

# **EXPERT WORK GROUP ON PEDIATRIC SUBSPECIALTY CAPACITY**

## **MEETING SUMMARY**

November 1-2, 2004  
Washington, DC

Prepared by

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**Welcome**

*Dr. Merle McPherson*, Director of the Maternal and Child Health Bureau's (MCHB) Division of Children with Special Health Care Needs, welcomed the federal Expert Work Group on Pediatric Subspecialty Capacity to its second meeting. She highlighted MCHB's goal of improving community-based systems of care for children and youth with special health care needs, which is being adversely affected by pediatric subspecialty capacity problems. The challenge facing the Expert Work Group involves not only expanding the availability of pediatric subspecialists, but also changing models of practice to encourage more meaningful collaboration between pediatric subspecialists, medical home providers, and families. Dr. McPherson then outlined the following goals for the meeting:

1. refine our understanding of the problem, causes, and consequences of pediatric subspecialty access difficulties to articulate to a broad audience,
2. begin to identify and prioritize strategies for improving access to pediatric subspecialty care within the context of the medical home,
3. consider ways for the Expert Work Group to engage most effectively together, possibly in committees, to accomplish specific tasks, and
4. further involve Work Group members and their respective organizations in moving a collaborative agenda forward on pediatric subspecialty capacity.

Dr. McPherson also reviewed the objectives that the expert panel established for itself at the first meeting:

- define the scope of current and projected pediatric subspecialty capacity problems and their effects on morbidity, productivity, quality, and costs;
- identify promising approaches for improving shared management among pediatric subspecialists and medical homes and other strategies for improving workforce capacity, organizational efficiencies, and financing; and
- develop policy recommendations and a tactical plan to improve access to pediatric subspecialty care within the context of a comprehensive, community-based medical home.

*Dr. Monique Fountain*, Director of MCHB's Medical Home and Healthy and Ready to Work Initiatives, described their recent awards to promote medical homes for children and youth with special needs. Among them, the AAP is operating the national resource center on medical homes. Florida's Institute for Child Health Policy is addressing improvements in pediatric subspecialty care through telemedicine. Six grants are going to support primary care practices to improve linkages with early intervention, child care, Head Start, schools, and other community programs. The National Initiative for Children's Healthcare Quality, using the Learning Collaborative methodology, plans on strengthening state Title V capacity to support medical homes and will lead a new collaborative with 30 primary care practices in 11 states. The University of Wisconsin is operating a medical home project for children with autism, and the

Crotched Mountain Foundation is planning to work with 10 managed care plans and 60 primary care practices to assess outcomes, using the Medical Home Index.

Several members of the group described recent activities they have been involved in surrounding the issue of pediatric subspecialty capacity, including:

- *Jennifer Cernoch* announced that Family Voices has begun collecting anecdotes and concerns from families about access problems related to pediatric subspecialty care.
- *Pete Willson* noted that NACHRI has developed recommendations to improve Medicaid reimbursement using Medicare payment rates.
- *Holly Mulvey* explained that the AAP plans to gather new information on medical student perceptions of pediatric subspecialties and also on primary care referral patterns to pediatric subspecialists. In conjunction with Dartmouth's Center for Evaluative Clinical Sciences, the AAP is working to develop an interactive Web-based database that will be used to improve the provision of pediatric care by supplying information on demographics, socioeconomic status, and geographic distribution of children and providers of pediatric care. In addition, the AAP is anticipating a publication on pediatric workforce and a companion policy statement authored by Richard Pan.
- *John Lewy*, in his role as AAP's Federal Government Affairs Chair, has been working with Senator Bingham to establish a Medicaid Payment Advisory Commission that would advise the Centers on Medicare and Medicaid Services (CMS) on physician coding and payment policies related to Medicaid, similar to the Medicare Payment Advisory Commission. He also noted that the Illinois AAP chapter successfully sued the state Medicaid agency for failure to ensure that children have access to pediatric care and EPSDT services.
- *Wun Jung Kim*, in his role with AACAP's Task Force on Workforce Needs, is involved in a multi-pronged effort to double the recruitment of medical students to child and adolescent psychiatry. He also announced success in gaining organizational support for the Child Healthcare Crisis Relief Act (H.R. 1359 and S. 1223).
- *Jim Stockman*, in his role as President of the ABP, noted that extensive workforce information on all ABP-certified specialties is published in April of each year. They have just begun to track the new dual certification in pediatrics and dermatology. The ABP is also in charge of designing fellowship training programs and, as of July, 2004, new subspecialty training requirements took effect.
- *Richard Behrman*, in his role as Chair of the Future of Pediatric Education II, announced an upcoming forum on improving pediatric subspecialty training programs – specifically, examining changes in the application process for subspecialties under the ABP.
- *Lise Youngblade*, of the University of Florida's Institute for Child Health Policy Studies, described her new MCHB-funded telemedicine project and their first year needs assessment. The biggest struggles they have encountered is accessing care from endocrinologists, developmental-behavioral medicine specialists, and neurologists and also obtaining reimbursement for telemedicine services.
- *Buzz Cooper* will soon have two papers published on specialty shortages – one in the Annals of Internal Medicine and the other in Health Affairs.
- *Richard Pan* announced that California is considering imposing a tax to fund medical homes for children with special needs. Also, the Sierra Sacramento Children's Health

Institute is looking at establishing a financing system in rural areas to ensure access to pediatric subspecialty care. Dr. Pan is involved with the AMA in examining workforce projections, which have not been updated since the 1980s. In addition, he's also involved with the Accreditation Council for Graduate Medical Education (ACGME) in looking at residency education.

