

**PEDIATRIC PROVIDER CAPACITY FOR
CHILDREN WITH SPECIAL HEALTH CARE NEEDS:
RESULTS FROM A NATIONAL SURVEY OF
STATE TITLE V DIRECTORS**

By

**Stephanie J. Limb
Margaret A. McManus
Harriette B. Fox**

March 2001

**PEDIATRIC PROVIDER CAPACITY FOR
CHILDREN WITH SPECIAL HEALTH CARE NEEDS:
RESULTS FROM A NATIONAL SURVEY OF
STATE TITLE V DIRECTORS**

**Stephanie J. Limb
Margaret A. McManus
Harriette B. Fox**

**MCH Policy Research Center
750 17th Street, NW, Suite 1025
Washington, DC 20006
www.mchpolicy.org**

March 2001



Acknowledgements

This study was supported by the federal Maternal and Child Health Bureau. We would especially like to thank Merle McPherson, Lynda Honberg, Bonnie Strickland, and Cassie Lauver for their support and assistance in designing the survey instrument and reviewing the study findings.

We also wish to thank other experts who reviewed the survey instrument for their insightful criticisms and comments. In particular, we wish to thank Richard Antonelli, Treeby Brown, James Bryant, Antoinette Eaton, Christopher Kus, Paul Newacheck, and Peters Willson.

Finally, we want to acknowledge the state Title V directors who participated in the survey. Their thoughtful answers and timely responses ensured that the survey yielded important and valuable information regarding access to care by children with special health care needs.

TABLE OF CONTENTS

I. Introduction	1
II. Overview of Key Findings	6
III. Study Results	11
A. Physician Services	11
1. Medical Homes.....	11
Strategies to Improve Access to Medical Homes.....	12
2. Pediatric Subspecialists.....	18
Strategies to Improve Access to Pediatric Subspecialists.....	19
B. Inpatient Hospital Care	24
C. Specialty Services	27
1. Home Health Care.....	27
2. Ancillary Therapies and Audiology Services.....	30
3. Dental Care.....	36
Strategies to Improve Access to Home Health Care, Ancillary Therapies, Audiology Services, and Dental Care.....	40
D. Mental Health Services	41
Strategies to Improve Access to Mental Health Services.....	43
IV. Summary and Recommendations	49

List of Tables

Table 1:	Title V Directors' Assessment of Access to Health Services Important to Children with Special Health Care Needs.....	9
Table 2:	Title V Directors' Assessment of the Most Significant Causes of Access Barriers to Health Services Important to Children with Special Health Care Needs	10
Table 3:	Title V Directors' Assessment of Access to Medical Homes.....	16
Table 4:	Title V Directors' Assessment of the Reasons for Primary Care Providers' Difficulties in Performing Medical Home Functions.....	17
Table 5:	Title V Directors' Assessment of Access to Pediatric Subspecialists.....	21
Table 6:	Title V Directors' Assessment of the Reasons for Access Barriers to Pediatric Subspecialists.....	23
Table 7:	Title V Directors' Assessment of Access to Inpatient Hospital Care	25
Table 8:	Title V Directors' Assessment of the Reasons for Access Barriers to Inpatient Hospital Care	26
Table 9:	Title V Directors' Assessment of Access to Home Health Care	28
Table 10:	Title V Directors' Assessment of the Reasons for Access Barriers to Home Health Care.....	29
Table 11:	Title V Directors' Assessment of Access to Occupational, Physical, and Speech Therapy and Audiology Services.....	31
Table 12:	Title V Directors' Assessment of the Reasons for Access Barriers to Ancillary Therapies and Audiology Services	33
Table 13:	Title V Directors' Assessment of Access to Dental Care.....	38
Table 14:	Title V Directors' Assessment of the Reasons for Access Barriers to Dental Care	39
Table 15:	Title V Directors' Assessment of Access to Mental Health Services.....	45
Table 16:	Title V Directors' Assessment of the Reasons for Access Barriers to Mental Health Services.....	47

I. INTRODUCTION

At the request of the federal Maternal and Child Health Bureau (MCHB), the Maternal and Child Health Policy Research Center conducted a survey of state Title V directors to obtain their assessment of the critical issues regarding pediatric provider availability for children with special health care needs. This report provides the findings of that survey. It was designed to elicit information regarding strategies to improve pediatric provider capacity but focused, in particular, on the availability of a variety of services important to children with special health care needs as well as the possible causes of access problems.

The survey follows on the activities of a pediatric expert work group, which was convened by MCHB in February 2000 and found that children with special health care needs in managed care plans face serious problems accessing necessary services, including medical homes, pediatric subspecialty services, and mental health services.¹ On the basis of its members' experiences and the available research, the group concluded that comprehensive pediatric provider networks to serve children with special health care needs are not consistently available for a variety of reasons, including inadequate reimbursement, provider shortages, referral barriers, and managed care plans' failure to include sufficient numbers of pediatric, rather than adult, specialists in their networks.

¹ McManus, M, Fox, H, Newacheck, P. *Pediatric Provider Networks for Children with Special Needs in the Current Health Insurance Market*. Washington, DC: Maternal and Child Health Policy Research Center, November 2000.

Based on MCHB's recommendations, the services addressed in the survey were:

- medical homes that provide a single source of comprehensive and continuous care in the community and that coordinate all necessary medical and non-medical services required to help children achieve their maximum potential;
- pediatric medical and surgical subspecialty care;
- inpatient care at hospitals with appropriate pediatric expertise and capacity;
- home health care;
- occupational, physical, and speech therapy and audiology services;
- dental care; and
- mental health services.

For each service, we asked the Title V program director to assess the adequacy of access by children with special health care needs in their state. We specified that all children with special needs² were to be included in their assessment, not just those who qualify for Title V services in their state. Respondents were asked to evaluate access on a scale of one to five, with one being more than adequate and five being not at all adequate.³ We also asked if access to selected services differed between children with public and private insurance and if children with particular diagnoses faced greater access barriers than other children with special health care needs. We then asked the respondents to assess the significance of possible causes of the access problems. We reviewed the

² Children with special health care needs were defined, according to the federal Maternal and Child Health Bureau definition, as those who have, or are at risk for, a chronic physical, developmental, behavioral, or emotional condition requiring health and related services of a type or amount beyond those required by children generally.

³ For all questions, respondents could answer that they were not sure. All of the "not sure" responses were eliminated from our analyses.

literature on physician satisfaction and access to care to generate the possible causes, which can be classified into four general categories: training, supply and distribution, managed care practices, and reimbursement and other causes. Again, respondents were asked to evaluate the importance of each possible cause on a scale of one to five, with one being extremely significant and five being not at all significant.³

The survey was mailed to state Title V program directors in all 50 states and the District of Columbia in December 2000. Thirty-six states, representing all regions and states of all sizes, completed the survey for a response rate of 71 percent.⁴

There are several limitations to this study, however, which stem primarily from the fact that assessments of access to the various pediatric services are based on state Title V directors' opinions and experiences. One limitation, therefore, is that the study is based on subjective data. The extent to which state Title V directors had access to needs assessment or other relevant data varied by service, although data were most often available to them for questions pertaining to medical homes.⁵ Another study limitation is that although we included questions on mental health access in our survey, most state Title V agencies serve primarily children with complex physical conditions, and their directors' perceptions regarding mental health service access may be less reliable than for the other services. This may explain the relatively high number of "not sure" responses

⁴ The states that did not complete the survey were: California, District of Columbia, Georgia, Indiana, Louisiana, Maryland, Maine, Michigan, North Carolina, New Hampshire, Nevada, South Dakota, Virginia, Washington, and West Virginia.

