

Summit for Children's Health in New Jersey



POLICY RESEARCH INSTITUTE FOR THE REGION

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Summit for Children's Health in New Jersey

October 17, 2008

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This Executive Summary of the proceedings offers an overview of the symposium. A complete report on the conference will be published at a later date.

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The Policy Research Institute for the Region was established by Princeton University and the Woodrow Wilson School of Public and International Affairs to bring the resources of the University community to bear on solving the increasingly interdependent public policy challenges facing New Jersey, metropolitan New York, and southeastern Pennsylvania.

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Preface

Everyday U.S. citizens and their elected officials agree that children's health care is a vitally important issue, both regionally and nationally. In testimony before the Senate, New Jersey U.S. Senator Robert Menendez argued in favor of the new law expanding SCHIP, the federal program designed to help working families who cannot afford private health insurance but earn too much to qualify for Medicaid healthcare coverage for the poor, stating, "For all of us, this is a matter of values. Do we value our children, and do our actions match our values?"

One of the first pieces of legislation signed by President Obama was the expanded SCHIP bill. The new legislation expands SCHIP by approximately \$35 billion over the next five years and will provide federally funded health care to an estimated four million children. The President stated that with the passage of the bill "We fulfill one of the highest responsibilities that we have- to ensure the health and well-being of our nation's children."

Even before the passage of the new federal law, New Jersey made serious efforts to improve children's health care with its expanded SCHIP program that requires every child in New Jersey to have health care insurance. There are 130,000 New Jersey children currently enrolled in FamilyCare, the state's children's health insurance program, and that number will be increased by an additional 100,000 as a result of the recently passed federal bill.

However, children's health care in New Jersey continues to encounter serious challenges, as evidenced by the state's bottom-quartile ranking in the Commonwealth Fund's recent Child Health System Performance State Scorecard. How and why does one of the country's wealthiest states miss the mark on an issue that is so important to the future of our citizenry, and what can be done to correct it?

On October 17, 2008 PRIOR convened a symposium that brought together scholars, practitioners, and leaders in the field to examine the topics of prenatal care and infant mortality; the pediatric workforce; infrastructure; the medical home; and SCHIP. The summit explored best practice models, presented the opportunity for comparative analysis, and considered the measures required to achieve progress in New Jersey.

Dr. Edward L. Schor, the Vice President of the Commonwealth Fund, discussed the Commonwealth Report and New Jersey's performance in relation to the other states surveyed. He pointed out the variations in health care performance from state to state,

and said that, “as a physician, I find it fairly abhorrent that the kind of healthcare you have available to you depends on where you live in this country.” He concluded that “universal health care matters,” and called for systemic solutions to the problems of the healthcare, family support, and medical care systems.

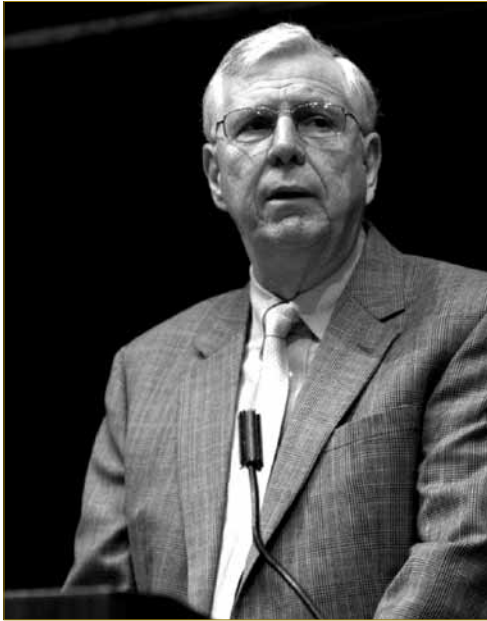
Dr. Renee Jenkins, President of the American Academy of Pediatrics, discussed the Academy and said that its mission is to look at health in a broad way, including physical, mental and social health. She stated that the vision of the Academy is “that children will have optimal health and wellbeing, and that they are valued.” She also discussed the issues of access to health care, oral health, mental health, prenatal care, and vaccinations. Finally, Dr. Jenkins presented the challenge of gathering the political will to implement change and make the investment in our children’s health.

Dr. Nancy Reichman, Professor of Pediatrics at UMDNJ and Visiting Professor of Economics at Princeton University, discussed birth outcomes and children’s health care in New Jersey. She pointed out that the gains against infant mortality lead to lower birth weight survivors with their own set of resultant health issues. She recommended a comprehensive needs assessment, a population-based survey in the state, and following up the information-gathering with an action plan.

Dr. Sara McLanahan, Director of the WWS Center for Research on Child Well Being and Princeton Professor of Sociology and Public Affairs, discussed the results of the Fragile Families study that looked at families headed by unmarried parents to assess the impact on children’s health. The findings were that socioeconomic factors other than family structure affected children’s health care outcomes in the New Jersey areas studied.

Dr. James M. Perrin, Professor of Pediatrics at Harvard Medical School, addressed the issues in improving the health of children and youth and emphasized the long-term benefits to the taxpayer of investing in children’s health care. He placed great emphasis on teamwork, prevention, assuring access, and supporting families.

