for children with special health care needs (Ireys et al., 1996; Kuhlthau et al., 1998).

A second goal is to extend the access to care literature with respect to the diversity of these children (and their families) by examining the relation between specific child and family characteristics and access to care issues. Investigators who examine whether children with special health care needs experience greater problems in accessing specialty medical care rarely identify whether there are par-

ticular child, parent, or family characteristics that are associated with different rates or types of access problems (Aday et al., 1993). Yet, children included within the definition of having special health care needs are a heterogeneous group, defined essentially by their greater utilization of health services and the persistence of their medical or behavioral conditions (McPherson et al., 1998). We hypothesized that within this broadly defined group of children, access problems are differentially experienced based upon a variety of specific factors, such as the stability of the child's health care needs, parental health and education, or the presence of other children with special health care needs in the family. We also specifically hypothesized a link between particular child medical conditions and access problems with specialty care from medical doctors.

In the analysis, therefore, we provide a special focus on the experiences of children with mental retardation, children with autism, and children with other types of special health care needs. Recently, there has been a renewed interest in the health care experiences and unmet needs of children and adults with mental retardation (Horwitz, Kerker, Owens, & Zigler, 2001), culminating in the 2002 Surgeon General's Conference on Health Disparities and Mental Retardation. In a comprehensive review of the health status and needs of individuals (primarily adults) with mental retardation, Horwitz et al. concluded that "Despite the . . . documented need for physical, mental, ocular, and dental health services for individuals with mental retardation, adequate services in this population are not frequently utilized" (p.137). There is a need for more focused research on the extent to which disparities in access to specialty medical care exist for children with mental retardation in contrast to children with other health care needs. Similarly, the health and related service needs of children with autism have attracted increased public health and scientific scrutiny. Recent reports have underscored their needs for comprehensive and coordinated specialized services, particularly during the early childhood period (Karp, 1996; Kohler, 1999; National Research Council, 2001). Consequently, we compared the reports of access difficulties with care from specialty medical doctors for children with autism, children with mental retardation, and a contrast group of children with other special health care needs.

Our third goal was to investigate the role of both public and private forms of insurance, com-

paring our access measures for parents with and without primary Medicaid coverage for their children. Traditional Medicaid benefits for children with special health care needs are far more comprehensive than those of most private insurance plans, including the provision of case management, rehabilitation services, personal care, psychological counseling, recuperative and long-term residential care, and many other services deemed necessary by a physician or other health care provider (Newacheck, Stoddard, & Halfon, 1994). As Delong, Poulsbo, and Beatty (2002) noted, studies indicate that people with disabilities and chronic conditions in managed care plans have less access to specialty care compared to those in traditional fee-for-service plans. We also investigated the role of public secondary coverage, such as that provided by Medicaid in many states. All the children in the analyses presented in this paper had health insurance, and some were also covered by a secondary health plan. This permits an examination of the extent and types of access problems experienced with care from specialty medical doctors that exist within an insured population of children with special health care needs, some of whom have both a primary health plan and a secondary plan.

With these three goals in mind, and using data from a recently completed survey of families of children with special health care needs (Krauss, Gulley, Leiter, Minihan, & Sciegaj, 2000), we investigated two research questions: (a) What types of problems in obtaining care from specialty medical doctors are reported by parents of children with mental retardation, autism, or other types of special health care needs? (b) To what extent are characteristics of the children, their families, and their health care coverage associated with the probability of having specific types of problems accessing this care?

