

medicaid  
and the uninsured

**ENROLLING CHILDREN IN MEDICAID AND SCHIP:**  
*Insights from Focus Groups with Low-Income Parents*

*Prepared by:*

Michael Perry  
Lake Research Partners

*and*

Julia Paradise  
Kaiser Commission on Medicaid and the Uninsured

**MAY 2007**

# kaiser commission medicaid and the uninsured

**The Kaiser Commission on Medicaid and the Uninsured provides information and analysis on health care coverage and access for the low-income population, with a special focus on Medicaid's role and coverage of the uninsured. Begun in 1991 and based in the Kaiser Family Foundation's Washington, DC office, the Commission is the largest operating program of the Foundation. The Commission's work is conducted by Foundation staff under the guidance of a bipartisan group of national leaders and experts in health care and public policy.**

James R. Tallon  
*Chairman*

Diane Rowland, Sc.D.  
*Executive Director*

kaiser  
commission on  
medicaid  
and the uninsured

**ENROLLING CHILDREN IN MEDICAID AND SCHIP:**  
*Insights from Focus Groups with Low-Income Parents*

*Prepared by:*

Michael Perry  
Lake Research Partners

*and*

Julia Paradise  
Kaiser Commission on Medicaid and the Uninsured

**MAY 2007**



## EXECUTIVE SUMMARY

Medicaid and the State Children's Health Insurance Program (SCHIP) provide health coverage to more than 30 million children in low-income working families. These programs have dramatically reduced the uninsured rate among low-income children over the last decade. Still, 9 million children, the vast majority of whom are eligible for Medicaid or SCHIP, remain uninsured. As Congress debates the reauthorization and funding of SCHIP, and a growing number of states take steps to broaden health coverage for children, the experience of low-income parents of both uninsured children and children enrolled in Medicaid or SCHIP provide valuable insights and information to guide policy.

The *Kaiser Commission on Medicaid and the Uninsured* sponsored this focus group project with low-income parents to understand their perceptions, motivations, and experiences related to enrolling their children in Medicaid and SCHIP. The research explores low-income parents' knowledge of these programs, their interest in enrolling their children, and the factors that pose barriers to their participation. The work also probes the value parents place on health coverage for their children and how low-income families without insurance cope with their children's health care needs.

Lake Research Partners conducted the project, which involved 11 focus groups in four cities (Chicago, Houston, Los Angeles, and Miami). The groups were held January 24 - February 21, 2007. Parents with income at or below 300% of the federal poverty level were recruited to participate. Seven focus groups were held with parents of uninsured children; three of these groups were conducted in Spanish. The remaining four focus groups were held with parents of children who are enrolled in Medicaid or SCHIP.

### *Findings*

The following key insights emerged from the research:

► **Uniformly, low-income parents consider health coverage for their children a top priority. Parents with uninsured children worry all the time and want to enroll their children in Medicaid and SCHIP once they learn about the programs.**

The overwhelming majority of parents say that having health coverage for their children is critically important. All believe that children need a regular doctor, check-ups, and access to prescription drugs, dental care, and other services in order to thrive and live healthy lives.

Parents without health coverage for their children say they worry all the time about their children getting hurt and needing medical care. Many say they

cannot afford unexpected medical bills and emergency room visits. They are also concerned that their children are receiving inconsistent and poorer quality medical care because they are uninsured. Most of all, the parents want a regular doctor who knows their children and their children's medical history, and they say this is impossible as long as their children are uninsured. In addition to these concerns, many parents also fear they are transmitting the stress of having no health coverage to their children, who sometimes hide their symptoms and downplay their health problems so that their parents will not worry. Once they learn about Medicaid and SCHIP, parents of uninsured children express strong interest in enrolling them in the programs.

**► Low-income working parents struggle to make ends meet and private health insurance is out of reach for their families.**

The family profiles of the low-income parents who participated in the focus groups are diverse, including two-parent working families, single parents and children, grandparents caring for grandchildren, and families with foster children. However, almost all have at least one working parent or guardian and, across the board, low-income families are struggling financially. Many parents report that the high cost of living in their area makes it hard for them to get ahead, no matter how hard they work. Their jobs simply do not pay enough for them to be financially secure, and their budgets are strained just to meet basic needs.

Generally, parents had given up on obtaining private health coverage for their uninsured children. Many work for employers that do not offer coverage. Others do not work enough hours to qualify for coverage that is offered, or have jobs that offer coverage to the employee but not the rest of the family, or cannot afford the premium for the coverage. Some parents observe that, even if they paid the high premium, they would have limited benefits and face high out-of-pocket costs for deductibles and co-pays. Parents also report that job changes and other family transitions sometimes lead to lapses in Medicaid and SCHIP coverage for their children, because program rules are sensitive to even small shifts in family circumstances.

**► Parents of children enrolled in Medicaid and SCHIP are grateful for the programs because they provide access to a regular doctor and comprehensive services.**

Parents of enrolled children praise Medicaid and SCHIP and are thankful for the programs. They say they have peace of mind knowing their children are covered. Many say their children would be uninsured without the programs. What parents value most is having a regular doctor for their children. Many say that having a doctor who knows their children and their children's medical history leads to better quality care. Parents of children with chronic health care needs, in particular, appreciate the comprehensive scope of services their

children can obtain and say that access to care under these programs is as good as or sometimes better than under private insurance. Finally, parents of enrolled children say that Medicaid and SCHIP are affordable, which is important to them.

**► Parents of uninsured children still have basic information gaps regarding Medicaid and SCHIP.**

Awareness and understanding of Medicaid and SCHIP are uneven and the gaps in parents' knowledge appear to be an important obstacle to their children's participation in the programs. Parents have a variety of misconceptions about who is eligible for Medicaid and SCHIP. Many low-income parents with uninsured children simply assume that Medicaid and SCHIP are not for working families. Others mistakenly assume that their earnings are too high for their children to qualify. If they have not sought assistance from any other public programs, parents are particularly likely to lack information about Medicaid and SCHIP.