The medical home was discussed by Dr. Irwin Redlener, President, The Children’s Health Fund, Professor of Clinical Population and Family Health, Mailman School of Public Health, Columbia University and Professor of Clinical Pediatrics, College of Physicians and Surgeons, Columbia University. He discussed the medical home idea in the context of healthcare for the medically underserved and stressed the importance of quality and accountability throughout the system.



PRIOR Director Richard F. Keevey

Mary Sibley, Deputy Commissioner of the Department of Human Services, State of New Jersey, spoke about New Jersey's SCHIP program, including the obstacles to its implementation and how New Jersey has addressed some of these barriers that included unwieldy forms, long waiting periods, and language difficulties.

Deborah Briggs, Senior Vice President, Health Policy and Advocacy, New Jersey Council of Teaching Hospitals, spoke about the preparedness and training of pediatricians, pediatric surgeons, and sub-specialists who care for children. She presented the efforts of the Council of Children's Hospitals to come together to "strengthen the network of services across the state and ultimately enhance the care of our children throughout the state."

Finally, Dr. Daniel A. Notterman, MD, FAAP, Professor of Molecular Biology, Princeton University, summarized the day-long conference and discussed how to incorporate best practices to improve and expand children's health care coverage in New Jersey.

The conference brought experts from both within and outside the region, and provided an opportunity for the conference participants and attendees to discuss this important topic in depth- they offered recommendations, analyses, and goals for improved children's health care in New Jersey.

The following agenda and executive summary of the proceedings offer an overview of the symposium—a complete report on the conference will be published at a later date.

Special thanks are offered to Thomas Hale for his work on this publication.

Sincerely,

A handwritten signature in cursive script that reads "Richard F. Keevey".

Richard F. Keevey, Director

Summit for Children's Health in New Jersey

October 17, 2008

On October 17, 2008, the Policy Research Institute for the Region (PRIOR) at the Woodrow Wilson School of Public and International Affairs, in conjunction with the Department of Molecular Biology, sponsored a forum on children's health in New Jersey. The event was the third in a series of conferences on "The Health Enterprise in New Jersey," and was in part a response to a report by the Commonwealth Fund that ranked New Jersey's performance in children's healthcare in the bottom-quartile of states.

As PRIOR Director Richard Keevey noted at the outset of the event, this low grade was particularly serious because New Jersey is one of the country's wealthiest states. Dr. Daniel Notterman of the Molecular Biology department termed the finding "embarrassing" and "galling," and told the audience that "it's going to be our job ... to try to understand these numbers, to understand why we seem to place, at least at the systems level, such a low priority on children's health."

To that end, the conference convened a variety of distinguished practitioners and academics to discuss the findings of the report and the state of children's healthcare in New Jersey, to compare it to other experiences, and to search for ways in which it might be improved. As Dr. Notterman noted, "our response to what we hear today, our response as a state and as citizens, will also tell us what kind of state we want to be, and actually to a large extent what kind of people we are."

State of the System: New Jersey and the Nation

Edward L. Schor, M.D.

Vice President, the Commonwealth Fund

Dr. Schor began the session by describing the findings of the Commonwealth Fund report and putting New Jersey's performance in national and global perspective. He first noted the "enormous variability" from state to state, a troubling finding because "the kind of healthcare you have available to you depends on where you live in this country." Schor also noted that the United States as a whole spends more on healthcare than any other country, but also has the highest infant mortality rate of any industrialized country.

A comparison focused specifically on children's health was necessary, Schor argued, because children's health needs differ from adults' needs. First, children are actively developing, particularly in their early years. Preventive care is thus crucial, as it can have life-long impacts on a child's health. Second, children's healthcare depends not on them but on their parents. Healthcare systems must thus address the role of families in order to be effective.

Schor then spoke to current challenges affecting children's healthcare. Many of the infectious diseases that used to plague children have now been controlled through vaccines, antibiotics, and other advances. Success on this front has increased the salience of what Schor termed "new morbidities:" drug abuse, teenage sexuality, learning disabilities, attention problems, behavioral disorders, etc. The healthcare system has not evolved to confront these new challenges, even though they constitute a



Dr. Edward Schor noted that the "enormous variability" of children's healthcare from state to state is a troubling finding because "the kind of healthcare you have available to you depends on where you live in this country." He also noted that as a whole, the United States spends more on healthcare than any other country, but also has the highest infant mortality rate of any industrialized country.

growing share of children's health problems.

But perhaps the greatest problem facing children is poverty. Children are the poorest group in the country, a grim fact with many repercussions for their health. One result is the high dependency of children on public support for medical care. About 30 percent of children in the U.S. depend on Medicaid; in some states Medicaid and SCHIP cover over half of children during their first five years.

The state is thus the key player in children's health. But states face enormous financial constraints. One problem is that Medicaid payment rates tend to be low and thus only cover part of the actual costs of medical care received. If that fraction, or reimbursement rate, is too low, many Medicaid patients find it difficult to find doctors who will treat them. New Jersey stands out in this regard, Dr. Schor noted, reimbursing only 34 percent of what Medicare covers for similar services, compared to the national average of 72 percent. But even were Medicaid or other insurance paying sufficiently, such policies may not be enough to ensure access; the federal government lists 13 of New Jersey's

21 counties as health provider shortage areas.