Method

Sample

In 1998–1999, 2,220 families of children with special health care needs in 20 states responded to a survey conducted by Brandeis University and Family Voices, a national organization of family and friends of children with special health care needs (see Krauss et al., 2000, for more detail on the study design and sampling strategy). The sample for the survey in each state was drawn from two sources. First, 42.6% of the sample was selected from state-based mailing lists of Family Voices. The mailing

lists contain names of families of children with special health care needs who wish to receive periodically distributed information on issues of concern to such families and, thus, may include more educated and advocacy-oriented families. Second, in order to ensure sufficient representation of children participating in the Medicaid program, 57.4% of the sample were families whose children received services from the participating state's Title V program. This program includes children who receive Supplemental Security Insurance and Medicaid coverage for services, and, thus, this portion of the sample includes families of children with more severe health conditions and lower income. Of the children covered by the Medicaid program, 74.8% were drawn from the Title V component of the survey sample, and 25.2% were drawn from the Family Voices mailing lists.

Surveys (available in English and Spanish) were distributed in 1998–1999. To be eligible to participate, respondents had to meet two criteria: (a) be the parent or guardian of a co-residing child who was age 18 or younger, who (b) had a special health care need, defined as having a health or medical condition that is expected to last for at least one year and who needs medications; special diets; medical technology; assistive devices; personal assistance; or occupational, physical, or speech therapy. The child's condition must also require care from physicians or mental health or other health professionals over and above what is usual for a child of the same age. This definition is consistent with the one used by the federal Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs (McPherson et al., 1998; Newacheck et al., 1998).

Of the 2,220 children on whom survey data were collected, virtually all (97%) were covered by a health plan. Uninsured children were not included in the analyses presented in this paper. Although almost half of the children (46%) were covered by health plans purchased privately (i.e., employer/family purchased), over a third (39%) had their primary plan paid for by Medicaid. The remaining children had plans either paid for fully by their family (9%) or the source of payment for the plan was unknown by the child's respondent (6%). Thus, the analyses presented below reflect the experiences of an *insured* group of children with special health care needs.

Children selected for the analyses presented here met additional criteria, as follows. First, the

child needed or received medical care from specialty doctors in the preceding year. Second, the respondent (the majority being the child's mother) provided information on the type(s) of health or disability condition(s) of the child from a list of 35 conditions that included medical conditions (e.g., allergies, asthma, diabetes, cancer, congenital heart disease, cystic fibrosis), cognitive disabilities (e.g., mental retardation), mental health/behavioral conditions (e.g., autism), sensory problems (e.g., hearing or vision impairment), and neurological problems (e.g., degenerative neurological disease, epilepsy, seizure disorder). Using these two criteria, we included 1,799 children (81.0% of the total sample) in the analyses presented here.

For this analysis, we compared three groups of children: those with mental retardation ($n = 434$, or 24.1% of the analysis sample), those with autism ($n = 152$, or 8.4% of the analysis sample), and children with special health care needs with other conditions ($n = 1,213$, or 67.4% of the analysis sample). The children with "other" conditions had a variety of disorders, including developmental delay, allergies, orthopedic problems, cerebral palsy, visual impairments, or behavior problems. We note further that slightly more than half of the children with either mental retardation or autism (58.5% and 57.2%, respectively) were from families sampled from the Family Voices mailing lists. About a third of the children (35.1%) with other types of special health care needs were also sampled from this source. Table 1 provides a demographic portrait of the three groups of children with regard to respondent and family characteristics, child characteristics, and insurance coverage.

Measures

Access to specialty medical care. Developed in close consultation with parents of children with special health care needs, advocates, and experts in health services and insurance, the measures used in the analysis reference a differentiated set of problems that may be experienced, recognizing that access problems can arise from multiple causes. Some causes may be the result of health plan policies or capacities (e.g., requirements for referrals or co-payments), whereas others may be attributed to limitations of the available providers of care (e.g., absence of appropriately trained providers within the plan's network).

