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## CHAPTER 2

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# Beyond Primary Care: Ensuring Access to Subspecialists, Special Services, and Health Care Systems for Medically Underserved Children\*

**Irwin Redlener, MD**

Associate Dean, Mailman School of Public Health, Columbia University;  
President, The Children's Health Fund, New York, New York

**Roy Grant, MA**

Director of Research, The Children's Health Fund, New York, New York

**David M. Krol, MD, MPH**

Assistant Professor of Clinical Pediatrics and Clinical Health Policy &  
Management (in Dentistry), Columbia University; Vice President  
for Medical Affairs, The Children's Health Fund, New York, New York

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**A**ccess to medical care for children remains one of the more intractable challenges facing pediatric providers and policymakers. Numerous barriers, in spite of Medicaid and the State Children's Health Insurance Program (SCHIP), contribute to the absence of comprehensive medical insurance coverage for 8.5 million children.<sup>1</sup> In addition to financial and insurance barriers, there are a host of other factors that limit access, irrespective of a family's insurance status. At least 3 million children have reduced access to needed

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medical care because of limited availability of affordable transportation.<sup>2</sup> Millions of children live in communities that are designated to be health professional shortage areas. Many families living in communities with limited health care options may not have access to health professional staff who speak their language or deliver care in a culturally familiar ambiance.

Health care activists and child health advocates have focused much of their attention on trying to eliminate financial barriers to care and ensuring access to primary care as principal goals. These strategies make sense on a number of levels. Primary care, especially the comprehensive, coordinated care provided in a context referred to as a “medical home,” is ideal for children. The medical home seeks to establish a long-term, sustaining relationship between provider and patient and functions as an entry point to the larger health care system, including and beyond primary care. In pediatrics, this means creating a health care environment that follows children from birth to young adulthood. Health care screening protocols, immunizations and other preventive interventions, care of acute and chronic illness, and provision of relevant health and lifestyle education all take place in the medical home.

However, even if these services occur in a family and child-friendly environment, with competent and available professional staff, primary care functions alone may not be sufficient. A key component of the medical home also needs to be identifying children who require subspecialty care and special services and connecting those children to that care. Ironically, the more medically underserved or economically disadvantaged the child and family, the more likely will be the need to access more advanced care.

So, the challenge for medically underserved children is actually 2-fold. The first is finding an appropriate medical home to ensure the delivery of primary care services. The second challenge is to ensure access to needed subspecialist care and tertiary services.

In this chapter, we review why access to subspecialty and special services is crucial for medically underserved children and how some barriers to such care may be overcome with directed program strategies. The Referral Management Initiative (RMI), designed and implemented by The Children’s Health Fund, is described as an example of an approach that has had substantial success in ensuring access to all levels of the health care system. Finally, we conclude with suggestions regarding advocacy for ensuring more effective access to vital services at all levels of the health care system.

## **ACCESS TO CARE FOR CHILDREN ON MEDICAID**

The literature on access to care for low-income and other high-risk children has focused mostly on primary care, and the principal issue tracked is economic, specifically health insurance, with a secondary emphasis on work force (availability and distribution of health care providers). Access to subspecialist care has been explored to a much lesser degree.

Many studies have raised concern about aspects of the quality of pediatric care received by children on Medicaid. While children with Medicaid coverage have better access to care than do poor children who are uninsured, they are more likely to have unmet medical needs, and less likely to have a usual source of care in a medical home model than are non-poor children with commercial insurance.<sup>3</sup> In a medical home, children have an ongoing relationship with a pediatric provider who knows their medical needs and history, and provides preventive care, management of chronic conditions, and anticipatory guidance.<sup>4</sup> A recent study in Alabama found that only 11.8% of Medicaid-enrolled children had a medical home relationship, indicated by a regular source of pediatric care and at least one well child visit in the year under review.<sup>5</sup>

An ongoing problem affecting access to care for children on Medicaid is low payment and burdensome paperwork requirements that serve as disincentives to participation in the Medicaid program for primary care office-based pediatricians.<sup>6</sup> Low fees similarly contribute to low Medicaid participation among pediatric dentists.<sup>7</sup> These are long-standing issues that have led to low-income children primarily receiving care at institutions (community health centers and hospital ambulatory clinics) rather than physician offices.<sup>8</sup> This may affect continuity of care if there is no consistency of provider.