Dr. Schor then gave a detailed explanation of New Jersey's performance across the five major categories measured in the Report: potential to lead healthy lives, access to medical care, quality of medical care, cost of medical care, and equity in the receipt of medical care. Comparing the state to New York (25th overall) and Pennsylvania (18th overall), Dr. Schor showed that it was mostly concerns about access—how many children had healthcare available to them—that brought New Jersey down to 41st overall. Here family income seems to be decisive. While about 70 percent of children from families whose income is 400 percent of the poverty rate received preventive care, only 48 percent of those living under the poverty line accessed such services.

What could the state gain from improving its performance? Working backwards from the estimates for the best states, Dr. Schor quantified the potential gains of healthcare reform in New Jersey. Universal coverage would mean 153,000 more children with insurance. It would mean 26,000 more children becoming fully vaccinated. It would mean 141,000 children with access to preventive care, and 76,000 more children free from the risk of developmental delays, meaning substantial savings for the educational system.

In closing, Dr. Schor noted that though the variation in state performance was troubling, it also means that states have the potential to make children healthier by changing policy. Specifically, providing coverage to more children and giving them access to a comprehensive medical system focused on their needs can do much to change outcomes in New Jersey and other states.

State of the Child: A Medical Perspective

Renee Jenkins, M.D., FAAP

President, the American Academy of Pediatrics

Renee Jenkins, having just finished her term as president of the American Academy of Pediatrics, spoke about the current challenges to children's health and what work the Academy was doing to meet them.

She began by citing a 2007 UNICEF report that ranked wealthy nations on broad measures of children's wellbeing. The United States came in second to last. One important finding, made by Paul Wise from Stanford, is the high correlation between income inequality and poor performance in the UNICEF report. This result emphasizes the role of socioeconomic forces on children's health, Dr. Jenkins argued, noting that the Academy is very concerned about the eight to nine million uninsured children in the United States, many of whom having working parents.

As Dr. Schor had also emphasized, the nature of children's caregivers is also an important determinant of their health. About one million children live in foster care, and about four times that many are taken care of by other members of their families. Such arrangements may not be well-served by the healthcare system, an issue the Academy is studying.

The Academy is also looking at children's oral health, which is often underemphasized. Dr. Jenkins reported the Academy's finding that oral health is one of the most common reasons children miss school, and so can have repercussions on children's lives beyond cavities.



Dr. Renee Jenkins reported the American Academy of Pediatrics' finding that oral health—often underemphasized—is one of the most common reasons children miss school, and can have repercussions on children's lives beyond cavities.

Similarly, children's mental health is also often addressed poorly. A major problem here is the lack of health professionals to deal with children's mental health needs. For this reason, the Academy is working with its members pediatricians to help them address, assess, and even treat mental health problems in clinics.

Vaccination is another element of the Academy's work, particularly educating parents about the benefits of vaccinating their children. Dr. Jenkins noted that in Washington State, for example, in some counties as many as 30 percent of children are not vaccinated because parents have filed for "philosophical exemptions." This growing trend is a major threat to public health, Dr. Jenkins argued. Because many parents today have never seen the kinds of diseases vaccinations protect against—precisely because vaccination programs have been so successful—they are perhaps less worried than they should be about these dangers, Jenkins argued.

The Academy also engages in broader advocacy work on children's health. Their

message is that children's health is not just good for children, but that it is an important and necessary investment in the future health of the country. In this regard, Jenkins had praise for New Jersey's recent decision to expand coverage to all the state's children, though she noted "there are issues with it."

During the question and answer period, Jenkins elaborated on two points. First, she noted the importance of prenatal care to children's health. Because healthy mothers give birth to health children, prenatal care is an important determinant of children's health. Jenkins thus advocated that New Jersey's universal coverage for children be extended to pregnant women as well.

Second, Jenkins expanded on the pro-vaccine advocacy of the Academy. Teachers, who see the effects of sickness on children every day, are a natural ally for this cause, and the Academy has been working with them to strengthen its educational work. They have also formed a National Immunization Alliance with other organizations, and have been exploring new ways to reach out to new mothers on the Internet.

Birth Outcomes and Children's Health Care in New Jersey

Nancy Reichman, Ph.D.

Professor of Pediatrics, UMDNJ – Robert Wood Johnson Medical School and Visiting Professor of Economics, Princeton University

Dr. Reichman presented a rich description of the state of children's health in New Jersey to supplement and expand on the Commonwealth Fund report. Specifically, she focused on birth outcomes and the

health of very young children, which are key determinants of children's health overall.

Low birth weight is the second leading cause of infant mortality in the U.S. (after birth defects), and is associated with numerous problems amongst survivors, including cognitive deficits and behavior problems. The overall rate for low birth weight in New Jersey is eight percent, similar to the national rate. However, there is substantial variation across counties. Newark, Trenton, Camden, and some of the rural counties are worst-affected, a trend that largely parallels poverty.