Parents also tend to view ineligibility as a static condition. Some who were previously denied Medicaid or SCHIP for their children based on their income report that they did not reapply even though their income changed, and families whose children are newly eligible for Medicaid or SCHIP due to changes in family income seem to know very little about the programs. Parents with more awareness and knowledge had typically encountered outreach about the programs in multiple forms and settings and over time. They describe schools as one of several important sources of information, but parents of younger children not yet in the school system do not benefit from this outreach.

**► Parents express enthusiasm for streamlined enrollment systems that make obtaining child coverage easy, but parents describe complex enrollment procedures that hamper their efforts to seek coverage for their children.**

Parents who described short and simple applications with minimal or no documentation requirements, and multiple application options (e.g., mail, online), were enthusiastic that they were able to enroll their children easily.

At the same time, for many parents, long applications and burdensome enrollment processes are a major barrier to obtaining coverage for their children. These parents state that excessive documentation is required and that it is often hard for them to obtain it. The new federal requirement that citizens provide documents proving their citizenship and identity in order to obtain for Medicaid had not been implemented in all states when the focus groups took place, but all parents stated their unwillingness to put original birth certificates and other important required documents in the mail.

Parents are critical of the in-person interviews sometimes required to enroll their children. Taking off time from work for the interview is difficult and some risk losing their jobs if they call in sick or miss work to apply. Many parents say they have waited all day in the welfare office for their appointments. Parents also experience poor treatment by caseworkers who they feel mistrust and look down on them. Finally, for some mothers, state pressure to pursue child support from the children's father as a step in the enrollment process is a major barrier to obtaining Medicaid for their children.

► **Children in Latino families face extra barriers to enrollment.**

Children in Latino families face a broader set of barriers to enrollment than others, as their parents appear to have the largest gaps in awareness and understanding of Medicaid and SCHIP. While they typically find program application materials available in Spanish, Latino parents cite language barriers where caseworkers are concerned and indicate that this difficulty can be an impediment to seeking or retaining coverage for their children. Among families with mixed immigration status, fears that applying for Medicaid or SCHIP for their children could jeopardize other family members' ability to gain U.S. citizenship in the future, or even lead to deportation of the family, continue to have a chilling effect on the enrollment of their children in these programs.

***Policy Implications***

The findings from the focus groups suggest a number of policy directions, outlined below, that could promote increased enrollment of eligible children. The ideas stem directly from the parents themselves.

- **Leadership.** Focus groups with parents in Illinois, where the Governor championed the *All Kids* program, promoted it vigorously himself, and invested in saturating outreach efforts, suggest that strong leadership can be an important catalyst to increasing enrollment in Medicaid and SCHIP.
- **Continuous and multi-pronged outreach:** Because the population of children eligible for Medicaid and SCHIP is dynamic, and program eligibility rules also change sometimes, continuous outreach and education about the programs are needed to strengthen families' awareness of the programs and of their potential eligibility. Also, because low-income families are diverse, using a diverse array of mechanisms (e.g., mass media, grassroots organizations) and strategies is instrumental to reaching eligible children most effectively. Finally, caseworker training and other efforts can help reorient a system that has welfare roots, to create an environment that advocates and facilitates enrollment.

- **Broad-based eligibility:** Broad-based eligibility simplifies and increases the effectiveness of outreach, and by reducing uncertainty and misconceptions about who is eligible, promotes broader participation. Programs that cover all children or that extend eligibility to children in higher-income families can help to dispel the misconception common among low-income parents that working families' children do not qualify for assistance.
- **Simplified enrollment and renewal:** Short application and renewal forms, minimal documentation requirements, and multiple options for enrollment and renewal are key elements of a family-friendly process for enrolling children in coverage and keeping them enrolled. Adopting these improvements in the enrollment process for parents as well as children is important to ensure that children's enrollment in coverage is not bogged down when applications are made for family coverage. In addition, information technology that permits electronic data sharing between Medicaid and SCHIP and the other assistance programs commonly used by low-income families can minimize the frequency of requests for information that burden families and delay or interrupt coverage.
- **Continuous eligibility:** Guaranteeing 12 months of continuous eligibility would reduce coverage losses that often occur as a result of procedural requirements at renewal time and, most importantly, would secure the health care gains from coverage that are largely lost when coverage is discontinuous. Continuous eligibility is a mechanism for modernizing Medicaid and SCHIP to promote child coverage goals.
- **Extra assistance for Latino families:** Special efforts are needed to reach and support Latino families, whose children are much more likely than others to be uninsured, and whose awareness and understanding of Medicaid and SCHIP is more limited. In addition to Spanish-language outreach materials and applications, Latino families need access to culturally competent caseworkers who can assist them. Further, clear and accurate information is needed to address fears among some families in the immigrant community that enrolling their children could jeopardize other family members' ability to obtain U.S. citizenship or result in the family's deportation.
- **Parent coverage:** Many of the focus group parents lack health coverage and struggle with their own health problems and medical bills. They point out that to raise their children, hold down jobs, and create stable lives for their families, they need health coverage, too. As one mother of an uninsured child in Los Angeles put it, "*If I get sick, then you know the whole show stops.*" The low-income parents who do not have access to any health insurance strongly favor the idea of being able to enroll along with their children in Medicaid or SCHIP.

## *Conclusion*

Because the large majority of uninsured children are low-income children eligible for Medicaid and SCHIP but not enrolled, efforts to reduce the number and rate of uninsured children must focus on increasing participation in these programs to achieve substantial progress. A distinct message from the focus groups is that to improve participation in Medicaid and SCHIP, more vigorous outreach and education, as well as modern and simple enrollment and renewal procedures to meet the needs of working families, are needed. The examples provided by parents who easily enrolled their children in Medicaid and SCHIP demonstrate that such effective outreach and enrollment strategies can make a difference.