⁵ Sixty percent of respondents relied on needs assessment or other relevant data to answer the medical homes questions, compared with just 30 percent for the pediatric subspecialty and mental health services questions. Only 17 percent relied on data to answer the inpatient hospital care questions; 39 percent relied on data for the questions on ancillary therapies, audiology services, home health care, and dental care.

for these questions.⁶ A third limitation is that state Title V directors were not always comfortable answering questions about managed care practices; this was particularly notable for the questions on home health and mental health care access, as evidenced by the number of “not sure” responses.⁷ Although we encouraged state Title V directors to seek input from other state agencies, particularly the mental health department, provider organizations, and family groups to answer the survey questions, only seven states (19 percent) did so. Finally, the study is limited by having response rates that varied by region. Although we had an overall response rate of more than 70 percent, response in the South was 59 percent, but 78 percent in the Northeast, 77 percent in the West, and 75 percent in the Midwest.⁸

The report has three sections. The first section provides an overview of our findings. The second section summarizes state Title V directors’ assessments of pediatric provider capacity to furnish medical home services; medical and surgical subspecialty services; inpatient hospital care; home health care; occupational, physical, and speech therapy and audiology services; dental care; and mental health services for all children with special health care needs. It also highlights innovative strategies to improve access to care. Tables on state Title V directors’ assessment of access and causes of access

⁶ Four states chose not to answer any of the questions in the mental health section. In addition, the proportion of respondents answering “not sure” for six of the 11 possible reasons for access barriers to mental health services ranged from 42 percent to 58 percent.

⁷ Some of these “not sure” responses came from directors in states where managed care is not widespread. Therefore, the questions dealing with managed care practices were not likely to be as important to access in their state.

⁸ We relied on the U.S. Census Bureau’s four regions: Northeast, South, Midwest, and West.

barriers follow each service description. The third section discusses recommendations MCHB could explore to improve access.

II. OVERVIEW OF KEY FINDINGS

Access to pediatric providers important to children with special health care needs varied significantly by service, by region, and even by insurance status and type of chronic condition, according to state Title V Directors of Programs for Children with Special Health Care Needs. Among the services we examined, access to inpatient hospital care by children with special health care needs was considered to be the most adequate by state Title V directors and access to dental care the least adequate, as shown in Table 1. Almost half of the respondents perceived that inpatient hospital care with appropriate pediatric capacity was adequate or more than adequate. In contrast, no respondent reported an adequate rating for dental care. Other health services that directors were particularly concerned about were mental health and home health. At least 75 percent of Title V respondents rated mental health services access as not very or not at all adequate, and almost two thirds of directors rated home health care the same.

Access to the selected services reportedly varied by region of the country. State Title V directors in the West reported the lowest access ratings for eight of the 13 services we examined: medical homes, pediatric subspecialty services, occupational, physical, and speech therapies, audiology services, mental health therapies, and medication evaluation and management. State Title V directors in the Northeast gave the lowest access ratings for home health care, psychiatric and psychological evaluations, and dental care. Our study also revealed that state Title V directors in eight of the 36

states⁹ that responded to our survey perceived that access to all of the services that we examined was not very adequate.

State Title V directors also reported access differences for children with special health care needs with public insurance and those with private coverage. With the exception of mental health services and dental care, directors commonly reported that access was better for the publicly insured children. In addition, state Title V directors reported that children with autism experienced greater difficulties than other children with special health care needs in accessing needed care, particularly medical homes, pediatric subspecialty services, and mental health services. Other conditions associated with access disparities were behavioral health conditions, complex or rare conditions, developmental disabilities, and cerebral palsy.

Although the likely causes of access barriers and their significance varied by type of service, as shown in Table 2, we found three causes to be commonly reported across most or all health services. The first cause that was commonly identified as very or extremely significant (by between 61 and 84 percent of state Title V directors) was the uneven distribution of pediatric providers in the state. The second reason that was commonly cited by a somewhat smaller proportion of respondents was the limited number of providers able to serve multicultural and non-English-speaking populations. The third reason consistently cited as a serious problem affecting access to most health services was restrictive medical necessity interpretations by managed care organizations.

⁹ These states were Alaska, Arizona, Colorado, Mississippi, Montana, New Mexico, Oklahoma, and Wyoming.

With respect to causes of access barriers that differed in significance by type of health service, we found that restrictive managed care policies were particularly important explanations for mental health services barriers and were very important for pediatric subspecialty services, ancillary therapies, and audiology services but were reportedly not as important as supply and distribution and reimbursement problems for access to medical homes, inpatient hospital care, home health care, and dental care. Among the managed care policies contributing to access difficulties, state Title V directors most commonly cited plans' failure to include sufficient numbers of providers with pediatric expertise in their networks.

Table 1

Title V Directors' Assessment of Access to Health Services Important to Children with Special Health Care Needs

Table 1 Title V Directors' Assessment of Access to Health Services Important to Children with Special Health Care Needs	Average Access Rating*	More than Adequate (1)	Adequate (2)	Somewhat Adequate (3)	Not Very Adequate (4)	Not At All Adequate (5)
Services						
1. Medical Homes (n=36)	3.00	2.8%	25.0%	47.2%	19.4%	5.6%
2. Pediatric Subspecialists (n=36)	3.15	2.8	19.4	47.2	22.2	8.3
3. Inpatient Hospital Care (n=36)	2.63	13.9	27.8	41.7	13.9	2.8
4. Home Health Care (n=30)	3.73	3.3	6.7	26.7	40.0	23.3
5. Occupational Therapy (n=36)	2.98	2.8	33.3	30.6	30.6	2.8
6. Physical Therapy (n=36)	2.81	2.8	36.1	38.9	22.2	0.0
7. Speech Therapy (n=36)	3.03	2.8	25.0	38.9	33.3	0.0
8. Audiology Services (n=36)	3.12	2.8	16.7	52.8	22.2	5.6
9. Dental Care (n=35)	4.57	0.0	0.0	5.7	31.4	62.9
10. Psychiatric Evaluations (n=32)	4.33	0.0	3.1	18.8	18.8	59.4
11. Psychological Evaluations (n=32)	4.08	0.0	3.1	21.9	37.5	37.5
12. Mental Health Therapy (n=32)	4.33	0.0	3.1	15.6	25.0	56.3
13. Medication Evaluation and Management (n=30)	4.43	0.0	3.3	16.7	13.3	66.7

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V/Children with Special Health Care Needs Program Directors in December 2000.

Notes: * 1=More than Adequate
 2=Adequate
 3=Somewhat Adequate
 4=Not Very Adequate
 5=Not At All Adequate

Table 2

Title V Directors' Assessment of the Most Significant Causes* of Access Barriers to Health Services Important to Children with Special Health Care Needs

	Medical Homes	Pediatric Subspecialists	Inpatient Hospital Care	Home Health Care	Occupational Therapy	Physical Therapy	Speech Therapy	Audiology Services	Dental Care	Mental Health Services
Training, Supply, and Distribution	36.4%	n/a	n/a	65.5%	37.6%	37.5%	34.4%	34.4%	66.6%	n/a
1. Lack of Training										
2. General Supply Shortages	44.0	41.2	20.6	58.0	36.4	38.2	50.0	30.3	73.5	70.9
3. Uneven Distribution of Providers Throughout the State	70.6	69.5	61.1	74.2	65.8	65.8	65.8	65.7	77.2	83.8
4. Limited Number of Providers Able to Serve Multicultural and Non-English-Speaking Populations	44.1	56.3	n/a	67.8	58.6	56.6	62.1	58.6	65.5	74.0
Managed Care Practices and Reimbursement										
1. Insufficient Numbers of Pediatric Providers in Networks	n/a	37.5	15.4	50.0	57.9	57.9	57.9	68.4	64.7	84.3
2. Referrals to Providers with Adult Expertise	n/a	24.0	n/a	58.3	35.3	35.3	41.2	47.0	53.3	86.7
3. Administrative Burdens	n/a	43.4	n/a	n/a	n/a	n/a	n/a	n/a	n/a	55.6
4. Restrictive Medical Necessity Interpretations	n/a	50.0	21.7	60.0	58.4	54.2	56.5	52.4	55.0	n/a
5. Inadequate Reimbursement	65.8	44.0	37.9	69.3	50.0	40.0	46.7	40.0	66.7	70.0

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V/Children with Special Health Care Needs Program Directors in December 2000.

n/a = not applicable because this cause was not included as an access barrier

Notes: * The most significant causes are defined by the proportion of states who assigned a ranking of extremely significant (1) or very significant (2) to a particular cause.

III. STUDY RESULTS

A. Physician Services

1. Medical Homes

Most children with special health care needs have a usual source of primary care, but not all primary care providers are able to offer the full array of services recommended in a medical home. According to the American Academy of Pediatrics and the Maternal and Child Health Bureau, these services include the provision of appropriate preventive care, ambulatory care and inpatient care, consultation by and referral to subspecialists, interaction with schools and community agencies, and centralized recordkeeping.