The good news, Dr. Reichman reported, is that New Jersey has quite a low infant mortality rate, tenth best in the nation, and it is improving over time, decreasing 27 percent from 1994 to 2004, compared to a 15 percent decrease for the U.S. as a whole. So if New Jersey is underperforming in children's health care, it is not because of infant mortality, Dr. Reichman argued.

Rather, Dr. Reichman identified three reasons for New Jersey's low ranking. First, precisely due to the gains against infant mortality, New Jersey is confronted with an increasing number of low birth weight survivors, children who tend to be at risk for many other kinds of health problems, many of them very costly. While the number of children is not large enough to explain the entire disparity New Jersey exhibits, it could be a significant part of the problem, Dr. Reichman argued. The irony is that, in Dr. Reichman's words, "A positive on one dimension that is measured in the report, infant mortality, along with ...another dimension that was not measured, low birth weight survival...cause some of the negatives, cost and risk for developmental delay, for example."

Second, Dr. Reichman noted the high rate of uninsured children in New Jersey, as identified by the Commonwealth Fund report. Third, Dr. Reichman noted that New Jersey fared poorly because of low rankings in specific types of care—some of which tend to be uncovered or poorly covered by health insurance.

Dr. Reichman then turned to how the state might improve its health care system performance for children. An ideal strategy would be to reduce low birth weight. Progress is difficult, however, because the causes of low birth weight are not well understood. Many programs have tried to reduce low birth weight by increasing prenatal care, but have met with limited success, perhaps because prenatal care may be "too little too late" to make a substantial change. The implication is not that prenatal care should not be provided; rather, these findings suggest that prenatal should probably be expanded to include pre-conception care.

An important obstacle to effective healthcare for children—and one that could potentially



New Jersey has a quite low infant mortality rate, 10th best in the nation, noted Dr. Nancy Reichman. New Jersey's low ranking for providing children's healthcare, therefore, can be attributed to three factors—low birth weight survivors tend to be at risk for other, more costly health problems; a high rate of uninsured children in the state; and the suboptimal use of resources, particularly preventive care.

explain at least part of New Jersey's poor ranking, according to Dr. Reichman—is the immigration status of a child's parents. Children born of immigrants are far more likely to lose their insurance, perhaps because the parents fear registering their children will expose them to legal scrutiny. About 32 percent of the children born in New Jersey were born to immigrant mothers, the fourth highest rate in the nation. Discovering ways to serve this population is thus crucial to improving children's health in the state.

Dr. Reichman then turned to issues of quality of care. Disaggregating the Commonwealth Fund data, she argued that it is not preventive care, referrals, or proper management of asthma that are lowering New Jersey's ranking on this front, but rather administering vaccines, mental health care, and follow-up for specialty services. These types of quality issues are likely linked to the insurance problem, she noted. Though recent gains have been made, in 2003 New Jersey ranked the lowest out of all states for Medicaid fee-for-service reimbursement.

During the question and answer period, one audience member noted that all the day's speakers had identified access to insurance as a major cause of New Jersey's poor performance. This was, he thought, "missing the forest for the trees," because insurance intermediaries claim 50 cents of every dollar in administration fees, he stated. In Canada, 95 percent of spending goes to patient care. Without radical reform of this system, simply expanding insurance is not likely to be financially sustainable, he argued.

The Family in Newark, New Jersey: Insights from the Fragile Family Study

Sara McLanahan, Ph.D.

William S. Todd Professor of Sociology and Public Affairs, and Director, Bendheim-Thoman Center for Research on Child Wellbeing, Woodrow Wilson School, Princeton University

Dr. McLanahan reported on the results of the Fragile Families study, a multiyear investigation of unmarried parents in 20 cities across the country, including Newark that sought to determine the effect of parenting arrangements on children's wellbeing. This question is important, Dr. McLanahan explained, because there has been a dramatic increase in the number of children born to unmarried parents. Today, about 25 percent of white children and 70 percent of African-American parents are born outside of marriage.

The researchers interviewed mothers after they had given birth, then determined who the fathers were and interviewed them as well. Follow-up interviews were then conducted over the phone when the child was one, three, and five, as were home visits in some cases. The study, begun in 1996, thus draws from a large range of detailed data.

The first question Dr. McLanahan and her colleagues sought to answer was what the parents' capabilities were. Unmarried parents tend to be younger than married ones, less educated, and more likely to have children with another partner. This leads to what Dr. McLanahan termed "multi-partnered fertility," an increasingly common phenomenon in which parents have children with two, three, or more different partners over time, creating



Princeton University's Dr. Sara McLanahan presented data from the multiyear Fragile Families study that indicated that the increase in the number of children born outside of marriage may have a causal effect on children's wellbeing.

complicated family structures that have real impacts on parents' capabilities.

Newark differed from other cities in the study in some important respects. Sixty percent of the married couples in Newark were immigrants, meaning their educational attainment was in fact lower than the unmarried couples, unlike in other cities where married couples tended to have more education. The Newark parents also showed higher levels of depression than those in other cities, but similar levels of drug and alcohol use. A particularly shocking finding was that 41 percent of the unmarried fathers in Newark have been incarcerated at some point, a trend common throughout the cities sampled.