As Congress debates the reauthorization and funding of SCHIP and an increasing number of states take action to broaden child health coverage, the voices of low-income parents underscore the value of health coverage for their families and provide insights about the program approaches that most assist their efforts to enroll their children in Medicaid and SCHIP.

## **Table of Contents**

<b>Executive Summary</b>	<b>i</b>
<b>Introduction</b>	<b>1</b>
<b>Methodology</b>	<b>2</b>
<b>Findings</b>	<b>3</b>
<b>I. Value of child health coverage to low-income parents</b>	<b>3</b>
▪ <i>Health coverage for children is a top priority for low-income parents.</i>	3
▪ <i>Low-income working parents struggle financially and private insurance is out of reach for their families.</i>	6
▪ <i>Parents of children enrolled in Medicaid and SCHIP are grateful for the programs because they provide access to a regular doctor and comprehensive services.</i>	9
<b>II. Barriers to obtaining child coverage</b>	<b>10</b>
▪ <i>Parents of uninsured children still have basic information gaps regarding Medicaid and SCHIP.</i>	10
▪ <i>Parents express enthusiasm for streamlined enrollment systems that make obtaining child coverage easy. But many describe procedures that hamper their efforts to seek coverage for their children.</i>	11
▪ <i>Children in Latino families face extra hurdles to enrollment.</i>	14
<b>Policy Implications</b>	<b>15</b>
<b>Conclusion</b>	<b>17</b>
<b>Appendix</b>	<b>18</b>

## INTRODUCTION

Medicaid and the State Children's Health Insurance Program (SCHIP) provide health coverage to more than 30 million children in the United States. Over the last decade, these two programs succeeded in reducing the uninsured rate among low-income children by one-third, even while the rate of job-based insurance fell steadily and uninsurance among non-elderly adults grew. Still, 9 million children, most of whom are eligible for Medicaid or SCHIP, remain uninsured. To significantly reduce the number of uninsured children, an improved understanding of what promotes enrollment of children in these programs, and what impedes it, is critical.

The *Kaiser Commission on Medicaid and the Uninsured* (KCMU) sponsored this focus group project with low-income parents to understand their perceptions, motivations, and experiences related to enrolling their children in Medicaid and SCHIP. The research explores low-income parents' knowledge of these programs, their interest in enrolling their children, and the factors that pose barriers to their participation. The work also probes the value parents place on health coverage for their children and how low-income families without insurance cope with their children's health care needs.

KCMU conducted a similar research project in 2000, just a few years after Medicaid was de-linked from welfare and SCHIP was implemented. Since that time, important developments have occurred. Many states took steps to promote broader coverage of children in Medicaid and SCHIP, including simplifying enrollment, reducing documentation requirements, increasing outreach, and expanding eligibility. However, progress in simplifying enrollment for parents lags, and the more burdensome process often required when families apply for coverage still prevents eligible children from gaining easy access to the programs.

In the economic recession, job-based health insurance eroded significantly due to rising health care costs, unemployment, workforce changes, and downward shifts in family income. At the same time, some states under difficult fiscal pressures cut outreach and reversed simplification measures for public coverage. Each year, the ranks of the uninsured have continued to grow, reaching 46 million in 2005. In July 2006, states were required to implement a provision of the Deficit Reduction Act of 2005 that requires citizens to document their citizenship and identity to qualify for Medicaid, introducing a new obstacle to state efforts to automate and facilitate enrollment.

To learn about parents' recent experiences enrolling their children in Medicaid and SCHIP, this focus group project both revisits many issues explored in the earlier focus group work and explores new issues of policy importance. As Congress debates the reauthorization and funding of SCHIP, and a growing number of efforts to broaden children's coverage – all of which rely on Medicaid and SCHIP as an essential building block – take shape, the experiences of low-income parents of uninsured children and children enrolled in Medicaid or SCHIP provide valuable insights and information to guide policy.

## **METHODOLOGY**

Lake Research Partners conducted the project, which involved 11 focus groups in four cities (Chicago, Houston, Los Angeles, and Miami). The groups were held January 24 - February 21, 2007. Parents with income at or below 300% of the federal poverty level were recruited to participate. Seven focus groups were held with parents of uninsured children; three of these groups were conducted in Spanish. The remaining four focus groups were held with parents of children enrolled in Medicaid or SCHIP.

Focus group participants were recruited using focus group facility databases of low-income households. Data on low-income households were screened to identify those with uninsured children and those with children enrolled in SCHIP or Medicaid. A few participants were identified by local organizations that work with uninsured families. To reduce citizenship-related uncertainty about the eligibility of their children, parents could participate in the focus groups only if their children were born in the U.S.

The four cities selected for the focus groups were chosen because they are located in the states with the largest number of uninsured children in the nation. Together, the four states account for 45% of all uninsured children in the U.S.

Each focus group lasted two hours and was audio-taped and videotaped. The analysis for this report is based on the transcriptions of the audio tapes. Participants were paid for their involvement. The make-up and organization of the 11 focus groups are displayed in the Appendix to this report.

## FINDINGS

Two main themes emerged from the focus group discussions. First, the feedback from nearly all the focus group parents emphasizes the importance that low-income parents attach to having health coverage for their children. The parents of children covered by Medicaid or SCHIP value the access to care these programs provide and the security that their children’s health needs can be met. The parents of eligible-but-uninsured children very much want health coverage for them. The responses from this latter group of parents concerning the reasons they have not enrolled their children illuminate the second major theme – that significant barriers to enrollment in Medicaid and SCHIP persist, leaving out many eligible low-income children who remain uninsured as a result. The following sections present the findings along these two thematic lines in detail.