State Title V directors estimated that more than half of primary care providers for children with special health care needs are pediatricians; about a third are family physicians; and the remainder are internists, specialists, or nurse practitioners. However, when asked to evaluate the extent to which children with special health care needs had access to primary care that could be considered a “medical home,” states reported, on average, that access was only somewhat adequate. In fact, a quarter of Title V directors rated access to medical homes as not very or not at all adequate, as shown in Table 3. Directors in the West reported the most serious difficulties while those in the South reported the least difficulties. Access problems were also commonly reported for children with private insurance coverage. In addition, children with autism, behavioral health diagnoses, and complex or rare conditions reportedly had less access to medical homes than other children with special health care needs.

While state Title V directors cited many explanations for limitations in primary care providers' capacity to furnish medical homes, the most significant was the lack of time to dedicate to medical home functions, as shown in Table 4. About 80 percent of Title V directors found this cause to be very or extremely significant. In addition, uneven distribution of trained providers throughout the state, insufficient reimbursement, and inability to provide care coordination functions were each cited as serious concerns in about two thirds of the states.

Strategies to Improve Access to Medical Homes

State Title V agencies appeared to be very involved in collaborating with other agencies and organizations on initiatives to improve medical home availability and access. More than 80 percent reported working with their state Medicaid programs and Family Voices organizations around the medical home issue, and about half reported working with managed care organizations, providers in the community, and other parent/family groups as well.

Most of these collaborations involved participating in workgroups and advisory boards, attending meetings, strategic planning, providing input on Medicaid managed care contracts, engaging in efforts to improve reimbursement rates, and providing technical assistance and information. Other initiatives to improve access to medical homes included:

- working with the state chapters of the American Academy of Pediatrics (AAP) and the American Academy of Family Physicians to educate primary care providers about medical homes and how they could work with the Title V program to provide medical homes that include care coordination services (Illinois).

- collaborating on a provider survey to identify areas of needed education regarding medical homes (Iowa).
- sponsoring a training program for providers and families on medical homes with representatives from the state Medicaid program, managed care organizations, the AAP, Family Voices, and other parent/family organizations involved in planning and serving as participants (Kentucky).
- working with hospital-based subspecialists at an academic medical center to develop standards for community-based multidisciplinary diagnostic and treatment and planning teams. The teams design a treatment plan that is shared with the medical home physician and other treatment providers, including the child's school. The treatment plan assists the primary care provider in managing the child's routine needs and assists in the decision making process regarding specialty needs. Primary care providers have the opportunity to ask questions directly of the treatment and planning teams, and staff from the Title V program review the teams periodically for quality assurance purposes (Nebraska).
- contributing information to a statewide data system that collects information from all state agencies working with special needs children, including the state Department of Mental Health. The system does not contain medical information but allows care coordinators and medical home providers to identify other agencies that are involved in a child's care and to contact them. The project is currently being piloted in one region of the state (Tennessee).

When asked to identify state strategies or initiatives they would like to see implemented to improve the availability of and access to medical homes, Title V directors most frequently responded that increased reimbursement rates were essential. Increasing the rates would enable providers to provide needed care coordination, family support, and telephone consultations. Another initiative frequently suggested was additional training in medical home concepts for pediatricians, family practitioners, and other health care providers and education in medical home benefits for families and managed care organizations. Other suggestions to improve access to medical homes were:

- apply the current children with special health care needs safeguards developed by the Health Care Financing Administration (HCFA) to all managed care plans,¹⁰
- require managed care plans to develop and implement critical pathways for children with special health care needs to access services, and
- designate certain physician practices as medical home practices and provide them with enhanced reimbursement.

State Title V directors also made many suggestions for ways that the federal Maternal and Child Health Bureau (MCHB) could help improve medical home availability and access. Most respondents hoped MCHB would continue to fund medical home demonstration projects, through SPRANS or other sources, and to conduct medical home training programs and would provide greater funding to state Title V programs to conduct their own training and outreach. Many also suggested working with HCFA to ensure that providers receive adequate compensation, particularly for providing care coordination services. Other suggestions were:

- set standards for physician education and for medical homes,
- highlight and disseminate information to state Title V programs about medical home models that work,
- promulgate practical guidelines and methods for physicians' offices to provide medical home services and provide specific strategies and definitions of medical home elements, such as what does care coordination look like in practice,
- work to make medical home access a quality performance measure in HEDIS,
- provide mobile clinic grants,

¹⁰ The current safeguards are available on-line at www.hcfa.gov/medicaid/smd11901.pdf. For more information on these safeguards, see Fox, HB, McManus, MA, and Austrian, JS. *An Analysis of Safeguards for Children with Special Needs in States' Medicaid Managed Care Contracts, 1999*. Washington, DC: MCH Policy Research Center, December 2000.

- define medical home for the Title V block grant reporting measure, and
- change the name of medical home to avoid the appearance that it is a place of care.

Table 3

Title V Directors' Assessment of Access to Medical Homes

Overall Access Rating Distribution Percent of States Reporting (n=36)					
More than Adequate (1)		2.8%			
Adequate (2)		25.0%			
Somewhat Adequate (3)		47.2%			
Not Very Adequate (4)		19.4%			
Not at All Adequate (5)		5.6%			
State Access Ratings* by Region					
Northeast	2.86	MS	4	WI	2
CT	3	OK	3	West	3.50
MA	2	SC	3	AK	4
NJ	3	TN	2	AZ	4
NY	3	TX	3	CO	5
PA	4	Midwest	2.89	HI	3
RI	2	IL	5	ID	3
VT	3	IA	3	MT	4
South	2.70	KS	2	NM	2
AL	3	MN	4	OR	4
AR	1	MO	3	UT	3
DE	3	NE	2	WY	3
FL	2	ND	3	National Average	3.00
KY	3	OH	2		

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V directors in December 2000.

Notes: * 1=More than Adequate
 2=Adequate
 3=Somewhat Adequate
 4=Not Very Adequate
 5=Not at All Adequate

Table 4**Title V Directors= Assessment of the Reasons for Primary Care Providers=
Difficulties in Performing Medical Home Functions**

Reasons	Average Rating	Extremely Significant (1)	Very Significant (2)	Significant (3)	Somewhat Significant (4)	Not at All Significant (5)
1. Insufficient Time (n=33)	1.8	33.3%	48.5%	18.2%	0.0%	0.0%
2. Inadequate Reimbursement (n=35)	2.0	42.9	22.9	22.9	11.4	0.0
3. Uneven Distribution of Trained Providers Throughout the State (n=34)	2.0	41.2	29.4	20.6	5.9	2.9
4. Inability to Provide Care Coordination (n=33)	2.1	30.3	36.4	27.3	6.1	0.0
5. Limited Number of Providers Able to Serve Multicultural and non-English-Speaking Populations (n=34)	2.4	26.5	17.6	41.2	14.7	0.0
6. Lack of Training in Medical Home Concepts (n=33)	2.7	15.2	21.2	45.5	18.2	0.0
7. Insufficient Number of Trained Providers in the State (n=34)	2.8	17.6	26.4	17.6	32.4	5.9

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V/Children with Special Health Care Needs Program Directors in December 2000.

2. Pediatric Subspecialists

Children with special health care needs often rely on pediatric medical subspecialists and surgical subspecialists for evaluation and treatment. We questioned Title V directors about 20 specific pediatric subspecialties and found that access varied by specialty, with the most serious access problems reported for neuropsychologists and behavioral/developmental pediatricians, and the fewest access problems reported for pediatric cardiologists and otolaryngologists, as shown in Table 5. State Title V directors reported access to pediatric subspecialists as a whole was somewhat adequate, but a third found access to be not very or not at all adequate. Directors in the West and the South reported greater difficulties than directors in the Northeast and Midwest.

Not unlike the access differences reported for medical homes, Title V directors perceived that certain groups of children with special health care needs experienced greater access difficulties. They reported that privately insured children had less access to pediatric subspecialists than publicly insured children, attributing this difference to state oversight of public insurance programs. Title V directors also reported that children with autism faced greater access barriers to pediatric subspecialists than children with other conditions.