Respondents were, thus, asked whether they had "any problems getting medical care from spe-

Table 1 Respondent, Family, and Child Characteristics and Insurance Coverage by Group

Characteristic	Contrast group (<i>n</i> = 1213) % or mean	Mental retardation (<i>n</i> = 434) % or mean	Autism (<i>n</i> = 152) % or mean
Respondent and family			
Respondent has high school degree or less (%)	33.5	23.3	21.1
Respondent has some college or more (%)	66.5	76.7	78.9
Family income (%)			
(\$0–\$19,999)	34.1	23.5	29.1
(\$20,000–\$39,999)	32.5	30.6	29.7
(\$40,000 and up)	33.4	45.9	41.2
Mean ^a	\$33,472 (22,446)	\$39,156 (22,929)	\$36,621 (22,679)
Median	\$25,000	\$35,000	\$35,000
Respondent is not married (%)	26.7	23.1	26.0
Respondent is not employed (%)	48.0	46.3	46.4
Respondent's health is fair or poor (%)	13.1	13.7	16.4
More than one child with special health care needs in family (%)	24.2	20.0	32.2
Child			
Child's age (mean)	8.3 (4.5)	9.9 (4.5)	8.4 (3.7)
Child is a racial/ethnic minority (%)	27.3	20.1	20.7
Child's health is fair or poor (%)	20.2	24.0	16.4
Child's health care needs are not stable (%)	25.0	30.8	26.8
Insurance coverage			
Medicaid pays for child's main health plan (%)	38.3	36.3	35.8
Child has public secondary health coverage (%)	36.0	39.9	32.6

^aStandard deviations presented in parentheses.

cialty doctors” for their children with special health care needs during the preceding 12 months. Of the seven problems listed, four were focused on problems typically associated with policies used by health plans to limit or regulate access to care, including: (a) getting referrals for services, (b) getting the number of visits from specialty doctors needed, (c) the amount the family had to pay, and (d) denial of the child's health plan to pay for the services. Three of the listed problems focused on provider-based issues, including (e) getting appointments with specialty doctors, (f) finding specialty doctors with the skill and experience to care for the child, and (g) coordinating between the child's specialty doctor and other providers. For the analysis, we examined the percentage in each of the three groups within the sample who experienced the seven spe-

cific problems. We also examined the percentages reporting any plan-related problem (items a through d) or any provider-related problem (items e through g). Finally, we examined the percentages of individuals in each of the three groups reporting any (e.g., one or more) of the seven possible access problems.

Child characteristics. The following child characteristics were used in the analysis: age (in years), being nonwhite (0 = no, 1 = yes), health status (0 = excellent to good, 1 = fair to poor), and stability of health status (0 = generally or always stable, 1 = unstable, changing all the time).

Family characteristics. The following characteristics of the child's family were also examined in the analyses: responding parent/guardian's level of education (0 = some college or more, 1 = high school education or less), family income (0 = \$0

to \$19,999, 1 = \$20,000 to \$39,999, 3 = \$40,000 and over), marital status of parent/guardian (0 = married, 1 = single), employment status of parent/guardian (0 = employed, 1 = not employed), parent/guardian health status (0 = excellent to good, 1 = fair to poor), and whether there were multiple children with special health care needs in the family (0 = no, 1 = yes).

Health care coverage. We examined whether having Medicaid as the payer of the child's primary health plan (0 = no, 1 = yes) and whether having a publicly provided secondary health plan (0 = no, 1 = yes) were associated with access to specialty medical care providers.

Data Analysis

The analyses presented here first compare three groups of children: children with mental retardation (without autism), children with autism (with or without mental retardation), and a contrast group of children with special health care needs who have neither of these two conditions. These three groups were examined descriptively with respect to the child, family, and health care coverage measures described above. Reports of the seven potential access problems from the parent/guardian of the three groups of children were examined, and differences were tested using the chi-square distribution. Reports of any (e.g., one or more) plan-related access problems and any (e.g., one or more) provider-related access problems were compared across the three groups of children. Next, we compared and tested the percentage of parents reporting *any* (e.g., one or more) of the seven possible access problems, again using the chi-square distribution.

Three logistic regression analyses were conducted, one on each of the three dependent variables: plan-related access problems (0 = no problems reported, 1 = one or more such problems reported), provider-related access problems (same coding), and any access problem (same coding). In each analysis, we examined the same child, family, and health coverage variables described earlier. In addition, a dichotomous variable to record whether the child had mental retardation or autism was included. The contrast group of children with special health care needs who had neither mental retardation nor autism was, thus, set as the base case. Parameters were estimated separately for each of the three models, along with odds ratios and overall model tests of significance.