Children on Medicaid who experience continuity of their health care setting but not their health provider per se have a greater likelihood of being hospitalized than do patients who have continuity of both setting and provider.<sup>9</sup> Lack of continuity of care is also associated with a greater likelihood of using hospital emergency departments.<sup>10,11</sup> This especially applies to children with chronic conditions such as asthma, for whom effective and continuous treatment in primary care can reduce emergency department utilization.<sup>12</sup> Lack of continuity of care is a particular problem for young children, for whom preventive care including developmental surveillance and anticipatory guidance may be compromised.<sup>13</sup> Continuity of care is associated with improved identification of chronic conditions, including diabetes and hypertension.<sup>14</sup>

Access to and continuity of primary care are also affected by stability of health insurance coverage. The problem of “churning,” by which patients must reestablish their Medicaid eligibility or lose coverage, results in frequent discontinuities in a patient’s Medicaid enrollment (despite continued eligibility) during the course of a year. The problem is so severe that twice as many people (younger than 65 years) in America are uninsured at some time during a year as are uninsured continuously for a full year. Low-income children and families are disproportionately affected.<sup>15</sup> The American Academy of Pediatrics estimates only 30.3% of uninsured children in America are ineligible for both Medicaid and SCHIP.<sup>16</sup> A 28-state study showed that only 39% of children in Medicaid managed care programs met federal requirements for continuous enrollment. More than one fourth, 27%, of 2-year-old children experienced at least one break in their insurance coverage.<sup>17</sup> These discontinuities in coverage undermine all of the health status benefits associated with a medical home.

#### **UTILIZATION OF AND ACCESS TO PEDIATRIC SUBSPECIALTY CARE**

As noted above, the majority of the literature on access to care for low-income and high-risk children has been focused on primary care. For these children, especially those with health care needs that exceed the abilities of the primary care provider, access to and coordination with subspecialty care is critical to ensuring the provision of efficient and effective health care and in securing a comprehensive medical home.

There have been few studies to establish the prevalence of referrals from primary care to subspecialists. A large American Academy of Pediatrics, Pediatric Research in Office Settings study found that pediatricians refer patients to subspecialists during 2.3% of their office visits.<sup>18</sup> Because the unit of analysis was visits not patients, these data do not readily allow comparison of the need for subspecialty care of specific patient populations to this large national sample. This was facilitated by an analysis of the 1999 National Health Interview Survey data, which found that 13% of children used at least one subspecialist during a year. Rates were similar for children on Medicaid and children in commercial insurance.<sup>19</sup>

Interest in access to subspecialists increased as Medicaid, the major health insurance available to children in poverty, shifted from a fee-for-service to managed care model. Nationwide, as of December 31, 2003, 60.2% of all Medicaid enrollees were in a managed care plan.<sup>20</sup> Initially, there was concern that health maintenance organizations would overextend their “gatekeeper” function (required

primary care authorization of subspecialty referrals), making unilateral decisions restricting access to subspecialists to reduce expenditures and maximize profits.<sup>21</sup>

The impact of gatekeeping on access to subspecialist care is not clear. Data show that gatekeeping arrangements increased subspecialty referrals for children and adolescents. Problems were noted, however, in the coordination of subspecialty and primary care.<sup>22</sup> When a capitated insurance plan changed its gatekeeping system to open access to subspecialists, there was a minimal change in utilization of subspecialist care.<sup>23</sup> However, for children with chronic conditions, the transition to a gatekeeping arrangement reduced subspecialist visits without increasing the level of involvement of the primary care provider.<sup>24</sup> For commercially insured patients, a study of the 1996 Medical Expenditure Panel Survey data demonstrated that gatekeeping to control and possibly restrict access to subspecialists was not an effective pediatric health care cost-containment strategy.<sup>25</sup>

#### **A CASE STUDY: ACCESS TO PRIMARY AND SUBSPECIALTY CARE FOR HOMELESS CHILDREN**

Studies since the mid-1980s consistently show that homeless children, compared with similarly poor but housed children, have more acute and chronic illnesses. Mothers of homeless children are more likely to report that their children have had fevers, ear infections, diarrhea, asthma, or bronchitis in the past 6 months.<sup>26</sup> Homeless children were reported to have more behavioral problems and school failure than housed poor children.<sup>27</sup> School-age children in shelters are more likely to have behavioral and psychiatric problems,<sup>28</sup> to fail in school, and are less likely to receive special education services if needed.<sup>29</sup> Nutritional problems, including obesity, are exacerbated by restricted access to kitchen facilities as well as food insecurity.<sup>27</sup> Once homeless, access to and continuity of care are further undermined by the transient nature of shelter placements.<sup>30</sup> Also, immunizations are more likely to be delayed.<sup>31</sup> This is consistent with the finding that homeless children are also more likely to lack a regular source of health care, 59% in a Washington study, which also found that homeless children used hospital emergency departments at 2 to 3 times the rate of the general child population.<sup>32</sup>