### I. VALUE OF CHILD HEALTH COVERAGE TO LOW-INCOME PARENTS

#### **Health coverage for their children is a top priority for low-income parents.**

- *Parents see health insurance as key to obtaining access to care for their children.*

The overwhelming majority of the focus group parents view health coverage for their children as critically important. Whether their children are uninsured or enrolled in coverage, nearly all parents emphasize that children need access to health care to grow and thrive. “I think that it’s critical for the children to be healthy... because they’re our future and so you know we have to make sure that they’re okay,” explained a mother of an uninsured child in Los Angeles. All parents say that children need a regular doctor, check-ups, and access to prescription drugs, dental care, and other services to develop properly and live healthy lives.

Parents of children who are enrolled in Medicaid or SCHIP talk about the positive impact of this coverage. They cite the security it gives them that their children can get both the preventive and sick care they need, and the protection against devastating out-of-pocket costs that they cannot afford.

*“I think that it’s critical for the children to be healthy... because they’re our future and so you know we have to make sure that they’re okay.”*

Mother of an uninsured child in Los Angeles

- *Parents with uninsured children very much want health coverage for them. They agonize about their inability to meet their children’s health needs.*

The parents of children without health coverage express a strong desire for health coverage for their children and many say they are looking for a new job that offers coverage or are exploring buying coverage on their own. Without coverage for their children, many parents feel they are failing their children. “I believe that some people feel embarrassed and ashamed that they cannot pay... Even though we work so hard we cannot afford it,” said a parent of an uninsured child in Los Angeles. Once they learn about Medicaid and SCHIP, parents of uninsured children are eager to enroll them in the programs.

Many parents of uninsured children say they cannot afford unexpected medical bills and emergency room visits. They report that they avoid medical costs whenever they can by treating illnesses at home with over-the-counter medications and home remedies. Almost all say they postpone medical care for their children and put off buying prescription drugs when they can. A parent of an uninsured child in Miami said, “We try not to get sick. I try not to think about it too much.”

The parents of children who lack coverage are also concerned that their children are receiving inconsistent and poorer quality medical care because they are uninsured. Above all, they want a regular doctor who knows their children and their children’s medical history; this is impossible, they say, as long as their children are uninsured.

Some parents say their children do without check-ups and other preventive care, and others say they are putting off eye exams and buying glasses for their children because they cannot afford them. One mother explained how her uninsured child has to sit in the front of the classroom to see the board because she cannot afford glasses for him. Few of the uninsured children in these families are receiving dental care. This is causing acute problems for some. For example, one mother whose daughter is suffering from a toothache says she is postponing taking her daughter to the dentist as long as possible because she cannot afford an office visit. For now, she simply urges her daughter “to chew on the other side of your mouth.” Putting off needed care like this is heart-wrenching, parents say, and they are both sad and frustrated that their children are in this situation.

Almost all parents report that they visit emergency rooms when their children are too sick to be cared for at home, but they view the ER as a last resort and overwhelmingly describe the experience of seeking care in the ER as a negative one. They complain of long waits, poor quality care, faceless and nameless doctors, and the treatment of their children more as “numbers” than as patients.

*“I believe that some people feel embarrassed and ashamed that they cannot pay... Even though we work so hard we cannot afford it.”*

Parent of an uninsured child in Los Angeles

*“We try not to get sick. I try not to think about it too much.”*

Parent of an uninsured child in Miami

- *Parents of uninsured children worry all the time and many suffer an emotional toll.*

The parents of children without health coverage say they worry all the time about their children getting hurt and also about their needing medical care for unexpected illnesses. A few admit they keep their children indoors and discourage sports because they cannot afford medical care if their children get hurt. Many are already paying off large medical and emergency room bills and feel they cannot afford another.

Parents often say they feel depressed, ashamed, and anxious about lacking insurance for their children. “I feel nervous, depressed by not having the money to get care for my family,” said a parent of an uninsured child in Los Angeles. Some parents express concern that their children hide symptoms from them to avoid adding to their stress. They report that their children have downplayed colds and sore throats because they do not want their parents to worry about how they are going to pay for a doctor’s visit or antibiotic. Other parents say that their children have internalized the stress of not having insurance, becoming anxious as a result.

- *Having a regular doctor for their children is a chief reason parents value health insurance.*

A prominent theme that emerged from every focus group is that parents want a regular, consistent provider to oversee their children’s care. A priority for parents, and a key motivation for getting their children enrolled in Medicaid or SCHIP, is having a doctor who knows their children and their children’s medical history and has a relationship with their children. They see a strong connection between having a regular doctor and the quality of health care their children receive. Parents dislike getting care in the emergency room because it is virtually impossible for their children to see the same provider from visit to visit.

*“I feel nervous, depressed by not having the money to get care for my family.”*

Parent of an uninsured child in Los Angeles

- *Many parents need coverage for themselves, too.*

While their children come first, many uninsured parents say that they also need and would benefit from access to affordable coverage. They report that they earn too much to qualify for Medicaid but still cannot afford coverage from their employers, or that they work in jobs that do not offer health insurance. Parents without coverage state that they rarely seek health care and receive almost no preventive care. They are willing to pay out-of-pocket for medical care for their children, but not for themselves. Some have serious ongoing health concerns that have not been addressed because they cannot afford the doctor visits, lab work, or tests.

*“If I get sick, then you know the whole show stops.”*

Mother of an uninsured child in Los Angeles

Uninsured parents also emphasize that they need to be healthy themselves to care for their children properly and to be good parents. As one mother of an uninsured child in Los Angeles put it, “If I get sick, then you know the whole show stops.” Because most have not received health care services in a long time, they are concerned that they may have high blood pressure or other medical conditions, but not know it. Single mothers, in particular, worry about what will happen to their children if they become seriously ill. A parent of an uninsured child in Miami said, “I have cancer in my family. Then I think, ‘Oh God, my children, what if I die... what’s going to happen?’” Because they worry that their own health problems could jeopardize their children’s well-being, but do not have access to job-based or other affordable coverage, the overwhelming majority of uninsured parents voice support for allowing low-income parents such as themselves to enroll in the same programs as their children.