Title V directors most frequently attributed poor access to pediatric subspecialists to uneven distribution in their states; 70 percent reported this as a very or extremely significant problem, as shown in Table 6. The two other leading reasons were the limited number of pediatric subspecialists able to serve multicultural and non-English-speaking populations and access restrictions due to managed care organizations' (MCOs') medical

necessity interpretations. Not considered important by the state Title V directors were MCOs' use of adult specialists, states' population base to support pediatric subspecialists, MCOs' failure to pay for out-of-state care, and primary care providers' increased scope of practice.

Strategies to Improve Access to Pediatric Subspecialists

As with medical homes, state Title V agencies collaborated most closely with their state Medicaid programs on initiatives to improve access to pediatric subspecialists. In addition, nearly half reported working with the AAP and Family Voices organizations, and about a third reported working with managed care plans, providers in the community, and other parent/family organizations. Most of these collaborations involved participating in workgroups and advisory boards, providing input on Medicaid managed care contracts, engaging in efforts to improve reimbursement rates, and bringing providers to underserved areas.

State Title V directors frequently noted the need for state strategies or initiatives to overcome the uneven distribution of subspecialists. The most common strategies suggested were increased use of telemedicine, additional satellite and mobile clinics in rural areas, and loan repayment and other financial incentives to attract subspecialists to rural areas. Many respondents also suggested that managed care organizations be required to include a certain number of pediatric subspecialists on their panels. Other strategies suggested to improve access to pediatric subspecialists were:

- minimize the prior authorization and written referral requirements for the primary care provider,

- develop protocols for prior authorization for specific subspecialists for children with particular conditions,
- develop standardized guidelines of care for children with special health care needs,
- make out-of-plan referrals easier,
- educate managed care organizations about children with special health care needs' need for multidisciplinary care, and
- reimburse families for travel expenses.

As with medical homes, most of the recommendations for MCHB's involvement in improving access to pediatric subspecialists involved funding and training efforts.

Other suggestions were:

- advocate for a certain number of pediatric subspecialists to be included on each managed care organization's provider panel,
- work with the American Medical Association and other medical specialist professional organizations to help adult specialists provide health care services for adolescents with special health care needs to ease the transition from pediatric to adult providers,
- increase education efforts about the importance of pediatric subspecialty care for children with special health care needs,
- develop better ways of measuring pediatric subspecialty availability and access, and
- advocate that medical schools require students to take a longer rotation in the care of children with special health care needs.

Table 5

Title V Directors' Assessment of Access to Pediatric Subspecialists

States	Average Access Ratings* (n=36)	Allergy Immunology (n=31)	Behavioral/Developmental (n=34)	Cardiology (n=34)	Critical Care (n=33)	Emergency Medicine (n=33)	Endocrinology (n=34)	Gastroenterology (n=34)	Genetics (n=34)	Hematology/Oncology (n=34)	Infectious Disease (n=32)	Nephrology (n=32)	Neurosurgery (n=32)	Neuropsychology (n=29)	Orthopedics (n=34)	Ophthalmology (n=34)	Otolaryngology (n=34)	Pulmonology (n=33)	Rheumatology (n=33)	Surgery (n=34)	Urology (n=34)
Northeast	2.57	1.83	3.67	2.33	2.17	2.50	2.83	2.33	2.83	2.17	2.00	2.33	2.67	3.40	2.50	2.33	2.00	2.67	2.33	2.17	2.50
CT	4	2	5	2	2	3	2	2	2	2	2	2	2	3	2	3	2	2	2	2	2
MA	1	1	3	2	2	2	2	2	3	2	1	2	2	2	2	2	2	2	2	2	2
NJ	3	3	3	3	3	2	3	4	3	3	3	4	4	5	4	3	2	3	4	2	4
NY	3	2	4	3	2	2	3	2	3	2	2	2	2	3	2	2	2	2	2	2	3
RI	2	1	4	2	2	2	2	2	4	2	2	2	4	4	3	2	2	2	2	2	2
PA	2																				
VT	3	2	3	2	2	4	5	2	2	2	2	2	2	2	2	2	2	5	2	2	3
South	3.20	3.00	3.67	2.44	2.67	3.11	3.00	3.22	2.89	2.78	3.13	3.00	3.13	3.78	2.89	2.78	2.67	3.22	3.56	3.00	3.11
AL	4	5	5	3	2	5	3	3	3	3	3	3	3	4	2	2	2	3	3	3	3
AR	2	2	1	2	3	3	2	3	3	2	3	3	2	3	2	2	2	3	3	3	3
DE	3	2	3	1	2	3	3	3	2	4	3	2	2	3	1	2	2	2	3	2	3
FL	2	2	4	2	2	2	2	2	2	1				4	2	2	2	2	3	2	2
KY	3																				
MS	5	4	5	3	4	4	5	5	5	3	4	4	5	5	3	3	3	5	5	4	4
OK	4	4	4	4	4	4	4	4	5	5	5	4	4	4	5	4	4	5	5	5	5
SC	3	2	3	2	2	2	3	3	2	2	2	3	3	4	3	3	2	3	4	3	3
TN	3	3	5	2	2	2	2	3	1	2	2	2	3	4	5	4	4	3	3	2	2
TX	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3	3
Midwest	2.78	2.75	3.67	2.44	2.56	2.89	2.89	2.78	2.78	2.56	2.56	3.00	2.50	3.50	2.67	3.00	2.44	2.75	3.00	2.67	2.78
IL	3		4	3	3	3	3	3	3	3	3	3	3		3	3	3	3	3	3	3
IA	3	3	5	3	2	3	3	3	3	3	3	3	3	4	3	3	2	4	5	3	3
KS	3	2	4	2	2	2	3	4	2	2	2	4	2		2	3	2	2	2	2	2
MN	2	2	4	2	2	4	3	2	4	2	2	2	3	4	2	4	2	2	3	2	3
MO	3	5	4	3	3	3	3	3	3	3	3				3	3	3			2	3
NE	4	4	4	3	4	4	4	3	3	3	3	4	3	4	5	3	3	3	3	4	4
ND	2	2	2	2	3	3	2	3	2	3	2	3	2	2	2	3	3	3	3	3	2
OH	2	2	4	2	2	2	3	2	3	2	3	3	2	5	2	3	2	3	3	3	3
WI	3	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2

Table 5 (Cont.)

States	Average Access Ratings* (n=36)	Allergy/Immunology (n=31)	Behavioral/Developmental (n=34)	Cardiology (n=34)	Critical Care (n=33)	Emergency Medicine (n=33)	Endocrinology (n=34)	Gastroenterology (n=34)	Genetics (n=34)	Hematology/Oncology (n=34)	Infectious Disease (n=32)	Nephrology (n=32)	Neurosurgery (n=32)	Neuropsychology (n=29)	Orthopedics (n=34)	Ophthalmology (n=34)	Otolaryngology (n=34)	Pulmonology (n=33)	Rheumatology (n=33)	Surgery (n=34)	Urology (n=34)
West	3.80	3.00	4.00	2.40	3.22	3.44	3.50	3.70	3.20	3.60	3.33	3.90	3.70	4.33	3.00	3.40	3.10	3.50	3.90	3.40	3.80
AK	4	2	4	2	3	3	4	2	4	4	4	4	4	5	3	3	2	3	3	3	3
AZ	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4
CO	5		5	3	4	4	5	5	3	5		5	5	5	3	5	5	5	5	4	5
HI	3	2	4	2	2	2	2	2	3	2	2	2	2	2	2	2	2	2	2	2	2
ID	4	5	4	3			5	4	5	5	5	5	5	5	4	5	5	5	5	4	5
MT	3	3	3	2	4	4	5	5	2	4	4	4	3	4	3	4	2	3	3	4	4
NM	3	2	4	1	3	3	2	5	2	4	2	5	2	4	3	2	2	2	5	3	5
OR	4	4	3	2	3	4	2	4	3	2	3	3	5	4	3	3	3	4	4	3	3
UT	3	2	4	1	1	2	2	2	3	2	2	2	3	3	2	2	2	2	3	2	2
WY	5		5	4	5	5	4	4	3	4	4	5	4	5	3	4	4	5	5	5	5
National Average Rating	3.15	2.73	3.77	2.41	2.71	3.04	3.09	3.10	2.94	2.86	2.83	3.17	3.07	3.83	2.80	2.95	2.63	3.10	3.32	2.89	3.13

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V/Children with Special Health Care Needs Program Directors in December 2000.