Results

Differences Between Children With Mental Retardation, Autism, and Other Conditions Who Need Care From Specialty Doctors

There were significant differences across the three groups of children with respect to parental, family, and child characteristics (see Table 1). Notably, parents of children with mental retardation and those of children with autism had similar levels of education, but each had significantly higher education levels than respondents in the contrast group, $p < .001$. Regarding family income, the contrast group was significantly lower than the respondents for children with mental retardation (but not distinguishable from respondents for children with autism), $p < .001$. Further, children with mental retardation and autism had comparable percentages of racial/ethnic minority children (about 20%), whereas the contrast group had a significantly higher percentage of such children (about 27%), $p < .01$.

In addition, children in the autism group were more likely to have a sibling with special health care needs than were children with mental retardation, $p < .01$. The children with mental retardation were also somewhat older than children in the other two groups, $p < .001$. Importantly, no significant differences were found in the rates at which these three groups had primary Medicaid coverage or public secondary coverage.

Prevalence of Problems Accessing Care From Specialty Doctors

As shown in Table 2, there was a significant difference among the groups with respect to experiencing any problem accessing care from specialty medical doctors. Over a third of the children with autism were reported to have experienced an access problem with respect to specialty care from a medical doctor in the preceding 12 months. In contrast, about a fifth of the parents of children with mental retardation or of the parents of children in the contrast group reported an access problem with this type of care.

There was little difference in the percentage of parents in each of the three groups who reported a health plan-based access problem compared to a provider-based access problem. Yet, for both of these categories, children with autism were significantly more likely to experience difficulties than

were children in the other two groups. As can be seen in Table 2, over a quarter of the children with autism were reported to have had a health plan-based access problem and a similar percentage, a provider-based access problem.

Within the category of health plan-based problems, the most common difficulty for all three groups of children was “getting referrals for services.” Importantly, for all four specific types of access issues within the category of health plan-based problems, parents of children with autism were twice as likely to experience each issue compared with parents of children with either mental retardation or other types of special health care needs (e.g., the contrast group).

Within the category of provider-based access problems, the most common difficulty for parents of children with autism and for parents of children with mental retardation was “finding skilled and experienced specialty doctors.” In contrast, for children with other types of health care needs, the most common difficulty within this category was “getting appointments” (see Table 2). Coordination of care between specialty doctors and other providers was an issue for almost three times as many of the parents of children with autism as it was for parents of children with other types of special health care

needs and almost twice as common as was reported for children with mental retardation.

Predictors of Access Problems

Table 3 presents the results of the logistic regression analyses that examined the relation between three sets of independent variables—respondent and family characteristics, child characteristics, and insurance coverage characteristics—and the probability of experiencing a health plan-based access problem, a provider-based access problem, or any problem.

The odds of experiencing a health plan-based access problem were significantly increased for respondents who were in fair or poor health themselves and for those who had more than one child with special health care needs. The odds were also significantly increased for children with unstable health care conditions and, importantly, for children with autism in contrast to other children with special health care needs. Finally, the odds of experiencing a health plan-related access issue were significantly decreased for children covered by Medicaid or those with public secondary coverage.