- *Michelle Mayer*, of UNC's School of Public Health, described her new research on IMGs and women in the pediatric subspecialty workforce.
- *Chris Stille* is in the last year of a RWJ grant investigating generalist vs. specialist communication. He plans on writing an article on families' role in communication and coordination. He is also the co-principal investigator on a medical home project in Massachusetts that has been funded by MCHB. In addition, he is collaborating with the AAP and Shriner's Hospitals to develop a model for collaboration between generalists and subspecialists.
- *Cal Sia* has been working with the AAP on medical home care coordination legislation.
- *Tom Tonniges* announced that the Annie Dyson Community Pediatric Training Program has been transferred to the AAP.

### **Pediatric Subspecialty Mapping Results, Fellowship Fill Rates, and Workforce Updates**

*Stephanie Limb*, of the MCH Policy Research Center, presented her work on pediatric subspecialty mapping, the goal of which was to examine the geographic distribution of pediatric subspecialists and the ratios of subspecialists to the child population in each state. Data were obtained for 21 pediatric subspecialties from the American Board of Medical Specialties, as of June 2004. For each subspecialty and state, a ratio of subspecialists per 100,000 children was calculated and categorized into five color-coded groups (0, <0.5, 0.5-1.0, 1.0-5.0, and 5.0). Although this methodology has many weaknesses -- including not accounting for need or demand; the time a physician spends in direct patient care; or care provided by general pediatricians, family physicians, or adult specialists -- it nonetheless gives an indication of nationwide pediatric subspecialist capacity.

For the most part, pediatric subspecialties with the lowest ratios have been certified only in the last five to ten years while those with the highest ratios are those that have been around the longest. There is also a direct correlation with higher ratios and the number of training programs per state. Among the 21 subspecialties, seven have nationwide ratios of greater than 1 per 100,000 children: child and adolescent psychiatry, hematology/oncology, cardiology, emergency medicine, critical care, endocrinology, and infectious diseases. Nine subspecialties have nationwide ratios of fewer than 0.5: medical toxicology, rehabilitation medicine, sports medicine, rheumatology, allergy and immunology, neurodevelopmental disabilities, pathology, developmental/behavioral pediatrics, and adolescent medicine. Medical toxicology has the lowest ratio (0.03); only 11 states have any toxicologists, and the most any state has are 3.

There are several states -- Idaho, Montana, Wyoming, and Alaska -- that fare particularly poorly across all 21 pediatric subspecialties. Wyoming has a ratio of zero per 100,000 children for 18 of the 21 subspecialties -- in fact the only subspecialties represented in Wyoming are child and adolescent psychiatry (6), infectious diseases (1), and pathology (1). Montana has a ratio of

zero for 16 of the 21 subspecialties; Alaska for 14; North Dakota for 13; South Dakota for 12, and Idaho for 9. The states with the highest ratios are the District of Columbia, Rhode Island, and Massachusetts.

*Commenting on the mapping results, the Expert Work Group underscored the limits of mapping data and made several suggestions for improving its utility. First, relying on the absolute numbers of pediatric subspecialists in a state does not account for disease prevalence. In order to make meaningful statements about provider shortages, we need to know how many are actually required. Second, mapping information is not linked to outcomes, quality, and health status. Having more subspecialists may not necessarily be associated with better outcomes. Rather, what we need to know is, are families getting needed care for their children? If not, what are the social and economic costs of not providing subspecialty care? What is the difference in children's health status in low-ratio states compared with high-ratio states? Does a long wait for a subspecialist lead to poorer health outcomes or "only" patient dissatisfaction? Selecting "benchmark conditions" to examine these issues would be useful. Third, the maps do not address border issues where, for example, a child in El Paso may be impacted more by provider availability in New Mexico than in Texas. Having mapping data by region or MSA would be more useful. Fourth, there is a well-known maldistribution of pediatric subspecialists, and it is impossible to increase the numbers substantially over the short term. Thus, the more pressing issue is how can we manage children's specialty care needs more efficiently in collaboration with primary care practices and clinics? Fifth, because allergy is joint boarded, the maps don't fully reflect the supply and distribution. Sixth, ABP numbers are reliable, but other information on board certification is problematic. Seventh, a map for neonatology is needed, using an appropriate age denominator. Eighth, there was a suggestion to change the color coding.*