Notes: * 1=More than Adequate
 2=Adequate
 3=Somewhat Adequate
 4=Not Very Adequate
 5=Not at All Adequate

Table 16

Title V Directors= Assessment of the Reasons for Access Barriers to Mental Health Services

Reasons	Average Rating	Extremely Significant (1)	Very Significant (2)	Significant (3)	Somewhat Significant (4)	Not at All Significant (5)
1. Managed Care Organizations= Authorization of Services for Only Certain Diagnoses (n=17)	1.5	70.6%	17.6%	5.9%	5.9%	0.0%
2. Managed Care Organizations= Authorization of Too Few Services or Visits (n=21)	1.5	66.7	19.0	9.5	4.8	0.0
3. Managed Care Organizations= Failure to Include Sufficient Numbers of Pediatric Mental Health Providers in Networks (n=19)	1.6	63.2	21.1	10.5	0.0	5.3
4. Uneven Distribution of Mental Health Providers Throughout the State (n=31)	1.7	54.8	29.0	9.7	6.5	0.0
5. General Supply Shortages (n=31)	1.8	54.8	16.1	22.6	6.5	0.0
6. Managed Care Organizations= Referrals to Adult Specialists (n=15)	1.9	40.0	46.7	6.7	0.0	6.7
7. Reluctance of Available Mental Health Providers to Participate in Managed Care Networks Because Reimbursement is Inadequate (n=20)	1.9	45.0	25.0	25.0	5.0	0.0

B. Inpatient Hospital Care

Children with chronic conditions are far more likely to be hospitalized than children without chronic conditions. We asked State Title V directors about access to inpatient care at hospitals with appropriate pediatric expertise and capacity. Overall, states reported that access to inpatient care was adequate. Directors in the Northeast gave the highest access rating for inpatient hospital services. Seventeen percent of states cited access to inpatient hospital services as being not very or not at all adequate, as shown in Table 7. These states had large rural populations and few, if any, children's hospitals or academic medical centers. The majority of states did not report access differences to inpatient hospital care by insurance status. However, children and adolescents requiring hospitalization for mental health conditions reportedly faced more access difficulties than children with physical health conditions.

State Title V directors cited the uneven distribution of hospitals in their states as the most important reason for access barriers to inpatient hospital care -- 61 percent reported that where barriers existed, uneven distribution was a very or extremely significant reason, as shown in Table 8. States did not perceive that denial by MCOs of hospitalization at appropriate facilities, failure of MCOs to contract with hospitals with pediatric expertise, or willingness of MCOs to pay for out-of-state care were important factors limiting access to inpatient hospital care.

Table 7

Title V Directors' Assessment of Access to Inpatient Hospital Care

Overall Distribution of Access Ratings Percent of States Reporting (n=36)					
More than Adequate (1)	13.9%				
Adequate (2)	27.8%				
Somewhat Adequate (3)	41.7%				
Not Very Adequate (4)	13.9%				
Not at All Adequate (5)	2.8%				
State Access Ratings* by Region					
Northeast	1.86	MS	4	WI	2
CT	2	OK	4	West	2.80
MA	1	SC	2	AK	2
NJ	3	TN	2	AZ	3
NY	1	TX	3	CO	3
PA	3	Midwest	2.89	HI	2
RI	1	IL	3	ID	4
VT	2	IA	3	MT	2
South	2.80	KS	3	NM	4
AL	3	MN	5	OR	2
AR	3	MO	3	UT	2
DE	3	NE	3	WY	4
FL	1	ND	3	National Average	2.63
KY	3	OH	1		

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V directors in December 2000.

Notes: * 1=More than Adequate
 2=Adequate
 3=Somewhat Adequate
 4=Not Very Adequate
 5=Not at All Adequate

Table 8

Title V Directors= Assessment of the Reasons for Access Barriers to Inpatient Hospital Care

	Average Rating	Extremely Significant (1)	Very Significant (2)	Significant (3)	Somewhat Significant (4)	Not at All Significant (5)
1. Uneven Distribution of Hospitals with Appropriate Pediatric Expertise Throughout the State (n=36)	2.3	36.1%	25.0%	16.7%	13.9%	8.3%
2. Inadequate Reimbursement (n=29)	2.7	20.7	17.2	37.9	17.2	6.9
3. Inadequate Regionalization of Hospital Services (n=33)	3.0	15.2	24.2	18.2	27.3	15.2
4. General Supply Shortages (n=29)	3.5	10.3	10.3	24.1	27.6	27.6
5. Managed Care Organizations= Denial of Hospitalization at Appropriate Facilities (n=23)	3.7	13.0	8.7	13.0	21.7	43.5
6. Managed Care Organizations= Failure To Contract with Hospitals with Appropriate Pediatric Expertise (n=26)	3.9	0.0	15.4	15.4	30.8	38.5
7. Managed Care Organizations= Failure To Pay for Out-of-State Care (n=17)	4.0	0.0	11.8	11.8	41.2	35.3

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V/Children with Special Health Care Needs Program Directors in December 2000.

C. Specialty Services

1. Home Health Care

For children with special health care needs who are discharged from a hospital, short-term, sub-acute care provided in the home may be essential. In addition, some children with special health care needs may require intermittent or long-term home health care. Overall, state Title V directors reported that access to home health care was less than adequate. Almost two thirds of respondents rated home health care access as not very or not at all adequate, as shown in Table 9. Directors in the Northeast and West reported greater difficulties than those in the South and Midwest. In addition, directors across all regions reported that children with private insurance experience more difficulties accessing home health care services than publicly insured children, primarily because of the comprehensive home health benefits covered under Medicaid and most S-CHIP plans. Some respondents noted, however, that this scenario is changing as publicly insured children with special health care needs are being enrolled into managed care plans.

The four most important factors affecting access to home health care were the uneven distribution of providers in states, inadequate reimbursement, limited numbers of providers able to serve multicultural and non-English speaking populations, and insufficient training in pediatrics, as shown in Table 10. Other factors considered very important by at least half of respondents were MCOs' restrictive medical necessity interpretations, general supply shortages, MCOs' referrals to providers with adult expertise, and insufficient numbers of pediatric providers participating in MCOs.

Table 9

Title V Directors' Assessment of Access to Home Health Care

Overall Distribution of Access Ratings Percent of States Reporting (n=30)					
More than Adequate (1)	3.3%				
Adequate (2)	6.7%				
Somewhat Adequate (3)	26.7%				
Not Very Adequate (4)	40.0%				
Not at All Adequate (5)	23.3%				
State Access Ratings* by Region					
Northeast	4.60	MS	4	WI	
CT	5	OK	4	West	4.22
MA	5	SC	3	AK	4
NJ		TN	3	AZ	4
NY	4	TX	3	CO	5
PA		Midwest	3.29	HI	
RI	4	IL		ID	5
VT	5	IA	3	MT	4
South	3.11	KS	3	NM	4
AL	5	MN	5	OR	4
AR	2	MO	3	UT	4
DE	3	NE	4	WY	4
FL	1	ND	3	National Average	3.72
KY		OH	2		

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V directors in December 2000.

Notes: * 1=More than Adequate
 2=Adequate
 3=Somewhat Adequate
 4=Not Very Adequate
 5=Not at All Adequate

Table 10**Title V Directors= Assessment of the Reasons for Access Barriers to Home Health Care**

	Average Rating	Extremely Significant (1)	Very Significant (2)	Significant (3)	Somewhat Significant (4)	Not at All Significant (5)
1. Insufficient Training in Pediatrics (n=29)	2.1	41.4%	24.1%	20.7%	13.8%	0.0%
2. Limited Number of Specialty Providers Able to Serve Multicultural and Non-English-Speaking Populations (n=28)	2.1	35.7	32.1	21.4	7.1	3.6
3. Uneven Distribution of Providers Throughout the State (n=31)	2.1	25.8	48.4	19.4	6.5	0.0
4. Inadequate Reimbursement (n=26)	2.3	23.1	46.2	15.4	11.5	3.8
5. General Supply Shortages (n=31)	2.3	25.8	32.2	29.0	12.9	0.0
6. Managed Care Organizations= Failure To Include Sufficient Numbers of Providers with Pediatric Expertise in Networks (n=12)	2.4	25.0	25.0	33.3	16.7	0.0
7. Managed Care Organizations= Restrictive Medical Necessity Interpretations (n=20)	2.5	30.0	30.0	15.0	15.0	10.0
8. Managed Care Organizations= Referrals to Providers with Adult Expertise (n=12)	2.5	25.0	33.3	25.0	0.0	16.7

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V/Children with Special Health Care Needs Program Directors in December 2000.