*“I have cancer in my family. Then I think, ‘Oh God, my children, what if I die... what’s going to happen?’”*

Parent of an uninsured child in Miami

### **Low-income working parents struggle financially and private health insurance is out of reach for their families.**

- *Low-income families are diverse but share common concerns about their finances and health care.*

The parents who participated in the focus groups describe a variety of family, work, and living situations, but they sound strikingly similar when they talk about their family finances. Nearly all struggle to make ends meet and many feel their financial situations are worsening. A common frustration is that the high cost of living in their area makes it hard for them to get ahead no matter how hard they work. Their jobs simply do not pay enough, they say, for them to become financially secure, and their budgets are strained just to meet basic needs.

Most of the families include at least one working parent, although some parents in the focus groups were recently unemployed or are in between jobs. A number of the parents of uninsured children previously had health insurance for their kids through their jobs or through Medicaid or SCHIP.

Others report that their children have been uninsured for many years and, in some cases, for their entire young lives. The parents of children currently enrolled in Medicaid or SCHIP are often uninsured themselves.

For many low-income parents, the connection to health coverage for their children is fragile, and job changes and family transitions appear to be common risk factors for coverage lapses. Job-based insurance may be interrupted or lost due to a change in a parent's employment, and even small shifts in family circumstances may affect children's eligibility for Medicaid or SCHIP. Some parents report that something as simple as an address change triggered a loss of coverage for their children, because the renewal form was mailed to the old address and was never received.

A number of grandparents and foster parents who are raising children participated in the focus groups. In addition to the same challenges faced by low-income parents, these individuals must also contend with the emotional impact on the child of the absence or loss of his or her parents, their own poor health in some cases, confusion about health coverage options, missing documents, a lack of knowledge about the health coverage history of the children they care for, and other issues.

Most parents feel vulnerable and comment that one unexpected bill can throw their family into turmoil. A number of parents in the focus groups have already had this experience, and the bills are usually for an emergency room visit. "For six months [my son] didn't have [insurance] and he did get sick two times and one time a dog bit him and I had to take him to the emergency...and I'm still paying it off," said a mother of an enrolled child in Miami. A parent of an uninsured child in Houston described her situation: "When I took both [my children] to the hospital and I got the bill – one was for \$2,600 and the other bill was for \$2,700. I said there should be a break in the cost – I had to pay it all."

Parents of uninsured children report that because their children have ongoing health problems and chronic conditions, they must continually pay out-of-pocket for this care. Their children have conditions including, among others, asthma, eczema, cerebral palsy, and depression and other mental illnesses. The regular doctor appointments, specialist care, and medications necessary to meet their children's health care needs stretch family budgets to the extreme. Some parents say they are just going without care for now, or skipping medications or services and taking risks with their children's health. One mother of an uninsured child in Miami said:

*"When I took both [my children] to the hospital and I got the bill – one was for \$2,600 and the other bill was for \$2,700. I said there should be a break in the cost – I had to pay it all."*

Parent of an uninsured child in Houston

In my case, my daughter has to go to a neurologist consultation. Every time I go to that consultation, it's \$250 but the medication is \$90 a month. I have to cover that as well. Every so often she needs a check-up because it affects her liver when her sodium goes down. The check-up alone is \$1,000 every 4 months. I told them I can't afford it any longer – we have to maybe try alternate treatments – I just can't afford it.

Many of the uninsured families go to the emergency room for care or for needed medicine, although they feel that this kind of care is far from ideal for their children. In addition to facing long waits there, the parents complain that their children receive inconsistent and poor quality care in this setting and they worry because there is usually no follow-up or access to medications. Many express concern that the free and low-cost services they string together for their uninsured children are neither enough to keep their children as healthy as they could be, nor sufficient protection against the risk of medical bills that would devastate their family budgets.

- *Private health insurance is out of reach for low-income families.*

Generally, focus group parents had given up on obtaining private health coverage for their uninsured children. Although most parents in the focus groups are employed, many are not offered health coverage through their jobs. Others do not work enough hours to qualify for coverage that is offered, or are still in the employer's 9-month or 12-month probation period before they can qualify for coverage that may be offered. Some report that their employers resist increasing their hours in order to avoid offering them health coverage.

Some parents are offered insurance by their employers but say they cannot afford the premium. Several observe that, even after paying a high premium for coverage, they would have limited benefits and face high out-of-pocket costs for deductibles and co-pays. A few parents have insurance for themselves but not for their spouses or children, either because dependent care is not offered or because the cost is too high. One parent of an uninsured child in Houston explained, "You see, even if I put me and my kids [on my company's insurance] that's basically half my check." A grandparent of another uninsured child in Houston offered, "I'm not working but I am going to look for work now ... one of the main reasons is because of the insurance. My husband's insurance is too expensive for him to put me on there and my grandson." And from the mother of an enrolled child in Miami: "I don't [have to] pay for my [own] insurance... [but] for me to put my daughter it would be like almost \$400 to \$500 a month."

*"You see, even if I put me and my kids [on my company's insurance] that's basically half my check."*

Parent of an uninsured child in Houston

*"I think [Medicaid] has worked very, very well for my grandson. I mean I'm happy that he's been well taken care of."*

Grandmother of an enrolled child in Los Angeles

**Parents of children enrolled in Medicaid and SCHIP are grateful for the programs because they provide access to a regular doctor and comprehensive services.**

- *Low-income parents whose children are enrolled are grateful for Medicaid and SCHIP, without which their children would most likely be uninsured.*

Parents express that they have peace of mind knowing their children are covered. They feel their children are “cared for” by Medicaid and SCHIP. “I think [Medicaid] has worked very, very well for my grandson. I mean I’m happy that he’s been well taken care of,” said the grandmother of an enrolled child in Los Angeles.