At the time of birth, 44 percent of the unmarried couples are living together, another 34 percent are not living together but romantically involved, and just 20 percent have no relationship. This finding indicates that these types of birth are not simply the results of "one night stands," but rather unstable romantic relationships. This perhaps explains the fact that fathers are very involved

in the children's lives at birth (financially, and in person), but then become less involved as the child ages. All those interviewed, married and unmarried, stated that they believed marriage was the ideal environment for raising children, but many of the unmarried mothers also believed that it was possible for a woman to raise children alone.

Another question Dr. McLanahan sought to answer was what happens to these relationships over time. The answer is growing in complexity, she argued. When the child is five about 60 percent of the married couples and 50 percent of cohabiters remained together. The numbers are significantly less for those parents who were not living together at the time of birth. Many of the parents also now have children from other partners. This situation directly affects capabilities, as Dr. McLanahan argued, "you can imagine what that must be if you have three children. You are trying to arrange visitation for three different fathers. You are trying to collect child support from three different men, and there is a lot of jealousy that comes up."

Last, Dr. McLanahan asked what the impact of such families was on children's health. She noted that Newark had exceptionally high rates of asthma and obesity among children, even controlling for income, race, and other variables, but that there was little difference between the children of married and unmarried parents on these scores. She also found that children in Newark had slightly lower rates of health insurance than the other cities studied, but that this difference was small. In sum, it does not seem to be the case that it is family structures that are driving child health outcomes in Newark, but rather other socioeconomic factors.

Improving Child and Adolescent Health Care

James M. Perrin, M.D.

Professor of Pediatrics, Harvard Medical School and Director of the Division of General Pediatrics and the Center for Child & Adolescent Health Policy, Mass General Hospital for Children

Dr. Perrin made a strong case for investing in the health of children, explained why children's needs differed from those of adults, and presented a series of ways in which public policy could improve the health of children.

First, Dr. Perrin noted that healthier children would yield savings for the taxpayer. For example, improving birth weight can help prevent costly learning disabilities down the line. Moreover, healthier children ready to enter and participate in school at age five translate into a stronger workforce 15 to 20 years in the future. Dr. Perrin also noted an indirect economic benefit of children's health. One in five workers today has a child with a chronic health condition. "To be actually effectively present at the job, they do not need to be worrying about their children," Dr. Perrin argued, "And we know that if you have a child with substance abuse, or if you have a child with ADHD, or a child with depression, or a child with some other condition like asthma.... then the likelihood that you are actually going to be present on the job, doing your job right, goes down."

Second, Dr. Perrin emphasized some key differences between children's healthcare and adult healthcare, with prevention first among them. Simply put, a person's future health is deeply affected by what care he or she receives as a child. Some examples Dr. Perrin provided showed serious flaws in the state of preventive care today. Less than half of

children with asthma receive anti-inflammatory medications. Only half of children aged two are fully immunized. Only sixteen percent of children zero to three years old with high fevers have their urine checked for infection, and only forty-two percent of sexually-active adolescent girls were checked for Chlamydia. "These are not good numbers," Dr. Perrin warned.

The developmental framework in which children grow up, the fact that they are constantly changing, is also important. So is the dependence of children on adults for care, especially parents, but also teachers, schools, and other figures in children's lives. Because children receive care across many venues—schools, hospitals, at home, in the community—coordination of services is often key. This is a limitation of the report in the *New England Journal* regarding the quality of child health care, Dr. Perrin noted, because it focuses only on the care children receive in clinics.

Indeed even a child's "medical home"—the full panoply of medical services he or she receives, or should receive—is too narrow a focus to evaluate the state of children's healthcare. Dr. Perrin identified the mental health system, social services, education, vocational services, housing, juvenile justice, transportation, and community organizations as other crucial dimensions.

The largest challenges to children's health today are chronic conditions like asthma or obesity, problems that only recently came to dominate the concerns of physicians. In 1960 about 1.8 percent of children were reported to have a chronic disease that limited their daily activities; today the figure is eight percent, or four times as many. Out of a U.S. child population of about 80-90 million, there are



over 11 million obese children, five million with asthma, four million with ADHD, 3.5 million with depression, and half a million with autism spectrum disorders.

Part of this shift is attributable to gains in child survival, as new medicines and treatments save lives. Another reason may be increasing parental stress and decreasing parental availability. Children also have much less access to physical activity than they used to, in part because of the rise of television, the reduction of sports programs, and other changes in the way children's time is spent.

Chronic disease cannot be addressed through the traditional physician model alone, Dr. Perrin argued. Instead, teams of pediatricians and other professionals, including nurses and mental health specialists will be increasingly important. Children require a more comprehensive medical home in order to overcome the challenge of chronic diseases. Some preliminary research has shown that such holistic approaches can yield substantial improvements in children's health, Dr. Perrin explained. He concluded that more efforts focused on prevention of chronic conditions

and more team-based care that is effectively integrated into children's range of social environments is needed.

During the question and answer period, one audience member noted that team-care is relatively easy in a hospital

where many different specialists are clustered together, but harder in private practices.