2. Ancillary Therapies and Audiology Services

Many children with special health care needs require occupational, physical, and speech therapies and audiology services, particularly in early childhood, to improve or maintain their functioning. Overall, respondents reported that access to these services was somewhat adequate, with access to physical and occupational therapy being slightly better than access to speech therapy and audiology services, as shown in Table 11. Nonetheless, a third of states classified access to occupational and speech therapy as not very or not at all adequate, and about a quarter of states reported the same for physical therapy and audiology services. Title V directors in the West consistently reported the greatest access difficulties for all four services. Directors as a whole cited greater access difficulties for children with private insurance, noting that as with home health care, private insurance plans offer limited coverage for ancillary therapies and audiology services.

Title V directors reported the most influential factor affecting access to ancillary therapies was the uneven distribution of providers throughout the states, but for audiology services, it was the failure of MCOs to include sufficient numbers of audiologists with pediatric expertise in their networks. About two thirds of respondents reported each of these leading reasons to be very or extremely significant, as shown in Table 12. Other factors considered important by at least half the state Title V directors were the limited number of providers able to serve multicultural and non-English-speaking populations and limited access due to MCOs' restrictive medical necessity interpretations. Interestingly, inadequate reimbursement by insurers was considered an important cause of access difficulties by at least half of the respondents for occupational therapy and general supply shortages for speech therapy.

Table 11

Title V Directors' Assessment of Access to Occupational, Physical, and Speech Therapy, and Audiology Services

Overall Distribution of Access Rating	Occupational Therapy (n=36)	Physical Therapy (n=36)	Speech Therapy (n=36)	Audiology Services (n=36)
More than Adequate (1)	2.8%	2.8%	2.8%	2.8%
Adequate (2)	33.3%	36.1%	25.0%	16.7%
Somewhat Adequate (3)	30.6%	38.9%	38.9%	52.8%
Not Very Adequate (4)	30.6%	22.2%	33.3%	22.2%
Not at All Adequate (5)	2.8%	0.0%	0.0%	5.6%
State Access Ratings* by Region				
National Average	2.98	2.81	3.03	3.12
Northeast	2.71	2.43	2.86	2.86
CT	2	2	2	2
MA	2	2	3	2
NJ	3	3	3	3
NY	2	2	2	2
PA	2	2	2	3
RI	4	3	4	5
VT	4	3	4	3
South	2.80	2.50	2.90	3.10
AL	3	2	2	2
AR	2	2	2	2
DE	2	2	4	4
FL	1	1	1	1
KY	3	3	3	3
MS	3	3	3	4
OK	4	4	4	4
SC	4	3	3	3
TN	3	2	4	5
TX	3	3	3	3
Midwest	2.78	2.78	2.67	3.11
IL	2	2	2	3
IA	3	3	3	3
KS	2	2	2	2
MN	2	4	3	4
MO	2	2	2	3
NE	5	4	3	4
ND	3	3	3	3
OH	4	3	4	3
WI	2	2	2	3

Table 11 (Cont.)

Overall Distribution of Access Rating	Occupational Therapy (n=36)	Physical Therapy (n=36)	Speech Therapy (n=36)	Audiology Services (n=36)
State Access Ratings* by Region (Cont.)				
West	3.50	3.40	3.60	3.30
AK	4	4	3	3
AZ	4	4	4	4
CO	2	2	3	3
HI	4	3	4	3
ID	3	3	3	3
MT	4	4	4	4
NM	4	4	4	4
OR	3	3	4	3
UT	4	4	4	3
WY	3	3	3	3

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V Directors in December 2000.

Notes: * 1=More than Adequate
 2=Adequate
 3=Somewhat Adequate
 4=Not Very Adequate
 5=Not at All Adequate

Table 12

Title V Directors= Assessment of the Reasons for Access Barriers to Ancillary Therapies and Audiology Services

	Average Rating	Extremely Significant (1)	Very Significant (2)	Significant (3)	Somewhat Significant (4)	Not at All Significant (5)
1. Limited Number of Specialty Providers Able to Serve Multicultural and Non-English-Speaking Populations						
Occupational Therapy (n=29)	2.3	24.1%	34.5%	27.6%	10.3%	3.4%
Physical Therapy (n=30)	2.4	23.3	33.3	26.7	10.0	6.7
Speech Therapy (n=29)	2.2	27.6	34.5	27.6	10.3	0.0
Audiology Services (n=29)	2.3	27.6	31.0	24.1	13.8	3.4
2. Uneven Distribution of Providers Throughout the State						
Occupational Therapy (n=35)	2.4	22.9	42.9	14.3	14.3	5.7
Physical Therapy (n=35)	2.4	22.9	42.9	14.3	11.4	8.6
Speech Therapy (n=35)	2.4	22.9	42.9	11.4	14.3	8.6
Audiology Services (n=35)	2.4	17.1	48.6	17.1	14.3	2.9
3. Managed Care Organizations= Restrictive Medical Necessity Interpretations						
Occupational Therapy (n=24)	2.4	29.2	29.2	16.7	20.8	4.2
Physical Therapy (n=24)	2.5	25.0	29.2	20.8	20.8	4.2
Speech Therapy (n=23)	2.4	26.1	30.4	21.7	17.4	4.3
Audiology Services (n=21)	2.5	28.6	23.8	23.8	14.3	9.5

Table 12 (Cont.)

	Average Rating	Extremely Significant (1)	Very Significant (2)	Significant (3)	Somewhat Significant (4)	Not at All Significant (5)
4. Managed Care Organizations= Failure To Include Sufficient Numbers of Providers with Pediatric Expertise in Networks						
Occupational Therapy (n=19)	2.5	26.3%	31.6%	21.1%	10.5%	10.5%
Physical Therapy (n=19)	2.5	26.3	31.6	21.1	10.5	10.5
Speech Therapy (n=19)	2.5	26.3	31.6	21.1	10.5	10.5
Audiology Services (n=19)	2.2	31.6	36.8	15.8	10.5	5.3
5. Managed Care Organizations= Referrals to Providers with Adult Expertise						
Occupational Therapy (n=17)	2.8	11.8	23.5	47.1	5.9	11.8
Physical Therapy (n=17)	2.8	11.8	23.5	47.1	5.9	11.8
Speech Therapy (n=17)	2.8	11.8	29.4	35.3	11.8	11.8
Audiology Services (n=17)	2.6	17.6	29.4	35.3	5.9	11.8
6. Inadequate Reimbursement						
Occupational Therapy (n=30)	2.8	6.7	43.3	26.7	13.3	10.0
Physical Therapy (n=30)	2.9	6.7	33.3	36.7	13.3	10.0
Speech Therapy (n=30)	2.8	10.0	36.7	23.3	20.0	10.0
Audiology Services (n=30)	3.0	10.0	30.0	30.0	13.3	16.7

Table 12 (Cont.)

	Average Rating	Extremely Significant (1)	Very Significant (2)	Significant (3)	Somewhat Significant (4)	Not at All Significant (5)
7. Insufficient Training in Pediatrics						
Occupational Therapy (n=32)	2.9	18.8%	18.8%	21.9%	31.3%	9.4%
Physical Therapy (n=32)	3.0	15.6	21.9	21.9	28.1	12.5
Speech Therapy (n=32)	3.1	15.6	18.8	18.8	34.4	12.5
Audiology Services (n=32)	2.8	25.0	9.4	34.4	28.1	3.1
8. General Supply Shortages						
Occupational Therapy (n=33)	3.0	15.2	21.2	27.3	24.2	12.1
Physical Therapy (n=34)	3.1	8.8	29.4	20.6	26.5	14.7
Speech Therapy (n=32)	2.8	12.5	37.5	21.9	18.8	9.4
Audiology Services (n=33)	3.1	9.1	21.2	33.3	27.3	9.1

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V/Children with Special Health Care Needs Program Directors in December 2000.