Many parents state that without Medicaid or SCHIP, their children would be uninsured, as they have no other means of covering them. These circumstances were captured by the statement of the mother of an enrolled child in Miami: “If [my daughter’s Medicaid] got taken away, I don’t know what I would do, because Medicaid was the first insurance my daughter has had.”

- *Parents prize having a regular doctor for their children.*

For many, having a regular doctor of their choice is the best part of having a child enrolled in SCHIP or Medicaid. “I used to go to [the emergency room] and I didn’t always see the same doctor and I didn’t like that. Every time I went in it was somebody different so I [enrolled in SCHIP] and changed to Children’s Hospital and now [my daughter] has a private doctor. [She] sees the same lady every time,” explained the parent of an enrolled child in Los Angeles.

- *Most children enrolled in Medicaid and SCHIP have access to comprehensive and affordable care.*

In all four focus group cities, parents of enrolled children report having good access to and choice of preventive and primary care providers, and no one had been turned away by a provider because their child had Medicaid or SCHIP. The few parents who were dissatisfied with their doctors say they plan to switch and do not anticipate any problem in finding a new doctor. While parents’ satisfaction with access to preventive and primary care in Medicaid and SCHIP is high, for some parents of children with disabilities and other special health care needs, obtaining access to needed specialist care is an ongoing major problem.

*“If [my daughter’s Medicaid] got taken away, I don’t know what I would do, because Medicaid was the first insurance my daughter has had.”*

Mother of an enrolled child in Miami

Most parents of enrolled children praise the comprehensive coverage under Medicaid and SCHIP; they particularly value the dental and vision care. Based on their comments, these are the services parents are least likely to be able obtain for their children if they are uninsured. Parents also comment positively on the quality of the care their children receive through Medicaid and SCHIP.

Parents also say that the affordability of Medicaid and SCHIP are important to them. A number of the parents with children in SCHIP explained that they must pay premiums and co-payments. Some highlighted that they take careful steps, such as tacking boldly-lettered reminders on their calendars, because they worry that a late premium payment could result in their children losing coverage.

## II. BARRIERS TO OBTAINING CHILD COVERAGE

### **Parents of uninsured children still have basic information gaps regarding Medicaid and SCHIP.**

- *Limited awareness of Medicaid and SCHIP is common among parents of uninsured children.*

Awareness and understanding of Medicaid and SCHIP are uneven, and the gaps in parents' knowledge appear to be an important obstacle to their children's participation in the programs. Some low-income parents are not aware of Medicaid and SCHIP. This may come about if they are not eligible for or do not participate in other public assistance programs and are thus not directed to the public health coverage programs often under the same "roof." In very poor families, marginal circumstances can be an obstacle to awareness even of programs that target them for assistance. Just participating in the focus groups made the parents whose children are not enrolled want to learn more. "If you hear from people [about these programs,] you get curious about it. You know, like today," said a mother of an uninsured child in Los Angeles.

- *Misconceptions about the eligibility rules for Medicaid and SCHIP, and episodic rather than ongoing outreach, are also barriers to participation.*

Many parents who are aware of Medicaid and SCHIP nonetheless have misconceptions about who is eligible for the programs. Many simply assume that Medicaid and SCHIP are not for working families. Others mistakenly assume that their earnings are too high for their children to qualify. Some are uncertain whether they can own a car or a home or have a bank account, and still have their children qualify.

Parents tend to view ineligibility as a static condition. Some who were previously denied Medicaid or SCHIP for their children because their income was too high report that they did not reapply even though their

income changed. Also, families whose children are newly eligible for Medicaid or SCHIP due to changes in family income seem to know very little about the programs. Parents whose level of program knowledge is high have typically encountered outreach about the programs in multiple forms and settings and over time. They describe schools as one of several important sources of information, but parents of younger children not yet in the school system do not benefit from this outreach mechanism.

**Parents express enthusiasm for streamlined enrollment systems that make obtaining child coverage easy. But many describe complex enrollment procedures that hamper their efforts to seek coverage for their children.**

- *Working families appreciate streamlined and family-friendly application options that make it easy to enroll their children.*

Parents who described simple applications with minimal or no documentation requirements, and multiple application options (e.g., mail, online), were enthusiastic about being able to enroll their children easily. The strongest illustration is in Illinois' *All Kids* program (*See Box*).

**Illinois' *All Kids***

As its name suggests, *All Kids* is a universal health coverage program for children in Illinois. All Illinois children, regardless of family income, are eligible. Outreach for the program has been vigorous and effective. The fact that all children are eligible has made broad outreach simple and largely eliminated confusion about who can qualify. Further, prominent and sustained promotion of the program by the Governor has led to the program's high popularity.

Parents in the Illinois focus groups were knowledgeable about *All Kids* and described a "buzz" about the program; many had been to the state's website to learn more. Parents say they felt encouraged to apply because the Governor has been so vocal about the program and health coverage in general.

Parents can apply for *All Kids* for their children in multiple ways. In the focus groups, parents commented that they especially value the option to enroll their children online. Like other parents in this study, they are eager to avoid going to welfare and other enrollment locations, enduring lengthy waits, and dealing with caseworkers. For that reason, applying by mail is also attractive to them. "I [applied] online. I got the name *All Kids* from my cousin, Googled it, got on the website and it is really self-explanatory. It pinpoints you everywhere to go. And you just mail the information," said a mother of an enrolled child in Chicago. Another parent in Chicago said, "I went online and got the application. It was on the State of Illinois website. They have a little [tab] on the side if you want to sign up for *All Kids*, then you click on it, it gives you the application, you fill it out and [send it in]."

- *Burdensome enrollment processes hinder parents from enrolling their children in coverage.*

Often, parents say the enrollment process itself is a barrier to enrolling their children in Medicaid and SCHIP. Many have experienced the enrollment process first-hand; others have heard negative accounts of it from parents who have sought to enroll their children. Many parents describe a process that is difficult, frustrating, and humiliating. Some admit that the thought of going through the enrollment process keeps them from applying for their children. “I would like to get [SCHIP] but I get so upset – they ask me so many questions [during enrollment] about insignificant things,” explained a parent of an uninsured child in Miami. A number of specific concerns about the enrollment process emerged, as follows below.