With respect to the odds of experiencing a provider-based access problem, respondents with higher levels of education and respondents who were

Table 2 Access Problems of Children With Special Health Care Needs to Specialty Medical Care Services by Group (in %)

Access problem domain	Contrast group	Mental retardation	Autism	χ^2 (2, N = 1799)
Health Plan-Based Access				
Getting referrals for services	7.7	8.8	15.8	11.03**
The health plan would not pay	6.3	7.6	13.8	11.60**
Getting the number of visits needed	4.7	4.4	11.2	12.32**
The amount the family had to pay	4.0	4.6	11.2	15.19**
Percentage with at least one health plan-based access problem	14.9	15.4	28.3	18.03***
Provider-Based Access				
Getting appointments	8.7	9.0	15.8	8.20*
Finding skilled and experienced specialty doctors	7.0	9.9	18.4	23.32***
Coordination between specialty doctor and other providers	5.6	7.6	15.8	22.04***
Percentage with at least one provider-based access problem	14.3	17.1	28.9	21.46***
Percentage with any access problem	21.0	22.6	36.8	19.25***

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 3 Odds of Experiencing Health Plan-Based, Provider-Based, or any Access Problem

Independent variable	Plan-based access problem ^a		Provider-based access problem ^b		Any access problem ^c	
	Parameter estimate	Odds ratio	Parameter estimate	Odds ratio	Parameter estimate	Odds ratio
Respondent and family characteristics						
Respondent has high school degree or less	-.01	.99	-.59**	.55	-.31	.73
Low income family (\$0–19,999)	.09	1.09	.13	1.14	.07	1.07
Middle income family (\$20,000–\$39,999)	-.13	.87	.25	1.28	-.03	.97
Respondent is single	.16	1.18	.10	1.11	-.01	.99
Respondent is not employed	-.06	.94	-.12	.88	-.10	.90
Respondent’s health is poor or fair	.64**	1.89	.80***	2.23	.82***	2.27
More than one child with special health care needs in family	.48**	1.62	.32	1.37	.36*	1.43
Child characteristics						
Child’s age	-.01	.99	-.01	.99	-.00	1.00
Child is a racial/ethnic minority	.26	1.30	.27	1.30	.21	1.23
Child’s health is poor or fair	.07	1.07	.28	1.31	.24	1.27
Child’s health care needs are not stable	.54**	1.71	.70***	2.00	.60***	1.82
Child has mental retardation	.06	1.06	.17	1.19	.06	1.06
Child has autism	.59	1.81	.78***	2.18	.64**	1.89
Insurance characteristics						
Medicaid pays for child’s primary health plan	.45*	.64	-.15	.86	-.29	.75
Child has public secondary health coverage	-.41*	.66	-.36*	.70	-.49**	.61

^aModel significance: $\chi^2 = 57.129, p < .001$. ^bModel significance: $\chi^2 = 87.019, p < .001$. ^cModel significance: $\chi^2 = 88.169, p < .001$.

* $p < .05$. ** $p < .01$. *** $p < .001$.

themselves in fair or poor health were significantly more likely to report such an issue. Further, the same two characteristics of the child, namely, having an unstable health condition and having autism, significantly increased the odds of experiencing a provider-based access problem. As with problems at the health plan level, the odds of having a provider-based issue were decreased for those children with secondary health insurance coverage.

Last, with regard to overall access (e.g., experiencing one or more of the seven potential problems), the results were largely reflective of the previous two analyses. Namely, the odds of experiencing any type of access problem were greater for parents who were in fair or poor health, who had multiple children with special health care needs, for

children whose health conditions were unstable, for children with autism, and for children without secondary health care coverage.

Discussion

In this analysis we examined the experiences of children with mental retardation, children with autism, and children with other types of special health care needs regarding the extent to which problems in obtaining specialty medical care were reported and the types of problems encountered. Over a third of the parents of children with autism reported problems when accessing needed specialty care for their child, whereas about a fifth of the parents of children with mental retardation or other

types of special health care needs reported problems. In general, these rates are consistent with those reported by Newacheck et al. (2001), who examined access to specialty medical care among a nationally representative sample of children enrolled in managed care plans and found that one fifth of all children had difficulties obtaining care. Three specific findings warrant further discussion.