3. Dental Care

Children with special health care needs, like all children, require dental services. Some, however, have dental care needs that are more involved, including lengthier preventive visits as well as more restorative and orthodontic or oral surgical care. When asked about access to dental care for children with special health care needs, state Title V directors reported that access was a serious problem. Almost 95 percent of respondents ranked dental access as not very or not at all adequate, as shown in Table 13. Title V directors in the Northeast reported greater access difficulties than directors in the other regions. State Title V directors also reported that publicly insured children face greater dental access barriers than privately insured children, unlike for the other types of health services we examined (medical homes, pediatric subspecialists, home health care, and ancillary therapies), primarily because low reimbursement rates discourage dentists from participating in public programs. Children with cerebral palsy, developmental disabilities, and behavioral health conditions also reportedly experience greater difficulties accessing dental care than other children with special health care needs.

While state Title V directors reported many important reasons limiting access to dental care, the two most important were the uneven distribution of dentists throughout the state and general supply shortages, as shown in Table 14. About three quarters of respondents found these reasons to be very or extremely significant. Four other reasons were each cited as important by about two thirds of respondents: inadequate reimbursement, insufficient training in pediatrics, limited number of dentists able to serve

multicultural and non-English-speaking populations, and the failure of MCOs to include sufficient numbers of dentists with pediatric expertise in their networks.

Table 13

Title V Directors' Assessment of Access to Dental Care

Overall Distribution of Access Ratings Percent of States Reporting (n=35)					
More than Adequate (1)		0.0%			
Adequate (2)		0.0%			
Somewhat Adequate (3)		5.7%			
Not Very Adequate (4)		31.4%			
Not at All Adequate (5)		62.9%			
State Access Ratings* by Region					
Northeast	4.86	MS	5	WI	4
CT	5	OK	5	West	4.50
MA	5	SC	3	AK	5
NJ	5	TN	5	AZ	5
NY	5	TX		CO	5
PA	4	Midwest	4.56	HI	4
RI	5	IL	5	ID	3
VT	5	IA	4	MT	5
South	4.44	KS	5	NM	5
AL	5	MN	5	OR	5
AR	4	MO	5	UT	4
DE	4	NE	4	WY	4
FL	5	ND	4	National Average	4.57
KY	4	OH	5		

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V directors in December 2000.

Notes: * 1=More than Adequate
 2=Adequate
 3=Somewhat Adequate
 4=Not Very Adequate
 5=Not at All Adequate

Table 14**Title V Directors= Assessment of the Reasons for Access Barriers to Dental Care**

	Average Rating	Extremely Significant (1)	Very Significant (2)	Significant (3)	Somewhat Significant (4)	Not at All Significant (5)
1. Uneven Distribution of Dentists Throughout the State (n=35)	1.9	42.9%	34.3%	14.3%	8.6%	0.0%
2. Managed Care Organizations= Failure To Include Sufficient Numbers of Dentists with Pediatric Expertise in Networks (n=17)	1.9	52.9	11.8	23.5	11.8	0.0
3. General Supply Shortages (n=34)	2.0	44.1	29.4	8.8	14.7	2.9
4. Insufficient Training in Pediatrics (n=33)	2.0	42.4	24.2	24.2	9.1	0.0
5. Limited Number of Dentists Able to Serve Multicultural and Non-English-Speaking Populations (n=29)	2.1	34.5	31.0	27.6	6.9	0.0
6. Inadequate Reimbursement (n=33)	2.2	30.3	36.4	24.2	6.1	3.0
7. Managed Care Organizations= Referrals to Dentists with Adult Expertise (n=15)	2.5	20.0	33.3	26.7	13.3	6.7
8. Managed Care Organizations= Restrictive Medical Necessity Interpretations (n=20)	2.7	30.0	25.0	15.0	10.0	20.0

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V/Children with Special Health Care Needs Program Directors in December 2000.

Strategies to Improve Access to Home Health Care, Ancillary Therapies, Audiology Services, and Dental Care

With respect to all of these specialty services -- home health care, ancillary therapies, audiology services, and dental care -- state Title V directors most frequently reported working with state Medicaid programs, Family Voices organizations, and other parent/family groups to improve access. About a third of states reported working with other professional organizations, including the American Dental Association and home health care providers, as well. As with medical homes and pediatric subspecialists, most of these collaborations involved participating in workgroups and advisory boards, attending meetings, engaging in efforts to improve reimbursement rates, and bringing providers to underserved areas. One state -- Oregon -- reported collaborating with several other Western states on an oral health continuing education program for children with special health care needs.

Most of state Title V directors' recommended strategies to improve access to these four specialty services involved changing managed care's policies and practices. State Title V directors suggested simplifying and standardizing the prior authorization process, requiring managed care organizations to include a certain number of pediatric providers in their networks, increasing the number of covered home health and ancillary therapy visits in private health insurance plans, and liberalizing medical necessity definitions. Other suggestions were:

- increase reimbursement rates and offer other financial incentives to work with children with special health care needs,

- expand training in pediatrics and in the needs of children with special health care needs, particularly those with attention deficit hyperactivity disorder, autism, and other developmental disabilities, and
- develop more mobile clinics to provide ancillary therapies and dental care.

As with medical homes and pediatric subspecialists, most of the recommendations for MCHB's involvement in improving access to these pediatric specialty providers involved funding and training efforts. State Title V respondents also suggested that MCHB provide scholarships to providers who choose to practice in underserved communities and promote national loan repayment and other incentive programs for specialty pediatric providers. Other suggestions were:

- encourage specialty providers to serve a certain number of children with special health care needs,
- provide data on reimbursement under Medicaid for occupational, physical, and speech therapy services, and
- develop training for ancillary therapists in how to work with children with special health care needs.

D. Mental Health Services

Children with special health care needs who have a primary mental health diagnosis typically require mental health care that includes psychiatric and psychological evaluations, ongoing mental health therapy, and medication evaluation and management. Other children with special health care needs may also require mental health care to cope with depression, anxiety, or adjustment difficulties that are secondary to their physical diagnosis. We asked state Title V directors about their perceptions of access to various components of mental health services -- psychiatric evaluations, psychological

evaluations, mental health therapy, and medication evaluation and management. As many as 75 percent or more of states rated access to all components of mental health care as being not very or not at all adequate, as shown in Table 15. Directors in the Northeast reported the greatest access difficulties for psychiatric and psychological evaluations, and directors in the West the greatest difficulties for mental health therapy and medication evaluation and management. Because of low reimbursement rates and other reimbursement hassles deterring providers from participating in public programs, publicly insured children reportedly face greater mental health services access barriers than privately insured children. In addition, children with autism and those with a mental health diagnosis secondary to a physical condition reportedly have less access to mental health providers than children with other primary mental health diagnoses.

State Title V directors found that managed care policies were the most important factors deterring children's access to mental health services, as shown in Table 16. The most significant of these was MCOs' authorization of services for only certain diagnoses. As many as 88 percent of respondents found this cause to be very or extremely significant. MCOs' referrals to mental health providers with adult, rather than pediatric, expertise; their authorization of too few services or visits; their failure to include sufficient numbers of mental health providers with pediatric expertise in their networks to be important factors; and the uneven distribution of mental health providers throughout the state were also considered by more than 80 percent of respondents to be major causes of access difficulties. Additional factors that negatively impact access to mental health services that were reported by more than 50 percent of respondents are listed in Table 16.

Strategies to Improve Access to Mental Health Services

Not surprisingly, given Title V agencies' limited involvement with mental health issues, most state Title V directors did not report collaborating with other stakeholders to improve access to mental health services. While the most common collaborators for improving mental health services access were the state Medicaid programs and Family Voices organizations, only about a third of directors reported working with these groups.