Stephanie Limb also presented fellowship fill rate data, including the proportion filled by IMGs. Unfortunately, no single entity manages the match for all pediatric subspecialties. The National Residency Matching Program (NRMP) currently manages the match for seven subspecialties: child and adolescent psychiatry, cardiology, critical care medicine, emergency medicine, hematology/oncology, radiology, and surgery. It will also begin managing the match for rheumatology next year (2005). San Francisco Match manages the match for otolaryngology. Fellowship programs for the other subspecialties are not coordinated so data on fill rates are not available. In 2004, according to NRMP information only one subspecialty filled all of its available fellowship slots: emergency medicine. Five subspecialties had fill rates of 90% or fewer: child and adolescent psychiatry (86%), hematology/oncology (86%), critical care medicine (70%), otolaryngology (48%), and radiology (24%). The proportion of IMG fellows ranged from 0% in emergency medicine (emergency medicine track) to 40% in child and adolescent psychiatry. Looking at changes between 2000 and 2004, most of the seven subspecialties experienced at least modest increases in fill rates. Otolaryngology and surgery are exceptions. IMG trends are more mixed. *The Expert Work Group commented on the limits of fellowship fill rate data. Specifically, match data do not accurately represent who goes into fellowship programs because not everyone goes through the match programs.*

Colleen Owens, also of the MCH Policy Research Center, summarized the major changes from the 31 subspecialty fact sheets and presented new information on indebtedness of pediatric

subspecialists. Briefly, each of the 31 pediatric subspecialty fact sheets was updated to include the most current data on total number of board certified in the U.S. by the American Board of Pediatrics, the American Board of Medical Specialties, and other medical specialty boards. From the most recent ABP data, between 2002 and 2004, ten subspecialties experienced an increase in the total numbers certified: adolescent medicine (by 7%), endocrinology (6%), gastroenterology (8%), infectious diseases (9%), neonatal-perinatal medicine (6%), nephrology (5%), pathology (6%), child and adolescent psychiatry (4%), sports medicine (9%), and surgery (6%). Eleven subspecialties experienced no change in the total number certified: cardiology, critical care medicine, developmental-behavioral pediatrics, emergency medicine, hematology-oncology, medical toxicology, neurodevelopmental disabilities, pulmonology, radiology, rehabilitative medicine, and rheumatology. The only subspecialty to experience a decrease in the number certified was neurology, which experienced an 8% decline. Data on indebtedness reveal that, in 2004, pediatric subspecialists have a somewhat higher debt burden than internal medicine subspecialists -- \$112,931 versus \$106,329.

### **Pediatric Subspecialty Literature Reviews – Peggy McManus and Michelle Mayer**

Both Peggy McManus, of the MCH Policy Research Center, and Michelle Mayer, of the University of North Carolina, summarized their findings from reviewing the pediatric subspecialty workforce literature. The MCH Policy Research Center's literature review examined 26 articles published since 1990 related to practice choice and experience, utilization, referral and coordination, access, and income and reimbursement. (Literature review and annotated bibliography are available from the MCHPRC.) UNC's review, which was published in the December 2004 issue of *Archives of Pediatric and Adolescent Medicine*, examined 41 articles published since 1992 primarily related to workforce supply and distribution.

The main findings from the MCH Policy Research Center review are as follows:

#### *Practice Choice and Experience:*

- Research indicates that residents' interest in pursuing a pediatric subspecialty career goal more than doubled – from 13% in 1997 to 27% in 2002. The most likely reasons for this are increased emphasis on subspecialty practice by residency faculty, new loan repayment programs, greater flexibility in fellowship requirements, more fellowship programs and slots, and an improving job market.
- Pediatric subspecialty fellows are more likely than those intending to practice in primary care to be males, international medical graduates, unmarried, and have educational debt under \$50,000.
- Not since 1993 has there been a study examining what proportion of pediatricians are trained and certified in a specialty and how many actually practice a specialty without going through a board-certified program. At that time, 15% of pediatricians were trained and certified in a board-certificate subspecialty; 11% were subspecialty trained, but not certified; 7% were trained in noncertified subspecialties; and as many as 35% practicing in a pediatric subspecialty had not had formal training in that specialty.
- Compared to general pediatricians, pediatric subspecialists work longer hours, have significantly higher levels of burnout and job stress, and serve a higher percentage of

non-English speaking and Medicaid-insured children than both general pediatricians and internal medicine subspecialists.

- One of the major limits of our understanding of practice choice and experience is the fact that not since the late 1990s has pediatric subspecialty practice pattern information been published. Further, we know much more about practice choice than we do about practice experience.

#### *Utilization:*

- In general, little has been written about patterns of pediatric subspecialty utilization, primarily because most databases do not distinguish physician type.
- Only one national trend study provided overall visit rate information, showing visits to pediatric subspecialists increased from 1.6% in 1980 to 4% in 2000, with children ages 1-4 and 11-17 accounting for the largest increase. This increase was not surprising given that the number of pediatric subspecialists increased more than five-fold during that time period.
- Another study found extensive variation in specialist utilization by condition.
- Further, a 20-state survey of families whose children have complex medical conditions found in the late 1990s that almost half of parents said the doctor most important to their child's care was a specialist. The vast majority of children in this study (89%) saw a specialist on an outpatient basis at least once in the previous year and a fifth had seen a specialist more than eight times in the last year.
- There are several limitations of studies on utilization – they fail to adjust for need, underuse or unnecessary variations; and they do not distinguish physician type nor specific service.