Dr. Perrin responded that this was certainly true, and noted a new and promising trend in which private practitioners agglomerate in shared offices, making it easy for patients to avail themselves of a wide range of care. Dr. Perrin also noted the role that nurses and other healthcare professionals could play in a team-based system, easing the burden on physicians.

The Medical Home: Models and Opportunities

Irwin Redlener, M.D.

President, The Children's Health Fund, Professor of Clinical Population and Family Health, Mailman School of Public Health, Columbia University and Professor of Clinical Pediatrics, College of Physicians and Surgeons, Columbia University

Dr. Redlener began by noting some important misperceptions about what is meant by access to healthcare. For most, "access"

simply means having health insurance, Medicaid, SCHIP, or something similar. "Healthcare," meanwhile, means any kind of medical treatment, including simply dropping in on an emergency room. Dr. Redlener noted President George Bush's now infamous June 2007 comment to this effect.

Such views are obviously incomplete, Dr. Redlener argued. Instead, we need to provide children (and adults) with meaningful access to a wide range of medical services across a wide range of areas—"from screening and prevention to the diagnosis and treatment of acute and chronic diseases, the management coordination of relevant specialists and special services"—a concept known as the medical home. But even that is not truly sufficient, Dr. Redlener argued, echoing Dr. Perrin. An "enhanced medical home" would also include mental health, behavioral health issues, case management, oral health and other aspects which may be important to particular populations.

Without a medical home, an individual loses opportunities to receive important screenings that may be key to future health. Preventive care is not systematically applied. Follow-up on acute illnesses is weak. Access to specialists is reduced, a problem especially important for children with chronic illnesses. Medical education is also more difficult.

The Children's Health Fund began by trying to apply the concept of an enhanced medical home to a particularly vulnerable population, homeless children in New York City. Because such children were transient and often moved from shelter to shelter, it was impossible to provide them with systematic care. One of the Children's Health Funds' innovations was to bring back the house call in the form of a fully-equipped mobile clinic, which could go to where the children are. The Fund's work has

since expanded to include stationary clinics and programs in 22 sites around the country.

The challenging nature of this work has created opportunities for CHF to develop additional innovations, which may be helpful for other practitioners, Dr. Redlener noted. First, the Fund uses electronic records which can easily be accessed remotely. Second, the Fund has developed a system for managing referrals. Before implementing this system only about seven percent of patients actually saw the specialists to whom they were referred. Now the figure stands at 70 percent.

Dr. Redlener identified some promising results from the Fund's efforts. Homeless children have extremely high prevalence rates of severe asthma, often exceeding 30% and almost always characterized by high rates of hospitalization and emergency room visits. After CHF implemented its "Childhood Asthma Initiative," rates of hospitalization of children with asthma fell from 29% to only 2%; and ER visits dropped to 19% from a high of 61%.

Dr. Redlener concluded with some observations about what meaningful access to healthcare means. Obviously the first priority is insurance, which eight to nine million American children lack. Expanding the SCHIP program is thus crucial, Dr. Redlener argued.¹ But insurance is only the first step. Many children live in isolated areas where standard healthcare, much less an enhanced medical home, is simply not available. And even children living close to healthcare providers may not be able to get to a clinic because public transportation does not exist or parents are not available to drive them. Dr. Redlener estimates that some 20 million American children face some kind of barrier to healthcare.

¹ Editor's note: In February 2009 the SCHIP program was significantly expanded.

Dr. Redlener concluded with some recommendations for policymakers. First, universal coverage is key. Second, medical care must aim at the idea of the enhanced medical home. Third, existing programs like SCHIP and community health centers should be strengthened. And fourth, more work needs to be done to understand and eliminate all barriers to access.

During the question and answer period, one audience member asked Dr. Redlener if he thought enough savings could be squeezed out of the current medical system to expand coverage and improve quality without overstressing public finances. Dr. Redlener responded that, though getting massive savings will be difficult without radical reform; at least a third of the \$2.1 trillion spent on healthcare last year was wasted on unnecessary paperwork and bureaucracy.

Another audience member asked how Dr. Redlener imagines convincing those opposed to or reluctant about the idea of universal coverage of its benefits. Drawing on his experience with the Clinton administration's efforts in the early 1990s, Dr. Redlener replied that the problems have become so massive in the intervening 15 years that a new sense of urgency has changed many minds.

SCHIP: New Jersey Experience and Other Models

Mary Sibley

Deputy Commissioner, Department of Human Services, State of New Jersey

Ms. Sibley spoke about the hopes and challenges New Jersey faced as it seeks

to cover all children in the state under its expanded SCHIP program. In July 2008 Governor John Corzine signed a law that requires every child in New Jersey to have health insurance, though it does not, like the Massachusetts program, impose a penalty on those who do not. Low-income residents of the state are brought under this "soft mandate" through what is called the Family Care program, which enrolls adults (some 105,000) as well as children (126, 230). This creates difficulties, Ms. Sibley noted, because the adults can be quite expensive, but is good for health outcomes because healthy parents make for healthy children. Furthermore, research shows that parents who have coverage themselves are more likely to get coverage for their kids, meaning that there are synergies to covering both parents and children.