Nonetheless, state Title V directors made many suggestions for initiatives and strategies to improve access to mental health services. The most frequent suggestions were more mental health funding and better reimbursement rates for providers of children's mental health services, particularly for providers participating in Medicaid, to overcome the shortage of qualified mental health providers. They also suggested that managed care organizations be required to cover non-traditional, community-based services and be required to cover mental health services for as long as the provider deems medically necessary. Other strategies suggested were:

- adopt mental health parity legislation,
- increase the number of inpatient psychiatric beds available for children with behavioral and emotional problems,
- develop incentives for mental health providers to work in underserved areas,
- enhance the ability of primary care providers to recognize behavioral and emotional problems and to refer children to mental health providers,
- change the Medicaid rules regarding the reimbursement of mental health workers, and
- require all insurers to cover services provided at community mental health centers.

Only about 20 percent of survey respondents had recommendations for MCHB's involvement in improving access to mental health services. Those that made recommendations suggested that MCHB:

- make mental health part of the Title V program's mission,
- increase support for developmental/behavioral pediatrics fellowships and provide incentives for providers to practice in rural areas,
- collaborate with other federal agencies and national provider groups involved in mental health issues,
- provide funding to recruit child psychiatrists and psychologists,
- lobby HCFA for reimbursement rates that accurately reflect the cost of providing services to children with special health care needs, and
- develop a national performance measure for the Title V block grant and for state mental health programs.

Table 15

Title V Directors' Assessment of Access to Mental Health Services

Overall Distribution of Access Rating	Psychiatric Evaluations (n=32)	Psychological Evaluations (n=32)	Mental Health Therapy (n=32)	Medication Evaluation and Management (n=30)
More than Adequate (1)	0%	0%	0%	0%
Adequate (2)	3.1%	3.1%	3.1%	3.3%
Somewhat Adequate (3)	18.8%	21.9%	15.6%	16.7%
Not Very Adequate (4)	18.8%	37.5%	25.0%	13.3%
Not at All Adequate (5)	59.4%	37.5%	56.3%	66.7%
State Access Ratings* by Region				
National Average:	4.33	4.08	4.33	4.43
Northeast	4.83	4.50	4.67	4.50
CT	5	5	5	5
MA	5	4	3	5
NJ	5	5	5	5
NY	5	4	5	4
PA				
RI	5	5	5	5
VT	4	4	5	3
South	4.11	3.89	4.22	4.33
AL	4	4	4	5
AR	3	3	3	3
DE	4	4	4	5
FL	5	5	5	5
KY	3	3	4	3
MS	5	5	5	5
OK	5	4	5	5
SC	5	4	5	5
TN	3	3	3	3
TX				
Midwest	3.86	3.57	3.71	4.00
IL	4	4	4	4
IA	5	5	5	5
KS	2	2	2	2
MN	4	4	4	4
MO	3	3	3	
NE				
ND	4	3	4	4
OH	5	4	4	5
WI				

Table 15 (Cont.)

Overall Distribution of Access Rating	Psychiatric Evaluations (n=32)	Psychological Evaluations (n=32)	Mental Health Therapy (n=32)	Medication Evaluation and Management (n=30)
State Access Ratings* by Region (Cont.)				
West	4.60	4.40	4.70	4.78
AK	5	5	5	5
AZ	5	5	5	5
CO	5	5	5	5
HI	3	3	4	
ID	3	3	3	3
MT	5	5	5	5
NM	5	5	5	5
OR	5	4	5	5
UT	5	4	5	5
WY	5	5	5	5

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V directors in December 2000.

Notes: * 1=More than Adequate
 2=Adequate
 3=Somewhat Adequate
 4=Not Very Adequate
 5=Not at All Adequate

Table 16

Title V Directors= Assessment of the Reasons for Access Barriers to Mental Health Services

Reasons	Average Rating	Extremely Significant (1)	Very Significant (2)	Significant (3)	Somewhat Significant (4)	Not at All Significant (5)
1. Managed Care Organizations= Authorization of Services for Only Certain Diagnoses (n=17)	1.5	70.6%	17.6%	5.9%	5.9%	0.0%
2. Managed Care Organizations= Authorization of Too Few Services or Visits (n=21)	1.5	66.7	19.0	9.5	4.8	0.0
3. Managed Care Organizations= Failure to Include Sufficient Numbers of Pediatric Mental Health Providers in Networks (n=19)	1.6	63.2	21.1	10.5	0.0	5.3
4. Uneven Distribution of Mental Health Providers Throughout the State (n=31)	1.7	54.8	29.0	9.7	6.5	0.0
5. General Supply Shortages (n=31)	1.8	54.8	16.1	22.6	6.5	0.0
6. Managed Care Organizations= Referrals to Adult Specialists (n=15)	1.9	40.0	46.7	6.7	0.0	6.7
7. Reluctance of Available Mental Health Providers to Participate in Managed Care Networks Because Reimbursement is Inadequate (n=20)	1.9	45.0	25.0	25.0	5.0	0.0

Table 16 (Cont.)

Reasons	Average Rating	Extremely Significant (1)	Very Significant (2)	Significant (3)	Somewhat Significant (4)	Not at All Significant (5)
8. Limited Number of Mental Health Providers Able to Serve Multicultural and non-English-Speaking Populations (n=27)	2.0	44.4%	29.6%	11.1%	14.8%	0.0%
9. Primary Care Providers= Lack of Time to Identify Emotional or Behavioral Difficulties (n=27)	2.1	40.7	29.6	18.5	3.7	7.4
10. Reluctance of Available Mental Health Providers to Participate in Managed Care Networks Because of Administrative Burdens (n=18)	2.2	38.9	16.7	27.8	16.7	0.0
11. Primary Care Providers= Lack of Training to Identify Emotional or Behavioral Difficulties (n=28)	2.3	35.7	25.0	25.0	3.6	10.7

Source: Information was obtained by the MCH Policy Research Center through a mail survey of state Title V/Children with Special Health Care Needs Program Directors in December 2000.

IV. SUMMARY AND RECOMMENDATIONS

State Title V directors perceive that access to all types of pediatric providers important to children with special health care needs is problematic. They report the most serious access difficulties for dental care, mental health treatment, and home health care. The difficulties reportedly stem from a variety of causes, but three reasons are prominent: uneven distribution of providers, limited number of providers able to serve multicultural and non-English-speaking populations, and restrictive medical necessity interpretations by MCOs. The uneven distribution of providers creates particular access difficulties for children requiring medical homes, pediatric subspecialty services, inpatient hospitalization, home health care, ancillary therapies, dental care, and mental health treatment. The limited number of providers available to serve multicultural and non-English-speaking populations most negatively impacts access to pediatric subspecialists, home health care providers, ancillary therapists, audiologists, and dentists. MCOs' restrictive medical necessity interpretations have a particularly negative impact on access to mental health providers but are also a significant factor in access to pediatric subspecialists, ancillary therapists, and audiologists.

These causes suggest several strategies that the federal Maternal and Child Health Bureau might consider to improve access to care by children with special health care needs in collaboration with other federal agencies, managed care organizations, provider groups, family organizations, and state program staff. First, various strategies could be pursued by MCHB for improving the distribution of pediatric providers in underserved areas, such as providing financial incentives and increasing the use of telemedicine as well as mobile and satellite clinics. Second, options could be examined for increasing the number of minorities pursuing health care

careers in pediatrics and improving the training of students and health care professionals in culturally competent behaviors, attitudes, and policies to work effectively in cross-cultural situations. Third, MCHB could continue to encourage state Medicaid and S-CHIP programs and employers to establish meaningful managed care safeguards and reasonable payment policies to assure children's access to high quality care.¹¹ Finally, in light of the survey's findings of access difficulties for every service of importance to children with special health care needs, MCHB might also consider ways to obtain quantitative information to assess the reliability and validity of state Title V directors' perceptions of access problems.

¹¹ Two sources of information states might want to examine regarding managed care safeguards are Fox, HB, McManus, MA, and Austrian, JS. *An Analysis of Safeguards for Children with Special Needs in States' Medicaid Managed Care Contracts, 1999*. Washington, DC: MCH Policy Reserch Center, December 2000 and *Optional Purchasing Specifications: Medicaid Managed Care for Children with Special Health Care Needs* available at www.hrsa.dhhs.gov/cmc. The former analyzes how states have applied the current children with special health care needs safeguards developed by the Health Care Financing Administration to Medicaid managed care contracts, and the latter provides illustrative language on covered benefits and the delivery of services to children with special health care needs in managed care arrangements.