First, we found a range of potential problems associated with access to medical care from specialty doctors for these children. Access to this care is not a binary outcome, whereby children with special health care needs simply receive or do not receive the care they need. Instead, there appears to be a variety of potential hurdles for families that are associated with the process of accessing this care, even when it is received. The incidence of specific problems was low, yet the odds of experiencing one or more specific problems were substantial for many of these families. We also found that the types of problems encountered reflect both features of contemporary health plans, such as requirements of getting referrals to care, and provider characteristics, such as the availability of physicians with the skills and experience necessary to serve these children. Taken together, these findings underscore the complexity of improving access to medical care from specialty doctors for these children. Although they do suggest that some actions could be of benefit, such as easing the referral process or working to ensure that provider networks include physicians with the special competencies required to serve children with more complex health conditions, they do not suggest that such actions will necessarily provide easier access for all children with special health care needs.

Second, we find that among this heterogeneous group of children with special health care needs, there are characteristics of children and their families that are associated with higher risks of experiencing problems accessing medical care from specialty doctors. Families in which the parent was in less than good health and where there were multiple children with special health care needs were each at greater risk of reporting access problems, suggesting that a “pile-up” of family-level stressors exacerbates parental efforts to obtain needed care for these children. These findings are important for because they emphasize the fact that families of children with disabilities and special health care needs are often confronted with multiple stressors (Leiter, Krauss, Anderson, & Wells, in press).

Importantly, across all the measures, parents of children with autism stand out with respect to reporting access problems. A number of factors could be responsible for this difference. Children with autism manifest a complex array of deficits in communication and social interaction skills as well as behavior patterns (Rogers, 2000). Because autism is a complex disorder, obtaining an accurate diagnosis is often the culmination of a long and protracted evaluation period, including the efforts of multiple professionals from a variety of disciplines (Seltzer, Krauss, Osmond, & Vestal, 2000). Once diagnosed, children with autism need early and intensive therapeutic interventions, involving a variety of specialists (Kasari, Freeman, & Apparels, 2000) and often requiring specialty care from educators and behavioral specialists who may not be within the provider networks of health plans. The difficulty families face in obtaining accurate information regarding their child's condition and needs and in securing appropriate services has been well-described in the literature (Gray & Holden, 1992), and our findings underscore the relation between autism and access problems with care from specialty medical doctors.

We also found that parents who reported that their child's health care needs were not stable were more likely to report access problems—whether at the plan level, provider level, or overall. As with our findings regarding autism, this suggests that within the population of children with special health care needs, there may be children with particular constellations of medical problems that necessitate more involved medical services, making parental efforts to secure needed care from specialty doctors especially complex or difficult. The identification of specific risk factors within a broad population of children (and families) such as these is, therefore, important because it provides health plans and providers an opportunity to make special efforts to ensure that needed care is provided. In many plans specialized case-management strategies and/or specialty clinics are used for patient groups with particular problems, and these findings suggest that children with autism, unstable health conditions, or other special health care needs whose parent(s) have health problems each warrant particular concern. There may be other subgroups within the population of children with special health care needs who are at particular risk for access problems with specialty care (and other important care, such as mental health, home health, and rehabilitative

therapies). Further efforts to identify and respond to the needs of specific children and families may present one avenue for change.

Third, our findings regarding primary and secondary Medicaid coverage are encouraging with regard to the access provided to children with special health care needs by these public programs. Parents in this study with primary Medicaid coverage for their child reported health plan-related problems with access to medical care from specialty doctors about three fifths as often as did parents with private insurance for their child. Further, we found that public secondary health coverage, most commonly provided by Medicaid, is associated with significantly lower odds of reporting problems with access to this care, whether at the health plan level, the provider level, or overall. Last, access problems among parents who have primary or secondary Medicaid coverage for their child were reported less frequently, regardless of whether the child had mental retardation, autism, or another type of special health care need. These are especially important findings in light of the continuing national efforts to pass the Family Opportunity Act, which would allow families of children with special health care needs to secure Medicaid coverage for their child regardless of family income. These findings are also timely in light of current budgetary pressures on state and federal health resources that are resulting in widespread fears of retrenchment in Medicaid funding.