#### *Referral and Coordination:*

- A relatively small proportion of office visits to pediatricians are referred to subspecialists, although the volume and complexity of specialty referrals are increasing, particularly for certain subspecialists. The pediatric subspecialties reporting higher than average increases in referral volume and complexity, in the FOPE studies in the late 1990s, were pulmonology, endocrinology, critical care medicine, dermatology, and neurology.
- A relatively small number of conditions account for the majority of referrals.
- General and specialty pediatricians agree that communication problems are substantial. They also agree on the barriers to communication and effective ways for improving communication. A particularly important finding is that only 22% of generalists and 45% of specialists reported discussing sharing care. Most agreed, however, that discussing responsibility for routine follow-up care, acute situations, and feedback to family along with negotiating the division of responsibility over time was important. They also concurred that improved generalist-specialist communication has the potential to improve quality of care. Other literature has shown that referral completion and physician satisfaction increased with communication.
- Families whose children have complex medical conditions also report experiencing difficulties with referral and coordination. In 1998-1999, almost a fourth of families reported problems receiving services from specialty doctors, including getting referrals and appointments. Those with autism and those who are publicly insured and uninsured face greater difficulties than privately insured children.

- A California study on access to orthopedic surgeons, conducted in 2001, found that almost all 50 orthopedic offices contacted were unable to offer an appointment to a child with Medicaid with a suspected fracture within seven days, but all were able to offer an appointment to a privately insured child with the same condition.
- We found no studies that examined the effects of different shared management or consultation or coordination approaches on productivity, quality, or cost. Also, little is known about family perspectives on referral and coordination.

*Access:*

- Estimates of access problems vary. FOPE's survey found that 38% of pediatric specialists reported a need for additional subspecialists in their communities in the next three to five years. Families' estimates of unmet need for specialists vary from 7%-19%, depending on the survey. Directors of State Title V Programs for Children with Special Needs also have reported problems -- 30% characterized access to pediatric subspecialists as inadequate in 2000. According to Dr. Cooper, 11% of medical school deans and 7% of medical society executives reported shortages in pediatric subspecialties in 2003.
- Access to certain subspecialties -- most notably child and adolescent psychiatry, developmental-behavioral pediatrics, and neurology has reportedly been most problematic. Also identified as problematic are adolescent medicine, critical care medicine, dermatology, emergency medicine, endocrinology, gastroenterology, clinical genetics, orthopedics, rheumatology, and surgery.
- The literature reveals that access to pediatric subspecialists varies by a child's condition and age, ethnic background, income and insurance status, and geographic location.
- Managed care has also been associated with access problems. Specifically, the literature indicates that plan networks of pediatric subspecialists are sometimes inadequate and that Medicaid and SCHIP plan officials often find it difficult to retain adequate networks of pediatric subspecialists. In addition, managed care authorization for specialty referrals has been identified as a problem along with administrative burdens and inappropriate referrals to adult specialists.
- There are several limitations with the literature on access. Most importantly, most of the research is based on assessments of families and physicians using a mix of subjective and vague measures, such as unmet need. Also, few studies have attempted to differentiate access issues affecting children needing particular pediatric subspecialists. In addition, there have been no longitudinal studies analyzing changes over time in access to pediatric subspecialists. Finally, few studies have examined the impact of pediatric subspecialty capacity problems on families, providers, and hospitals, except to comment on the added burden on primary care providers or the difficulties associated with recruitment and retention.

*Income and Reimbursement:*

- The AAP found that starting salaries for pediatric subspecialists did not significantly change from 1997 to 2002.
- Another study, conducted between 1996 and 1999, found that pediatric subspecialists earned significantly less than adult subspecialists -- \$156,284 versus \$192,006.
- Several articles have mentioned the inadequacy of Medicaid reimbursement for pediatric subspecialty care. A study of California orthopedists (described earlier), in 2001, found

that Medicaid reimbursement for an initial orthopedic consultation was \$49 for a community-based specialist and \$39.20 for a hospital-based specialist. The fee for a follow-up visit was \$19.80 and \$15.84. The authors then compared their Medicaid rates to veterinarian rates for a fracture and discovered that veterinarian rates were 2 to 3 times higher.

- Inadequate Medicaid and private health insurance reimbursement was also mentioned as an important explanation for low rates of coordination among physicians and difficulties sustaining multidisciplinary teams involved in the care of children.
- There are a number of limitations with the literature in this area. No current national studies have examined the adequacy of Medicaid, SCHIP, or private health insurance payment rates for services provided by pediatric subspecialists. Nor have there been any recent trend analyses of pediatric subspecialty participation rates in Medicaid and SCHIP. Further, there have been no large-scale studies that assess managed care plans' policies regarding network composition, authorization and medical necessity policies, or financial incentives for pediatric subspecialists.

The main findings from the UNC review are as follows:

*Multispecialty Studies:*

- Pediatric subspecialists are concentrated in academic medical centers.
- There is evidence from the FOPE studies and academic departments suggesting that there was not a shortage. However, there are concerns that existing studies are inadequate.