While some of the identified health problems of homeless children may be attributable to shelter conditions, such as increased rates of accidents and injuries including burns,<sup>33</sup> many predate the family's homelessness. For example, a study of asthma among chil-

dren entering the New York City shelter system during 1998-1999 found a 40% prevalence. Twenty-seven percent had a prior asthma diagnosis, and 13% did not have a diagnosis despite moderate to severe asthma symptoms.<sup>34</sup>

## **A WORKING STRATEGY: THE RMI**

The Children's Health Fund New York Program consists of the New York Children's Health Project (NYCHP), a health care for the homeless program that serves 13 homeless family shelter and domestic violence shelter sites, and the South Bronx Health Center for Children and Families (SBHCCF), a federally qualified health center in a medically underserved inner-city community in the Bronx. The NYCHP provides care either through mobile medical units (pediatric clinics on wheels) or through fixed-site clinics established at shelters when suitable space is available. The Project uses a medical home model, providing comprehensive care with access to subspecialists through its affiliated academic medical center. Half of the sites have mental health and case management services colocated with the primary care providers. The SBHCCF model is similarly comprehensive, with dental and mental health services available at the health center.

When homeless children enter a medical home relationship such as the NYCHP, they present, as expected, a very high level of need for subspecialty care, with a severely limited ability to access these needed services. As a baseline, in 1997, NYCHP patients referred to subspecialists by their primary care providers had a 7% adherence rate with specialty care appointments. The Children's Health Fund RMI was developed with a corporate partner\* to address this poor adherence rate and improve the coordination of care for these children.

The RMI model was designed by systematically analyzing the referral process and providing enabling services at each point where particular factors might interfere with adherence to the subspecialist appointment. The frequent barriers noted in the systematic analysis of the referral process included the interval between date of referral and date of appointment, broken appointments, transportation difficulties, insurance status questions, transfer of information between providers, language barriers, and difficulty navigating the health care system. For each of these barriers, an intervention was developed to smooth the process from referral to completion.

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\*SmithKlineBeecham, now GlaxoSmithKline, has supported the RMI since 1997.

The interval between date of referral to a subspecialist and first appointment has been found to be significantly associated with appointment keeping (patient adherence). The longer the lag time, the more likely the appointment will be broken.<sup>35</sup> A long interval between referral and appointment may also have negative clinical consequences in delaying delivery of urgently needed services. In its extensive “referral advice” document, the National Institute for Clinical Excellence (United Kingdom) recommends that referred patients be triaged for clinical urgency, as “immediate” requiring subspecialist appointment within 24 hours, “urgent” (within 2 weeks), “soon,” and “routine,” the latter two determined by local availability of subspecialists.<sup>36</sup> To the extent possible, the RMI team attempts to keep lag time as brief as possible, with the referring primary care provider rating each referral need by severity of referral problem on a 3-point scale. If necessary, the provider intervenes directly with the receiving subspecialist service for urgent referrals that do not receive an appointment soon enough.

If too much time elapses before the appointment, patients may forget the appointment date, which can lead to broken appointments.<sup>37,38</sup> Broken appointments can be a significant barrier to participation in Medicaid by providers. This is especially the case with respect to dentists, as it is consistently mentioned as a barrier to participation just behind poor reimbursement.<sup>39-41</sup> Appointment reminders are a proven strategy to improve patient adherence.<sup>42,43</sup> RMI includes a system of reminders—mail, phone, and to the extent possible, in-person by shelter staff.

Transportation to appointments is a powerful hidden barrier to access.<sup>44</sup> Even in New York City, with its excellent mass transit system, transportation may be problematic. Often parents must travel with their other children, who may also be ill. This adds to the round-trip cost of transportation, which is \$8 for one parent and one child for whom full fare must be paid. In today’s economy, this cost is significant for a poor family. The RMI covers the cost of round trip subway or bus fare for these families. For homeless families in particular, the distance to be traveled may be great because homeless shelters are generally located in isolated communities distant from hospitals where subspecialists practice. For these patients, car service may be required, and under these circumstances the costs are covered by the RMI.