- *In-person interviews are a major barrier for working parents.*

Since most low-income parents work, they must take time off from their jobs to go to enrollment interviews. This is a barrier that many cannot overcome because asking for the needed time off would jeopardize their employment or they cannot afford the lost income. Long waits for interviews in the welfare office are characteristic. A parent of an uninsured child in Miami gave this account: “They give you the appointment – they tell you 9:00 a.m. If you are working, you are in trouble – because you go in at 9:00 a.m. and leave the office at 3:00 or 4:00 p.m.”

Parents who have been through enrollment interviews are critical of other aspects of the experience as well. Some report that after waiting many hours for their interviews, they were asked for additional documentation, which again delayed the approval of coverage for their children. “If you’re getting Medicaid or like SCHIP or something, they want you to go all the way across town to get this paper and that paper, bring it back to them and if you bring that paper back, they tell you they want something else,” related a mother of an uninsured child in Houston.

*“They give you the appointment – they tell you 9:00 a.m. If you are working, you are in trouble – because you go in at 9:00 a.m. and leave the office at 3:00 or 4:00 p.m.”*

Parent of an uninsured child in Miami

Finally, many parents describe caseworkers who are rude to them and treat them “as if we are asking for a handout.” The parents feel debased by this treatment and are angry they are subjected to it when they are trying to do the right thing for their children.

- *Documentation requirements impede enrollment.*

Parents are frustrated and demoralized by the amount of paperwork and documentation required by some programs. Some parents were unable to

successfully enroll their child in the program because they could not secure all the documentation required. “It seems that there are so many requirements... I didn’t have some of the documents and they would not accept me,” said a parent of an uninsured citizen child in Los Angeles.

Although not all states had implemented it at the time the focus groups were held, the new federal requirement that citizens submit original birth certificates or other proof of citizenship to obtain Medicaid had already posed a hurdle to some parents seeking to enroll their eligible children. For example, one parent whose child was born in a different state did not have the child’s birth certificate. In another case, a mother who was recently divorced did not have access to all her documents.

All parents in the focus groups agreed they would not consider parting with their children’s original birth certificates by mailing them to the Medicaid office. They do not trust either the mail or the bureaucracy, they doubt they would see the documents again, and they need the original documents themselves. Therefore, to provide birth certificates, they must go to the Medicaid office in person or incur the cost of obtaining a certified copy of the document from the state to submit with the Medicaid application or renewal form.

- *Enrollment caps and designated open enrollment periods create confusion about eligibility and undermine outreach efforts by demoralizing parents who seek to enroll their children.*

In states that put a cap on SCHIP enrollment or permit enrollment only during designated periods, some parents voice frustration that although their children *qualify* for SCHIP, they cannot get coverage. Parents say this experience is discouraging and makes them question the motives of the state. “I am trying to [enroll my child]. They have a period of when you can apply with them and I don’t think it’s that period right now... When you send in your application, they will send you a letter back letting you know. There’s too many people [enrolled now],” explained a father of an uninsured child in Miami.

- *Child support enforcement deters some women from pursuing health coverage for their children.*

A few mothers seeking to enroll their children were told they had to file for child support from the father first. “[Enrollment] is a hassle with Medicaid and they drop you when they can’t find the child’s father. You know the Attorney General [requires this],” explained the mother of an uninsured child in Houston. Contacting the father was not a viable option for some mothers, whose eligible children thus remained uninsured.

- *Like some enrollment processes, some renewal processes are difficult for parents.*

Some parents had a variety of problems with the Medicaid and SCHIP renewal processes. In one case, a renewal notice was lost in the mail, resulting in the loss of coverage for a child who remained eligible. One or two parents stated that they lacked the documentation required to renew their children’s coverage or delayed too long in getting it, with the result that their children were disenrolled from the program. A few parents suggest that a longer “grace period” to gather documentation or take the other required steps could help prevent enrolled children from losing their coverage.

### **Children in Latino families face extra hurdles to enrollment.**

- *Language barriers and other obstacles hinder enrollment in coverage among children in Latino families.*

The misconception that Medicaid and SCHIP are not for working families appeared most pervasive among parents in the Spanish-language focus groups, suggesting that language barriers and outreach represent special challenges in Latino communities, where uninsured rates for children are highest.

In some families with mixed citizenship status, parents fear that enrolling their children in Medicaid or SCHIP could have adverse implications for other family members’ ability to gain U.S. citizenship in the future, or even lead to the family’s deportation. These fears persist even though Latino parents in the focus groups appear aware that their children born in the U.S., as citizens, are eligible for these programs. “There are people that don’t apply because they are scared of their status – especially if they are not legally here,” said a Latino parent of an uninsured child in Miami. Another Latino parent, of an uninsured child in Houston, commented, “We are in the process of immigration and the first thing that the lawyer said was not to have any government help because that would go against us.”

*“We are in the process of immigration and the first thing that the lawyer said was not to have any government help because that would go against us.”*

Latino parent of an uninsured child in Houston

## POLICY IMPLICATIONS

The findings from the focus groups suggest a number of policy directions, outlined below, that could promote increased enrollment of eligible children in Medicaid and SCHIP. The ideas stem directly from the parents themselves.

► **Leadership:** Focus groups with parents in Illinois, where the Governor championed the *All Kids* program, promoted it vigorously himself, and invested in saturating outreach efforts, suggests that strong leadership can be an important catalyst to increasing enrollment in Medicaid and SCHIP.