*Pediatric Medical Subspecialties:*

- Findings vary widely: some specialties call for a reduction in the number of trainees (gastroenterology and infectious diseases) and others predict shortages (developmental-behavioral pediatrics and emergency medicine).
- Workforce projections have only been estimated for gastroenterology, nephrology, and endocrinology. No studies are available for hematology/oncology, sports medicine, allergy, immunology, and adolescent medicine.
- In developmental-behavioral pediatrics, more than 60% of FOPE respondents thought communities needed more and the average wait time for an appointment was one month.
- In pediatric rheumatology, one-third of medical schools lack a pediatric rheumatologist on their faculty. Several studies demonstrate extensive involvement of internist rheumatologists in the care of children with rheumatic diseases.
- In pediatric endocrinology, the ratio of pediatric endocrinologists to child population varied from .13 to 1.19 per 100,000. Further, a workforce model estimated a current undersupply that, given current training trends, should be remedied by 2010.
- In pediatric cardiology, there is a potential for increased demand due to prenatal diagnosis. Of 594 geographic areas studied, two-thirds had no pediatric cardiologist. Increases in the supply between 1982 and 1992 were associated with a more equitable distribution.
- In gastroenterology, 60% described supply as "about right" and 30% said there were "too many." Reductions in trainees have been recommended and increased use of mid-level providers.

- In pulmonology, nearly 70% of FOPE respondents felt there was no need for additional providers. The percentage of pulmonologists in private practice more than doubled since 1995.
- In infectious diseases, a 1995 survey found one-third of infectious diseases fellows were international medical graduates (IMGs).

#### *Pediatric Surgical Subspecialties:*

- There is consistent support across pediatric surgical subspecialties for controlling the number of trainees, with the exception of pediatric neurosurgery.
- Workforce projections have been made for pediatric surgery, ENT, and urology. No studies are available for pediatric orthopedics.
- Pediatric surgery has controlled supply through training reductions and elimination of IMG
- For pediatric ENT, projection models argue for a reduction while the department chairs expect an increase in demand.

#### *Other Specialties:*

- Studies in child neurology, child and adolescent psychiatry, and pediatric radiology all suggest an inadequate supply. No studies are available for pediatric anesthesiology or pediatric dermatology.
- Child neurology estimates that supply is 20% below demand.
- Child psychiatrists per 100,000 children ratios range from .18 in Mississippi to 18.9 in Massachusetts.
- 70% of surveyed pediatric radiologists report an increase in volume; help wanted index shows an increase in advertised positions.

#### *Limitations:*

- Several limitations were noted. For example, many studies are based on physician surveys rather than on market-level analyses. Many of the included studies use data from the 1990s when managed care heavily influenced perceptions regarding the physician workforce. Lastly, the review does not look at the role of non-pediatrician specialists in providing care.

#### *Implications:*

- The adequacy of the current pediatric workforce is unclear. Future studies should investigate: provider-to-population ratios, accounting for percent time in patient care; wait times for appointments; market-level approaches to identify underserved areas; part-time employment and differential rates of retirement; role of adult specialists; and how supply affects pediatric subspecialists' roles in education and research.

#### *Ongoing Studies:*

- UNC is engaged in other related studies, including estimating pediatric subspecialist-to-population ratios, examining the role of women and IMGs in pediatric subspecialties, and assessing distance to pediatric subspecialty care. Studies on distance to subspecialty care using county level data have found that for most specialties, 75-80% of the under-18 population reside within 50 miles of a pediatric subspecialist, with the exception of

pediatric rheumatology, sports medicine, and toxicology. Lastly, it is important to consider supply relative to demand, provider availability for patient care, wait times for appointments, and insurance coverage.

*The Expert Work Group made several comments on the pediatric subspecialty workforce literature, primarily highlighting its limitations. While it is necessary to do this literature review, it is, by definition, “looking through the rear view mirror.” Decisions cannot be made based on this literature because long-term disease trends are not accounted for. Moreover, the literature tends to focus on pediatric subspecialists, not on the needs of families whose children have chronic conditions. Another limit is the fact that none of the studies were done in the same way and most are dated. What would be useful is to understand what is different now from the 1990s, when most of the literature was written – e.g., reimbursement, legal issues, changes in the scope of practice of general pediatricians, current and future pipeline projections, increasing demand for specialty care, changing demographics and insurance status of children, reduced use of managed care, and increased reliance on mid-level providers. It was also recommended that the literature address scope of practice issues, noting, for example, the Pediatrics supplement article by Judy Palfrey.*

### **Pediatric Subspecialty Problems, Causes, and Consequences: Report from Key Informant Interviews and Group Discussion**

*Harriette Fox, co-director of the MCH Policy Research Center, presented a summary of problems identified by key informant interviews, which were conducted just prior to the meeting with the leadership of 10 national organizations, including the AAP, NACHRI, Title V, Family Voices, and various pediatric subspecialty societies. Involved in these interviews were more than 100 individuals.*

Subspecialties identified as having the most serious problems were, in order of seriousness: psychiatry, neurology, developmental-behavioral pediatrics, endocrinology, rheumatology, gastroenterology, orthopedics, surgery, critical care medicine, neurodevelopmental disabilities, pulmonology, cardiology, dermatology, anesthesiology, urology, clinical genetics, radiology, adolescent medicine, and emergency medicine.

Subspecialties with less serious problems were: allergy and immunology, hematology/oncology, infectious diseases, medical toxicology, neonatal-perinatal medicine, otolaryngology, pathology, plastic surgery, rehabilitative medicine, and sports medicine.