Other elements of the RMI ensure that a family’s insurance status is clarified and managed before the subspecialist appointment, so no one is turned away because of a temporary lapse in Medicaid coverage or enrollment in a managed care plan not accepted by the

subspecialist. Chart notes from the subspecialist visit are obtained by an RMI staff person and provided to the patient's primary care provider to ensure that the referring provider has immediate knowledge of the results of the consultation. When necessary, translators are provided to ensure that the parents know the results of the visit and understand their child's care needs. Finally, an RMI staff person is available to the family at or near the hospital to help navigate through the medical center to the subspecialist's office.

### **IMPACT OF THE RMI**

Specialty referral rates of the homeless population served by the RMI were compared with those of a sample of US children with similar socioeconomic status and relatively similar needs for specialty care. In addition, for all subspecialist referrals managed through the RMI, data were recorded to identify the patient, referral site and provider, subspecialty clinic, referral problem, and adherence. Using these data, we were able to determine the rate of subspecialist referral need with the population of homeless children in shelters seen by the Children's Health Fund NYCHP and to compare it to another, similar population of children. A study performed by Kuhlthau et al<sup>45</sup> provided a comparable reference group of Medicaid-enrolled and uninsured children with which to make comparisons. As in the Kuhlthau study, NYCHP patients referred only to ophthalmology, psychiatry, or obstetrics/gynecology were excluded from the unduplicated patient count, since national studies do not cover these 3 specialty referral areas. Dental referrals were included if they were for a problem such as dental caries or gum infection identified by the primary care provider. Referrals for routine dentistry, though important within this population, were also excluded.

In 1998, 509 of 2205 NYCHP patients (23%) required at least one subspecialist referral. Two or more subspecialist referrals were required by 113 patients (5% of patients; 22% of referred patients). This population of homeless children had 1.77 times the referral rate of the Medicaid-enrolled children in the Kuhlthau study. In nearly all cases of multiple referrals, the children's specific health problems were coexistent but unrelated and included club foot, hearing loss, visual impairment, seizure disorder, failure to thrive, and hydrocephaly.

In 2001, 544 of 2425 NYCHP patients (22%) required at least one subspecialist referral. Two or more subspecialist referrals were required by 129 patients (5% of patients; 23% of referred patients). Thus, the population of homeless children served by the RMI con-

tinued to have an enhanced referral rate that was 1.7 times the national rate. In both cohorts, despite a 1998 asthma prevalence of 27% (based on retrospective chart review), fewer than 3% of referrals were for asthma. This may be attributable to enhanced asthma management in primary care without the need for subspecialty referral.

With the RMI enabling services, *adherence for medical subspecialty appointments among homeless pediatric patients increased from the 1997 baseline of 7% to 61%* (cumulative data, 1998-2001), for a total of 3504 pediatric patients requiring 4460 subspecialist referrals. This adherence rate declined since 2001 to approximately 55% as homeless families have been faced with increasing pressures under “welfare reform” to attend job training programs and, more recently, increasing pressure to locate housing as quickly as possible. In terms of impact on health care-seeking behavior, families frequently must choose between keeping a subspecialist appointment for their child and missing a mandatory appointment for job training or other Temporary Assistance for Needy Families-required appointments for which there may be sanctions if missed.

More important than the percentage of children and families aided in accessing subspecialty care is the number of serious health consequences that may have been averted because of this increased access. Focusing on patients from our 1998 cohort of homeless patients, the clinical and quality-of-life implications of continued failure to treat their identified health problems becomes clear. Subspecialist needs of this cohort of children included medical, surgical, dental, developmental, and mental health-related issues.

Several patients required cardiology consultation for conditions including class III-IV heart murmurs and tachycardia. One 3-year-old patient with Down syndrome had had a prior heart surgery but no follow-up. Five patients had a seizure disorder for which they were not receiving medication, placing them at serious risk of developmental delay. One patient, at 10 months of age, had seizures lasting up to 5 minutes, and was also diagnosed with cleft palate and macrocephaly. Ten patients were referred to audiology after failing office-based hearing screening or because of maternal concern about hearing (a sensitive risk indicator for hearing loss). Among the patients with newly diagnosed sensorineural hearing loss was a 14-year-old boy with an extensive history of special education and behavior problems. He received hearing aids after audiological testing.