Nonetheless, the federal government has criticized New Jersey's Family Care program for combining SCHIP with adult-focused healthcare. The federal government has also criticized the relatively generous income criteria for enrollment in the plan. Individuals with incomes at up to 350 percent of the poverty rate can enroll in Family Care, which costs them about \$128 per month. However, Sibley argued that this high threshold was necessary because New Jersey remains a very high cost-of-living state.

Ms. Sibley then addressed barriers to the program. One problem was the application form, which used to be 15 pages long and rather burdensome to complete. It is now one page long, and available online in many different languages. Furthermore, instead of forcing families to submit documentation of their income, Sibley and her colleagues are working with the state tax agency to gather this information automatically.

Another problem with the program was the mandatory waiting period. To prevent SCHIP from simply siphoning people out of employer-sponsored programs, it was required that individuals be without insurance for a length of time before enrolling in SCHIP programs. New Jersey shortened this requirement from six to three months.

Communication barriers constitute another problem. For example, highly transient families do not remain in one address long enough to receive re-enrollment forms in the mail. The Department has tried to solve this by moving toward an automatic re-enrollment policy.

Another example is language. Indeed, many of the children most in need come from immigrant families. It is often difficult for the parents in such families to learn about or access state resources aimed at their children, perhaps because they fear scrutiny of their citizenship status.

Ms. Sibley closed by emphasizing the importance of universal coverage for all Americans, even for those who already have insurance. Imagine “if your son has an accident, or your father has a heart attack, they are going to be rushed to the emergency room, and you know what they are going to find? ... What they are going to find is the emergency rooms are crowded. They are packed with people, and when you want your father to get in there to be seen, you are going to have to wait, because everybody else who does not have insurance is also in the emergency room.”

During the question and answer session, one audience member, a practitioner in Trenton, pressed Ms. Sibley on the issue of waiting times. He reported that some of his patients were waiting up to six or seven months to

become enrolled. Ms. Sibley noted that she was personally intervening with the contractor who administered the program in order to minimize the backlog.

Another questioner wanted to know if the state planned to do more to publicize the Family Care program, particularly the option of individuals not eligible for free coverage to buy into the plan. She said the state was moving quickly on this front as well.

Finally, a questioner asked what the state could do for the many non-citizen children resident in New Jersey who need assistance. Ms. Sibley noted that the state was prevented from extending SCHIP benefits to these children by federal law, but hoped Washington would soon change this policy.

Children's Hospitals and Pediatric Workforce in New Jersey: Are They Ready for the Job?

Deborah S. Briggs

Senior Vice President, Health Policy and Advocacy, New Jersey Council of Teaching Hospitals

Ms. Briggs spoke about the efforts of the New Jersey Council of Children's hospitals, an alliance of 12 children's hospitals in New Jersey that have recently been collaborating to evaluate and improve their capacities. “Our goal is to provide that comprehensive medical home for the children, and ultimately give us the ability to treat the whole family through our sponsoring or affiliated adult institutions,” Ms. Briggs stated.

New Jersey has quite exceptional childcare resources located in these institutions

and in the nearby metropolitan centers of New York and Philadelphia. The Council includes nine acute comprehensive children's hospitals, two rehabilitative hospitals, and the University of Medicine and Dentistry of New Jersey. Together these institutions provide 234 Level I NICU bassinets, 154 intermediate bassinets, 95 PICU beds, 16 cardiac ICU beds, 99 pediatric emergency department beds, 80 rehabilitation beds, and 63 skilled nursing beds. In 2007, alliance members cared for over 200,000 children in visits to emergency departments. They had over 45,000 inpatient stays, and over a million outpatient visits. Ms. Briggs stated that the Council members felt they were absolutely prepared to handle any increased demand for their services stemming from the growing Family Care program.

The Council is trying to improve its members' performance in several ways. One of the highest priorities for the Council is to accurately measure how many child healthcare providers actually practice in the state. Meshing American Medical Association records with state databases is difficult, as is learning what services registered practitioners actually perform. Nonetheless, the Council has carried out a comprehensive inventory of the state's resources, and is developing a website to share that information with the public.

Another program is information sharing between institutions. The Council is fostering best-practices sharing between its members. For example, St. Joseph's Hospital in Patterson has a very successful obesity prevention program that is being shared with other institutions. The Council also attempts to document its performance so that both patients and the institutions themselves can

identify strengths and weaknesses.

A major concern of the Council is attracting talented physicians to the state. Noting the low reimbursement rates New Jersey provides pediatricians, Ms. Briggs argued that fundamental changes had to take place in order to ensure that there will be doctors available to treat the future needs of New Jersey's children. Programs to encourage doctoral residents, both in and out of the state, to move here may also be needed.

Ms. Briggs closed by noting that "New Jersey has a lot of political will to address children's issues, and we need to harness that, and we need to grow it." She invited the audience to come to tour the Council hospitals, to ask questions, and offer suggestions.