*The Expert Work Group concurred that these subspecialties were the ones experiencing the greatest problems, with the addition of neurosurgery. Caution was noted, however, about making too much of a distinction between those with the most serious problems (“horrible”) and those with less serious problems (“terrible”), but the Group agreed that it was useful to begin to get a picture of where the most serious problems lie. Family members expressed concern that all pediatric subspecialties should be included, because there are serious service system issues affecting all pediatric subspecialists within the context of the medical home. Further, there are*

*so many geographic disparities in the availability of pediatric subspecialties, that it is difficult to make definitive problem statements. Members commented on the similarity of issues affecting the three pediatric subspecialties with the most serious problems – psychiatry, neurology, and developmental-behavioral pediatrics. They also noted that many of the subspecialties experiencing the greatest problems provide intensive, time-consuming, and frequent services and few procedures. Further, specialty shortages in adult medicine are very similar to pediatrics.*

Harriette Fox followed the discussion of problems with a summary of the *causes* identified by key informants. These causes were categorized into seven major areas – education and training of residents, reimbursement, changing workforce demographics and demands, primary care capacity, adult specialty capacity, changing health needs among children, and other issues. Below is a summary of the causes identified by the key informants and, *in italics*, additional causes identified by the Expert Work Group.

#### *Education and training of residents:*

- Not enough pediatric subspecialists (PS) being trained
- Lack of early exposure to PS and few mentors available
- Length of PS training
- Requirement to be double-boarded
- Bias against certain PS careers – e.g., psychiatry, neurology
- More pediatric subspecialties to choose from
- Debt burden
- *Inadequate training in the care of childhood chronic conditions*
- *Insufficient training in community practice; training every subspecialist to take on academic roles is “utopian”*
- *Continuity clinics being cut from residency training*
- *Junior faculty with little experience are running community clinics and clerkship directors are very young*
- *Residents only learn how to refer*
- *Residents are trained in everything but once they leave their residency, other dynamics stand in the way of their doing the full array of care they are trained to provide*
- *Differing expectations about what general pediatrics is – primarily well baby and acute care vs. chronic care*
- *Push to generalism has been a problem affecting interest in pediatric subspecialties; institutional bias toward primary care for past 25 years has compromised the development of pediatric subspecialties*
- *The Balanced Budget Act of 1997 froze residency slots at 1996 levels, resulting in an inadequate number of slots.*

#### *Reimbursement*

- Medicaid fees are grossly inadequate and PS are increasingly declining to serve publicly insured children
- SCHIP and Title V fees are also low
- Reimbursement levels do not adequately reflect time and complexity of evaluation and management services provided by PS

- Consultation, communication, and coordination by PS and PCPs not reimbursed by most public and private insurers
- Services provided by multidisciplinary teams (with mental health, nutrition, PT/OT/ST, nurse, and health education professionals) are not reimbursed.
- Same day visits to more than one physician is seldom covered
- Telemedicine equipment and services are seldom reimbursed
- No financial incentives are offered to extend PS capacity
- Managed care and insurance networks often restrict access to PS and often have a very limited network of PS.
- PCPs are unable to get reimbursement for monitoring patients with mental health problems
- High malpractice fees in certain areas
- *No organized system of financing and, as a result, reimbursement is chaotic*
- *Time interacting with schools and social services not reimbursed*
- *Lack of parity in payment for mental health*
- *PCPs and PS serving children with developmental or behavioral health conditions are financially penalized by insurers when they use accurate diagnoses*
- *Failure of private health insurance and managed care organizations to assume their fair share of financial responsibility*
- *PCPs and PS with training and qualifications in care of childhood chronic conditions should be rewarded for providing coordinated systems of care*
- *Financing of GME through Medicare is inadequate*
- *Market forces often affect where jobs are, although certain PS (psychiatry, neurology) have not responded to these market forces*

*Changing pediatric subspecialty workforce demographics and demands:*

- More women entering workforce; they generally work fewer hours; lifestyle demands are greater now than ever before
- IMGs facing difficulties returning to US
- Aging of the PS workforce (especially for neurology)
- Demands for teaching, research, and administration leave less time for clinical care
- Increasing demands from PCPs for consultation, leaving less time for seeing patients

*Primary care capacity:*

- PCPs with less and less time to see patients and are not screening as carefully or providing as much chronic care management as they potentially could, resulting in a loss of skills
- PCPs increasingly limiting patient population with special needs, leaving PS with more and more complex cases
- PCPs are over-referring with limited or no work-ups and background information
- *Training for chronic care exists but many fail to avail themselves of this training because of inadequate reimbursement*
- *PCPs caring for children with rare conditions often do not feel confident in their skills and prefer to refer*

- *Schools are increasingly involved with referring families for evaluation and follow-up (e.g., ADHD)*

*Adult specialty capacity:*

- Fewer adult specialists serving in a gap-filling role serving children because of the increasing demands to see elderly with chronic conditions
- Many are not trained or interested in serving adolescents and young adults with special needs who are attempting to transition to adult specialists
- *Shortage of adult specialists*

*Changing health care needs among children:*

- Increasing prevalence of certain conditions –e.g., diabetes, obesity, autism, and other conditions
- Increasing length of survival among children with complex chronic conditions
- New treatment advances – e.g., newborn screening tests
- *Changing school environment – e.g., no recess*

*Other Issues:*

- *Lack of organized systems of pediatric primary and specialty care*
- *Bifurcated physical and behavioral health systems*
- *More sophisticated consumers as a result of the increase in scientific knowledge and use of the internet*

*The Expert Work Group concurred that the causes identified by the key informants and those additional causes added by the Group are, in fact, the main causes affecting pediatric subspecialty capacity. Among these causes, three were the subject of most discussion – education and training, particularly of general pediatricians; reimbursement; and primary care capacity. It was also noted that, for the most part, these causes have not changed in recent years, despite the doubling of first-year fellows.*

Peggy McManus continued the discussion of the main *consequences* of pediatric subspecialty capacity problems in terms of access to care, health outcomes, physician practice patterns, and other. Again, key informant interview responses are first and expert work group comments follow *in italics*.