Of those children who required surgical referral, one newborn was identified with a tracheal abnormality associated with narrowing of the airway. Another patient, older than 2 years, required sur-

gical referral for an umbilical hernia. Four patients had club foot, and one child, at 17 months, had a prior surgery but no prescribed physical therapy or leg braces. Another patient, 44 months of age, had not been previously diagnosed and was prescribed leg braces at his first orthopedic visit. This child was also referred to neurology for seizure disorder and audiology to rule out hearing loss.

One child was initially seen at 15 months with hydrocephalus, which necessitated neurosurgical referral. On developmental assessment, she had a severe speech-language delay (>33%), with no communicative speech and no gestures to communicate needs. She did not respond to her name and could follow simple commands only if they were accompanied by gestures. On audiological assessment, hearing was within normal limits. Cognitive functioning was at the 3- to 6-month level. Toys were mouthed or thrown at random, and social behavior was marked by spontaneous screaming, hitting, biting, and scratching. A ventriculoperitoneal shunt was implanted at 17 months, and multiple surgeries followed. By 4 years of age, this patient was diagnosed with a speech-language disorder; cognitive and social functioning were within normal limits.

As is expected in a population of high-risk children with limited access to dental services, 47 patients had acute oral health needs identified by their primary pediatrician. Thirty-one of these patients were identified with dental caries; others had gum disease, which is the leading cause of lost teeth and other potentially more serious medical conditions.

Other subspecialty referrals facilitated by the RMI included 10 patients with diagnosed failure to thrive. Eight patients had strabismus, 3 of whom were 6 to 8 years of age, much older than optimal to prevent surgical intervention. Also identified and referred to ophthalmology were children with visual acuity problems serious enough to have a dramatic impact on their education (eg, 20/200 bilaterally in an 8 year old). Overall, among the subgroup of 113 patients who needed 2 or more subspecialist referrals in 1998, two thirds (69%) had a mental health or developmental diagnosis, also including depression, enuresis, and encopresis.

## **CONCLUSION AND RECOMMENDATIONS**

Low-income children, especially the homeless, are at increased risk of ill health not only because of their increased prevalence of disease, but also because of the difficulties they have in accessing a medical home. Their increased rates of acute and chronic disease may require services that go beyond the capabilities of the primary care provider, necessitating referral to a pediatric subspecialist or

other services not provided in the primary care setting. Numerous barriers exist that make access to pediatric subspecialty services difficult for low-income and homeless children and families. Addressing these barriers is a key component of guaranteeing a medical home and truly comprehensive care for these underserved children. The RMI of The Children's Health Fund is one model for addressing the barriers to subspecialty care that these children and families face.

Implementing such a referral management model does not come without significant costs, however. This type of model requires a work force that can facilitate appointment scheduling, ensure that reminders to families are provided, assist patients and families in navigating the health care system mentally and physically, translate medical information into layperson's terms as well as native tongue, and deliver subspecialist notes to primary care providers. Additional resources are also needed to support transportation of families to and from appointments.

Such financial and human resource requirements may represent difficult challenges for resource-strapped health care systems that serve large, medically underserved populations. In spite of these costs, the early recognition and referral to subspecialty care and treatment of children with disease conditions that would otherwise increase morbidity and mortality can substantially reduce future health care costs. Thus, it is worthwhile for policymakers and health system leaders to look at models like the RMI as strategies to lower future health care costs while improving the health of the neediest of children.

Various public policy strategies should be pursued that will improve access to subspecialty services that many low-income and homeless children require. The following are examples of what can be done to improve access to pediatric subspecialty care:

1. Because many referrals to subspecialty services result from late recognition of hearing, vision, and developmental problems, the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) provisions of Medicaid should be maintained and strengthened.
2. In an effort to determine best practice models that are feasible and replicable in other local, state, and regional health care systems, funding for the replication and expansion of models like the RMI should be made available.
3. Since barriers relating to transportation, language, and navigation of the health care environment diminish patient access to subspecialty care, insurers and health systems should ensure

that transport, translation, and patient support services are integral parts of the benefits provided to patients.

4. Strategies to coordinate the various funded transportation resources available in many communities (eg, for senior citizens, people with disabilities, and young children in Head Start Programs) would result in these resources being used more efficiently. It would then be possible to use currently available transportation resources to facilitate health care access for children in need without substantially adding to current budgeted transportation costs.

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