The federal government's Healthy People 2010 goals include the provision of a "medical home" for all children with special health care needs. Such a home would ensure the provision of coordinated care across multiple providers and multiple service systems, provide sensitive and skilled counseling to parents, and help ease many of the access problems described in this analysis. Importantly, many states are developing "medical home" initiatives (Cooley & McAllister, 2001).

In conclusion, in this paper we have illustrated the need for continued research on the experiences of families in accessing specialty care for their children with special health care needs. There is growing recognition among health care planners, public policy scholars, family advocacy organizations, and health services researchers that creative adaptations of traditional health plan features may be critical to our nation's ability to provide high quality, comprehensive, and coordinated care to this vulnerable group of children.

References

- Aday, L. A., Lee, E. S., Spears, B., Chung, C. W., Yourself, A., & Bloom, B. (1993). Health insurance and utilization of medical care for children with special health care needs. *Medical Care, 31*, 1013–1026.
- Cooley, W., & McAllister, J. (2001). *Building a medical home: Improvement strategies in primary care for children with special health care needs*. Lebanon, NH: Center for Medical Home Improvement. (Available online from www.medicalhomeimprovement.org)
- Delong, G., Poulsbo, S. E., & Beatty, P. W. (2002). The organization and financing of health services for persons with disabilities. *The Milbank Quarterly, 80*, 261–301.
- Ferris, T. G. G., Perrin, J. M., Manganello, J. A., Chang, Y., Causino, N., & Blumenthal, D. (2001). Switching to gatekeeping: Changes in expenditures and utilization for children. *Pediatrics, 108*, 283–290.
- Fox, H. B., McManus, M. A., Almeida, R. A., & Lesser, C. (1997). Medicaid managed care policies affecting children with disabilities: 1995 and 1996. *Health Care Financing Review, 18*, 23–36.
- Fox, H. B., Wicks, L. B., & Newacheck, P. W. (1993). Health maintenance organizations and children with special health care needs: A suitable match? *American Journal of Diseases in Children, 147*, 546–552.
- Gray, D. E., & Holden, W. J. (1992). Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities, 18*, 83–93.
- Horwitz, S. M., Kerker, B. D., Owens, P. L., & Zigler, E. (2001). *The health status and needs of individuals with mental retardation*. New Haven: Yale University.
- Horwitz, S. M., & Stein, R. (1990). Health maintenance organizations vs. indemnity insurance for children with chronic illness: Trading gaps in coverage. *American Journal of Diseases in Children, 144*, 581–586.
- Ireys, H. T., Grason, H. A., & Guyer, B. (1996). Assuring quality of care for children with special needs in managed care organizations: Roles for pediatricians. *Pediatrics, 98*, 178–185.
- Karp, N. (1996). Individualized wrap-around services for children with emotional, behavioral, and mental disorders. In G. H. Singer, L. E. Powers,