*Access to Care:*

- Long wait times, which differ by specialty, but are often 3-6 months
- Lengthy travel distances, causing families to miss work and students to miss school and also cause financial hardship
- Families sometimes have to go out-of-state
- Greater access difficulties for publicly insured and uninsured due to declining PS participation in accepting Medicaid, SCHIP, and Title V payment
- For some children (with mental health problems), they become “warehoused” in schools
- *Even when travel is possible for a family, they are still have problems accessing needed specialty care*

*Health Outcomes:*

- Delays in diagnosis and intervention
- Health problems exacerbated
- Inappropriate interventions by PCPs and adult specialists
- Inappropriate use of emergency room – e.g., for children needing psychiatric care. ERs are not staffed to handle these problems and follow-up care is problematic
- Difficult to meet quality and safety standards
- Shortages in one PS can affect another specialty, causing “care to come to a grinding halt”
- Medical student training is not as good when PS are overextended

*Physician Practice Patterns:*

- PS are overwhelmed, dissatisfied, taking early retirement, and some are leaving children’s hospitals and academic medical centers
- Greater pressure on PCPs to manage the care of children with chronic conditions – for some, this has resulted in becoming more broadly skilled and for others it has resulted in their restricting their patient population

*Other:*

- Children’s hospitals are spending millions of dollars to subsidize PS capacity and it is causing significant economic burdens
- Hospitals experiencing major recruitment difficulties
- More PS are considering suing Medicaid and other insurers to gain adequate reimbursement
- *Poor children face more difficulties and then the burden falls to the medical schools*
- *Parents are taking on more responsibility for care coordination and communication*
- *An industry of non-physician providers has been created because of PS shortages*

*The Expert Work Group highlighted that, although more information on outcomes and actual family experiences would be helpful, what we have gathered from the literature review and the key informant interviews on the problem, causes, and consequences is “powerful” information and internally consistent. It is important to move forward and tell the story with the information that we have and the consensus that is forming among the Expert Work Group members. Further, the Group concurred that the problem is twofold – a serious shortage problem as well as a serious financing and delivery system problem, which affects children of all income levels and with a broad range of conditions. It is important not to define the problem as only an issue of geographic maldistribution. Other comments regarding the problem definition include the need for more stories from families and more standardized collection of data on workforce dynamics and outcome possibly starting with a few pediatric subspecialties.*

Before adjourning for the day, *Merle McPherson* provided a few closing remarks. She reminded the group that there is federal authority to put community systems in place through the Title V Social Security legislation of OBRA 1989, the health goals of the nation, the Supreme Court *Olmstead* decision, and through the New Freedom Initiative. Further, six systems indicators have been adopted to monitor community systems of care, and the issue of pediatric

subspecialty capacity is a part of each indicator. These are: family-professional partnership, access to medical home, adequate insurance financing, early and continuous screening and identification, organization of services for easy use, and transition to adult care. Dr. McPherson urged the group to join together on the issue and look at enhancing the primary/specialty care interface, identifying promising practices, increasing recruitment and retention of subspecialists, and improving reimbursement.

## Day 2

*Bonnie Strickland*, opened the second day of the meeting with a discussion of short and long-term strategies to address pediatric subspecialty capacity problems. After presenting the strategies gathered from the key informant interviews, the Expert Work Group discussed their own list of strategies (*in italics*), which fell into four main topic areas: improving recruitment and retention of pediatric subspecialists, identifying promising service models for working with families and other community partnerships, enhancing the primary/specialty care interface, and improving reimbursement and funding strategies.

### *Improving Recruitment and Retention of Pediatric Subspecialists*

- Train more pediatric subspecialists and expedite training – “Are 6 years really necessary?”
- Continue recruitment efforts for 1<sup>st</sup> and 2<sup>nd</sup> year students, focusing particularly on understaffed PS
- Expand and fund integrated pediatric and psychiatric tracks
- Increase pediatric training among residents going into adult specialties
- Reduce amount of adult training time required by non-ABP-board specialties
- Consider creating a specialty track in nurse practitioner training programs
- *Increase flexibility and timing of specialty training requirements (community vs. academic)*
- *Increase training grants and loan repayment opportunities (National Health Service Corps)*
- *Have fellows participate in more continuity clinics*
- *Expose medical students to PS early on*
- *Offer more flexibility in specialty care career paths, including incentives for pursuing clinical practice*
- *Increase awareness and public relations regarding the subspecialty shortage – “if it is known, the market will respond accordingly”*
- *Incorporate medical home concepts into PS training*
- *Project pediatric subspecialty workforce needs ten years from now (e.g., with more women and more non-physicians)*
- *Examine the model of post-training/mentoring used in surgery*