► **Continuous and multi-pronged outreach:** Because the population of children eligible for Medicaid and SCHIP is dynamic, and program eligibility rules also change sometimes, continuous outreach and education about the programs and who is eligible for them are needed to strengthen families' awareness of the programs and of their potential eligibility. Also, because low-income families are diverse, using a diverse array of mechanisms (e.g., mass media, grassroots organizations) and strategies is instrumental to reaching eligible children most effectively. Finally, caseworker training and other efforts can help reorient a system that has welfare roots, to create an environment that advocates and facilitates enrollment.

► **Broad-based eligibility:** Confusion about who is eligible for Medicaid and SCHIP remains a substantial obstacle to enrollment of eligible children. Broad-based eligibility simplifies and increases the effectiveness of outreach, and by reducing uncertainty and misconceptions about who is eligible, promotes broader participation. Programs that cover all children or that extend eligibility to children in higher-income families can help to dispel the misconception common among low-income parents that working families' children do not qualify for assistance.

► **Simplified enrollment and renewal:** Short application and renewal forms, minimal documentation requirements, and multiple options for enrollment and renewal are key elements of a family-friendly process for enrolling children in coverage and keeping them enrolled. Adopting these improvements in the enrollment process for parents as well as children is important to ensure that children's enrollment in coverage is not bogged down when applications are made for family coverage. In addition, information technology that permits electronic data sharing between Medicaid and SCHIP and the other assistance programs commonly used by low-income families can minimize the frequency of requests for information that burden families and delay or interrupt coverage.

► **Continuous eligibility:** Guaranteeing 12 months of continuous eligibility would reduce coverage losses that often occur as a result of procedural requirements at renewal time, and most importantly, would secure the health care gains from coverage that are largely lost when coverage is discontinuous.

Continuous eligibility is a mechanism for modernizing Medicaid and SCHIP to promote child coverage goals.

► **Extra assistance for Latino families:** Special efforts are needed to reach and support Latino families, whose children are much more likely than others to be uninsured, and whose awareness and understanding of Medicaid and SCHIP is more limited. In addition to Spanish-language outreach materials and applications, Latino families need access to culturally competent caseworkers who can educate and assist them. Further, clear and accurate information is needed to address fears among Latino families with mixed immigration status that enrolling their children in Medicaid or SCHIP could jeopardize other family members' ability to gain U.S. citizenship in the future, or even lead to deportation of the family.

► **Parent coverage:** Many of the focus group parents lack health coverage and struggle with their own health problems and medical bills. They point out that to raise their children, hold down jobs, and create stable lives for their families, they need health coverage, too. The low-income parents who do not have access to any health insurance strongly favor the idea of being able to enroll along with their children in Medicaid or SCHIP.

## CONCLUSION

The insights gained from this focus group research confirm findings from earlier work that low-income parents consider health coverage for their children a major priority, but also that they face significant barriers to enrolling their children in Medicaid and SCHIP. These results have new importance in the present environment, in which the reauthorization and funding of SCHIP are being debated, an increasing number of states are moving forward with initiatives to expand children's coverage, and public sentiment in support of broadening health coverage for children is growing.

Because the large majority of uninsured children are low-income children eligible for Medicaid and SCHIP but not enrolled, efforts to reduce the number and rate of uninsured children must focus on increasing participation in these programs to achieve substantial progress. A distinct message from the focus groups is that to improve participation in Medicaid and SCHIP, more vigorous outreach and education, as well as modern and simple enrollment and renewal procedures to meet the needs of working families, are needed. The examples provided by parents who easily enrolled their children in Medicaid and SCHIP demonstrate that such effective outreach and enrollment strategies can make a difference.

As federal and state policymakers proceed on various fronts to expand health coverage for uninsured children, the voices of low-income parents underscore the value of health coverage for their families and provide insights about the program approaches that most assist their efforts to enroll their children in Medicaid and SCHIP.

## APPENDIX

### Focus Group Locations, Dates, and Composition

Group #	Location	Date	Time	Participant Profile
1	Houston, TX	Weds Jan 24	5:30-7:30pm	Parents of uninsured children at 300% of FPL or less, mixed ethnic background
2			5:30-7:30pm	Spanish-speaking households, Hispanic parents of uninsured children at 300% of FPL or less (groups held in Spanish)
3			7:45-9:45pm	Parents of children enrolled in Medicaid/SCHIP at 300% of FPL or less, mixed ethnic background
4	Miami, FL	Thurs Jan 25	5:30-7:30pm	Parents of uninsured children at 300% of FPL or less, mixed ethnic background
5			5:30-7:30pm	Spanish-speaking households, Hispanic parents of uninsured children at 300% of FPL or less (groups held in Spanish)
6			7:45-9:45pm	Parents of children enrolled in Medicaid/SCHIP at 300% of FPL or less, mixed ethnic background
7	Los Angeles, CA	Thurs Feb 1	5:30-7:30pm	Parents of uninsured children at 300% of FPL or less, mixed ethnic background
8			5:30-7:30pm	Spanish-speaking households, Hispanic parents of uninsured children at 300% of FPL or less (groups held in Spanish)
9			7:45-9:45pm	Parents of children enrolled in Medicaid/SCHIP at 300% of FPL or less, mixed ethnic background
10	Chicago, IL	Weds Feb 21	5:30-7:30pm	Parents of uninsured children at 300% of FPL or less, mixed ethnic background
11			7:45-9:45pm	Parents of children enrolled in Medicaid/SCHIP at 300% of FPL or less, mixed ethnic background

The Kaiser Family Foundation is a non-profit, private operating foundation dedicated to providing information and analysis on health care issues to policymakers, the media, the health care community, and the general public. The Foundation is not associated with Kaiser Permanente or Kaiser Industries.

1330 G STREET NW, WASHINGTON, DC 20005  
PHONE: (202) 347-5270, FAX: (202) 347-5274  
WEBSITE: WWW.KFF.ORG/KCMU

Additional copies of this report (#7640) are available  
on the Kaiser Family Foundation's website at [www.kff.org](http://www.kff.org).