- & A. L. Olson (Eds.), *Redefining family support: Innovations in public-private partnerships* (pp. 291–310). Baltimore: Brookes.
- Kasari, C., Freeman, S., & Paparella, T. (2000). Early intervention in autism: Joint attention and symbolic play. In L. Glidden (Ed.), *International review of research in mental retardation: Autism* (Vol. 23, pp. 208–238). San Diego: Academic Press.
- Kohler, F. W. (1999). Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disabilities, 14*, 150–158.
- Krauss, M. W., Gulley, S., Leiter, V., Minihan, P., & Sciegaj, M. (2000). *The family partners project: Report on a national survey of the health care experiences of families of children with special health care needs*. Waltham, MA: Brandeis University.
- Krauss, M. W., Wells, N., Gulley, S., & Anderson, B. (2001). Navigating systems of care: Results from a national survey of families of children with special health care needs. *Children's Services: Social Policy, Research, and Practice, 4*, 165–188.
- Kuhlthau, K., Walker, D. K., Perrin, J. M., Bauman, L., Gortmaker, S. L., Newacheck, P. W., & Stein, R. E. K. (1998). Assessing managed care for children with chronic conditions. *Health Affairs, 17*, 42–52.
- Leiter, V., Krauss, M. W., Anderson, B., & Wells, N. (in press). The consequences of caring: Impacts of mothering a child with special needs. *Journal of Family Issues*.
- McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., Perrin, J. M., Shonkoff, J. P., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics, 102*, 137–140.
- National Research Council. (2001). *Educating children with autism*. Committee on Educational Interventions for Children With Autism. Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.
- Newacheck, P., Hung, Y. Y., Marchi, K. S., Hughes, D. C., Pitter, C., & Stoddard, J. (2001). The impact of managed care on children's access, satisfaction, use, and quality of care. *Health Services Research, 36*, 315–334.
- Newacheck, P., McManus, M., Fox, H. B., Hung, Y., & Halfon, N. (2000). Access to health care for children with special health care needs. *Pediatrics, 105*, 760–766.
- Newacheck, P., Stoddard, J., & Halfon, N. (1994). Children with chronic illness and Medicaid managed care. *Pediatrics, 93*, 497–500.
- Newacheck, P. W., Strickland, B., Shonkoff, J. P., Perrin, J. M., McPherson, M., McManus, M., Lauver, C., Fox, H., & Arango, P. (1998). An epidemiologic profile of children with special health care needs. *Pediatrics, 102*, 117–123.
- Office of the Surgeon General. (2002). *Closing the gap: A national blueprint to improve the health of persons with mental retardation: A report of the Surgeon General's Conference on Health Disparities and Mental Retardation*. Rockville, MD: U.S. Department of Health and Human Services. (Available online from www.surgeongeneral.gov/topics/mentalretardation)
- Perrin, J. M. (2002). Health services research for children with disabilities. *The Milbank Quarterly, 80*, 303–324.
- Rogers, S. J. (2000). Diagnosis of autism before age three. In L. Glidden (Ed.), *International review of research in mental retardation: Autism* (Vol. 23, pp. 1–32). San Diego: Academic Press.
- Seltzer, M. M., Krauss, M. W., Orsmond, G., & Vestal, C. (2000). Families of adolescents and adults with autism: Uncharted territory. In L. Glidden (Ed.), *International review of research in mental retardation: Autism* (Vol. 23, pp. 267–294). San Diego: Academic Press.
- Simpson, L., & Fraser, I. (1999). Children and managed care: What research can, can't and should tell us about impact. *Medical Care Research and Review, 56*, 13–36.

Received 4/1/02, first decision 6/18/02, accepted 7/05/02.

Editor-in-charge: Steven J. Taylor

This study was supported by the David and Lucile Packard Foundation, the Jack E. and Zella B. Butler Foundation, and the U.S. Bureau of Maternal and Child Health, Division of Services for Children With Special Health Care Needs. Support for the preparation of this manuscript was provided by The Consortium for Children With Disabilities and Special Health Care Needs, a National Rehabilitation Research and Training Center funded by Grant H133B001200 from the National Institute on Disability Research and Rehabilitation of the

U.S. Department of Education. We gratefully acknowledge Valerie Leiter and Deborah Garnick for their helpful suggestions on earlier versions of this manuscript.

Authors:

Marty Wyngaarden Krauss, PhD (E-mail: krauss@brandeis.edu), John Stein Professor of Disability Research, The Heller School for Social Policy and Management; and **Stephen Gulley, MSW,**

Research Associate, Starr Center for Mental Retardation, The Heller School for Social Policy and Management, MS 035, Brandeis University, PO Box 549110, Waltham, MA 02454–9110. **Mark Sciegaj, PhD**, Associate Professor of Public Policy and Management and Director, Center for Research on Aging and Intergenerational Studies, Lasell College, 60 Seminary Ave., Newton, MA 02466. **Nora Wells**, Family Voices at the Federation for Children with Special Needs, 1135 Tremont St., Boston, MA 02120.