### *Identifying Promising Service Models for Working with Families and Other Community Partners:*

- Create a clearinghouse of best practices and funding sources to encourage more widespread adoption of improvements

- *Increase financing to support studies examining the role of families in service delivery models integrating primary and specialty care*
- *Examine family-centered models that already exist*
- *Support efforts that foster collaboration between various partners – families, communities, and institutions*
- *Expand collaboration at all levels of government around children physical and mental/behavioral health*
- *Refer to IOM report – Children’s Health and the Nation’s Health*
- *Analyze CSHCN Survey to identify family response to specialty care*
- *Expand the availability of web-based electronic health records that the family controls*

#### *Enhancing Primary and Specialty Care Interface*

- *Significantly expand consultation/partnership arrangements with academic medical centers, children’s hospitals, and PCPs*
- *Develop new clinical models, like those used in England, where the specialists act as consultants to the PCP*
- *Examine promising examples of collaboration in mental health, asthma, hematology, and HIV*
- *Retool CME to focus on what PCPs can do to better manage nutrition and growth disorders, basic neurological disorders, mental health problems, and other commonly occurring conditions*
- *Develop referral criteria for commonly occurring conditions*
- *Support PCPs in the management of chronic disease through education and training (refer to New York and Illinois Title V examples)*
- *Improve residency training around appropriate consultation and referral*
- *Improve availability of CME centers on chronic care management (applying research into practice)*
- *Use “detailing” as a method to translate research guidelines into practice*
- *Change core competencies at the residency training level (e.g., addressing specialty capacity shortage)*
- *Expand the use of telemedicine and other technologies to further the interface between PC and specialty care (refer to Florida, Iowa, and Michigan initiatives)*
- *Offer institutional support and financial incentives to PS to become more involved in teaching and training of PCPs*
- *Build on the chronic disease management model developed by Dr. Ed Wagner and adapted by NICHQ (e.g., with asthma and other conditions and as a part of the medical home learning collaborative)*
- *Better define boundaries of clinical practice – “Who does what?”*
- *Assure cultural effectiveness and literacy in the provision of integrated PS/PCP services*
- *To encourage the PS/PCP interface, have PS participate in PC grand rounds*

#### *Improving Reimbursement and Funding Strategies*

- *Increase Medicaid reimbursement to Medicare levels*
- *Allow reimbursement for communication, consultation, coordination, multidisciplinary teams, and telemedicine*

- Allow PCPs and medical subspecialists to bill for services provided to children with mental health problems
- Offer grants or other funding support to encourage PS to travel to rural and underserved areas on a routine basis
- Increase loan repayment programs and other financial incentives to attract medical students to PS
- *Establish a Medicaid Advisory Payment Commission*
- *Investigate activities of CMS' new Office of Children's Quality*
- *Encourage CMS to collect data on access, reimbursement, and financing*
- *Enforce equal access standards under Medicaid*
- *Examine how federally qualified health centers achieved cost-based reimbursement as a model*
- *Collaborate closely with CMS and the National Conference of State Legislatures on Medicaid issues*
- *Reduce disparities in payments between adult and pediatric subspecialists*
- *Adopt improvements in financial risk-sharing strategies (refer to ICHP issue briefs)*
- *Create more unanimity among pediatric groups about reimbursement strategies, including the need for equity in Medicare and Medicaid*
- *Encourage more research on the link between pediatric subspecialty care access and financing*

Additional suggestions were made from the key informants and the Expert Work Group (*in italics*) on communication strategies.

- Develop much more publicity to increase awareness about pediatric subspecialty capacity problems.
- Convene a symposium, partnering with government and private agencies, to bring together pediatric subspecialty societies and other national organizations to call attention to PS workforce shortages and the need for reforms.
- *Complete a scholarly piece that represents the consensus of the Expert Work Group*
- *Crystallize the message – best done from the family perspective*
- *Gather more stories from families on impacts*
- *Tap the PR resources at NACHRI, AAP, and Shriners for help with developing the message*
- *Figure out who the audiences are and tailor messages accordingly -- families and advocacy groups, providers/residents/training programs and payers .*
- *Convene a forum or summit in the future – caution against moving too quickly*
- *Focus more attention on the subspecialty needs of children that are not being met, and less on the needs of specific pediatric subspecialists.*

Merle McPherson provided a few remarks before concluding the meeting. She pointed out the value of the Expert Work Group and their role in addressing the pediatric subspecialty capacity problem. Prior to the next meeting, a scholarly piece will be drafted, building on the literature, the key informant interviews, and the recommendations of the Expert Work Group. She proposed staying with the four topic areas discussed above and working in committees. She

pledged support of MCHB around primary/specialty care interface and the role of the family through their medical home initiatives. Around the pipeline issue, she noted that although it was better addressed by the AAP, the ABP, and the Bureau of Health Professions. MCHB could play a significant role in bringing those organizations together. Lastly, reimbursement is an area best addressed by all public and private payers, as well as CMS, SAMHSA, HRSA, and the Department of Education. The next meeting will take place in approximately 4-6 months.