Summary and Synthesis: How to Incorporate Best Practices – Audience Participation and Panel Reflections

Moderator of Panel:

Daniel A. Notterman, MD, FAAP
Professor of Molecular Biology, Princeton University

During the concluding panel to the day's sessions, several themes addressed throughout the conference were discussed. First was the issue of Medicaid reimbursement rates. One audience member wanted to know if there was any information about how many practitioners refused to see Medicaid patients, or how many placed a cap on the number of Medicaid patients they would see,

because of low rates. Another questioner asked what the prospects for a rate raise in the state were. Ms. Sibley agreed that the low rates were a significant access barrier, and urged the audience to press their concerns with the Legislature.

Second, several audience members spoke to the key role information technology must play in improving the state's healthcare. One said, "We have a wealth of data that does not get turned into information to really improve the quality of care, and to be used for accountability and for quality improvement." Another said that technology was "the only ultimate answer" to the problem of rising complexity. Panel members noted that there is indeed a lot of data in the states from various branches of the government, ranging from tax data to children services data, that could be centralized and coordinated. Panel members noted that the government(s) are investing in information technology, including in a shared data warehouse.

Third, several commenters addressed barriers to healthcare created by culture, language, and immigration status. One said that, "the silent elephant in this room is our immigrant children." She called for the adoption of a free and universal healthcare system that would treat all residents of the state. Various panel members voiced their support for the idea, and noted that the states have sought to make their Family Care information available in over 100 languages. However, as Ms. Sibley pointed out that the states are prevented from directly supporting immigrant children by the federal government.



Dr. Daniel A. Notterman moderated the concluding panel, in which the roles of Medicaid reimbursement, information technology, and cultural, language, and immigration status barriers were discussed.

The following quote summarizes the feelings of the FORUM and panel members:

"A child is a person who is going to carry on what you have started. They are going to sit where you are sitting, and when you are gone, attend to those things which you think important. You may adopt all the Policies you please, but how they are carried out depends on them. They will assume control of your cities, states and nations. They are going to move in and take over your churches, schools, universities and corporation...The faith of humanity is in our children's hands. So, it might be well to pay him some attention.

Attributed to Abraham Lincoln

Appendix A

Conference Agenda

Summit on Children's Health Care in New Jersey

October 17, 2008

Sponsored by the Policy Research Institute for the Region at the Woodrow Wilson School of Public and International Affairs, Princeton University

Welcome and Opening Remarks

Richard F. Keevey, Director, Policy Research Institute for the Region, Woodrow Wilson School, Princeton University

Daniel A. Notterman, M.D., FAAP, Professor of Molecular Biology, Princeton University

STATE OF THE SYSTEM: New Jersey and the Nation

Edward L. Schor, M.D., Vice President, The Commonwealth Fund

STATE OF THE CHILD: A Medical Perspective

Renee Jenkins, M.D., FAAP, President, the American Academy of Pediatrics

Birth Outcomes and Children's Health Care in New Jersey

Nancy Reichman, Ph.D., Professor of Pediatrics, UMDNJ–Robert Wood Johnson Medical School and Visiting Professor of Economics, Princeton University

The Family in Newark, New Jersey: Insights from the Fragile Family Study

Sara McLanahan, Ph.D., William S. Todd Professor of Sociology and Public Affairs; Director, Bendheim-Thoman Center for Research on Child Wellbeing, Woodrow Wilson School, Princeton University

SCHIP: New Jersey Experience and Other Models

Mary Sibley, Deputy Commissioner, Department of Human Services, State of New Jersey

Improving Child and Adolescent Health Care (Lunch Presentation)

James M. Perrin, M.D., Professor of Pediatrics, Harvard Medical School and Director of the Division of General Pediatrics and the Center for Child and Adolescent Health Policy, Mass General Hospital for Children

The Medical Home: Models and Opportunities

Irwin Redlener, M.D., President, The Children's Health Fund, Professor of Clinical Population and Family Health, Mailman School of Public Health, Columbia University and Professor of Clinical Pediatrics, College of Physicians and Surgeons, Columbia University

Children's Hospitals and Pediatric Workforce in New Jersey: Are They Ready for the Job?

Deborah S. Briggs, Senior Vice President, Health Policy and Advocacy, New Jersey Council of Teaching Hospitals

Summary and Synthesis: How to Incorporate Best Practices—Audience Participation and Panel Reflections

Moderator: Daniel A. Notterman, M.D., FAAP, Professor of Molecular Biology, Princeton University

End of Forum Closing Remarks

Richard F. Keevey, Director, Policy Research Institute for the Region, Woodrow Wilson School, Princeton University

Daniel A. Notterman, M.D., FAAP, Professor of Molecular Biology, Princeton University

Commentary sponsored by the Policy Research Institute for the Region at the Woodrow Wilson School of Public and International Affairs at Princeton University.

The Policy Research Institute for the Region was established by Princeton University and the Woodrow Wilson School of Public and International Affairs to bring the resources of the University community to bear on solving the increasingly interdependent public policy challenges facing New Jersey, metropolitan New York, and southeastern Pennsylvania.

With a full-time staff augmented by project coordinators and guided by faculty associates and an advisory board, the institute reflects and understanding that the issues facing our region cut across not only state and municipal borders, but also across a range of traditional academic disciplines. Our mission is to bring together the University's greatest resources—its faculty and students, its research expertise, and commitment to public service—to find solutions across boundaries that improve the quality of civic life in our dynamic, multi-state region.

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