

MAY 2009

Covering Kids & Families[®] Evaluation

*Public Coverage Versus No Coverage for
Children: Perceptions and Experiences of
Parents in Four Cities*

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Design and Layout

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This report was written by the Urban Institute and Health Management Associates. Support for this publication was provided by the Robert Wood Johnson Foundation in Princeton, New Jersey.

This publication is available for downloading from the Foundation's Web site at
www.rwjf.org/goto/ckfpapers0509

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Acknowledgments

We are indebted to the many parents who took part in our interviews, for their time, honesty, and insights into how well systems of care are meeting the needs of their children. We also appreciated logistical and administrative support from Darlene Gregory of HMA and assistance in interviewing by Sara Hogan and Carlos Manjarrez of the Urban Institute. The authors sincerely thank the leaders of each organization we visited for their assistance in recruiting parents to speak to us and for providing office space for us to conduct private interviews. This project would not have been possible without their participation.

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About the *Covering Kids & Families*® Evaluation

Since August 2002 Mathematica Policy Research, Inc., and its partners, the Urban Institute and Health Management Associates (HMA), have been conducting an evaluation to determine the impact of the Robert Wood Johnson Foundation's investment in the *Covering Kids & Families* (CKF) program, as well as to study factors that may have contributed to, or impaired, its efforts.

The evaluation focuses on these key issues:

- Documenting and assessing the strategies and actions of CKF grantees and their coalitions aimed at increasing enrollment of children and families and the barriers to their implementation.
- Assessing the effectiveness of CKF grantees and their coalitions in conducting outreach; simplifying the application and renewal process; and coordinating efforts by existing health insurance programs to expand coverage measuring progress on CKF's central goal—expanding enrollment and retention of all eligible individuals into Medicaid and State Children's Health Insurance Program (SCHIP).
- Assessing the sustainability of CKF after RWJF funding ends.

Findings from the evaluation can be found at
www.rwjf.org/coverage/product.jsp?id=20929.

Executive Summary

The Covering Kids & Families® (CKF) initiative of the Robert Wood Johnson Foundation (RWJF) had two goals: to increase the enrollment of uninsured, eligible children and adults in Medicaid or State Children's Health Insurance Program (SCHIP), and to build the knowledge, experience, and capacity necessary to sustain the enrollment and retention of children and adults in those programs after the CKF program ends (Grant and Ravenell, 2002). To help the Foundation assess the effectiveness of the CKF initiative, Mathematica Policy Research, Inc., and its partners, the Urban Institute and Health Management Associates, have studied and assessed the strategies and actions of the CKF grantees since 2002. The evaluation included opportunities to explore issues around access to care as coverage expanded.

An emerging concern from the field was that a lack of providers willing to accept Medicaid and SCHIP might be reducing access to care, which could undermine parents' belief in the program and, perhaps, persuade some not to enroll or renew their children's coverage. In 2005 the CKF evaluation team conducted 13 focus groups in five urban and rural settings (Hill et al., 2005). The findings suggested that parents were not turning away from Medicaid or SCHIP, but that satisfaction with safety-net providers when their children were uninsured might reduce parents' motivation to enroll their children in public coverage, particularly if their children are healthy. The evaluation team sought to confirm the focus group findings and gain a better understanding of the perceptions and types of experiences that shape the enrollment decisions of parents whose children are uninsured. To do so, the evaluation team conducted individual interviews with low-income parents in four cities. This report summarizes the findings of these interviews.

Methods and Data. In February and March 2008 the Urban Institute and Health Management Associates (HMA) conducted face-to-face interviews with 80 parents or guardians in four geographically diverse cities. An interview protocol was developed to engage parents in conversation about their perceptions of the cost, quality, and availability of care for their children under various hypothetical medical scenarios, considering both their child's current insurance status (uninsured or publicly insured) and if their child had the other insurance status. Parents with a child currently uninsured were asked how their child lost coverage and what attempts they had made, if any, to regain coverage. Parents with insured children who had ever lost coverage were also asked about those circumstances and how they had regained coverage for their children.

Findings. Key findings of the face-to-face interviews with parents of publicly insured and uninsured children from February through March 2008 are:

Access to Care for the Uninsured is Limited.

- Parents perceive access to care to be most restricted for uninsured children and most available to privately insured children.
- Care without insurance was prohibitively expensive for most parents.
- Safety-net clinics are limited in number, scope of services, and populations they serve.
- Accessing dental and specialty care was particularly challenging for parents of uninsured children.

Access to Care in Medicaid and SCHIP is Generally Good.

- Parents of publicly insured children rarely had trouble getting needed care for their children and were satisfied with the access Medicaid provided.
- Nearly all publicly insured children had a usual source of care and resources to help them find needed care.
- Dental and specialty care were generally accessible, though the referral process for specialty care could be onerous.

Some Parents Experienced No Problems Enrolling and Maintaining Their Children in Public Coverage.

- Some children had had continuous public coverage since birth.
- Some children had enrolled in coverage during childhood and had had continuous coverage since initial enrollment.

Most Children Who Were Uninsured Had Faced Administrative Barriers Associated With Enrollment and Renewal.

- Nearly all parents of uninsured children were actively trying to enroll their children in Medicaid.
- Lost applications, eligibility system failures, and lack of coordination between Medicaid and separate SCHIPs, contributed to keeping many children uninsured.
- Parents' inability to provide required documents, lack of understanding of the process, and failure to renew coverage when necessary also contributed to keeping children uninsured.

Spanish-Speaking Parents Faced Additional Barriers Due to Language, Perceived Discrimination and Immigration Status.

- Spanish-speaking parents had trouble communicating with eligibility workers and reading written communications sent by Medicaid.
- Lack of translators in some cities limited access to care for children of Spanish-speaking parents.
- Some Spanish-speaking parents reported being treated differently by eligibility workers because of the way they looked or spoke.
- Undocumented immigrant parents had difficulty obtaining proof of income and residency because of their position in the informal economy, hindering their citizen children from obtaining public coverage.

Conclusions. The findings from these interviews do not support the hypothesis that parental concerns about access to and quality of care under Medicaid and SCHIP reduce enrollment of eligible children in these programs. The positive feedback on the programs from parents whose children were enrolled—and the strong desire of almost all parents of uninsured children to enroll their children—attest to the success that states have had in publicizing their public health insurance programs and addressing prevalent concerns associated with them. There is a widespread perception among parents that Medicaid and SCHIP increase access to care for their children and that the care they receive is generally of good quality. However, the administrative barriers faced by parents often serve as a deterrent to enrollment and renewal, particularly for families whose life circumstances are in flux. Addressing these barriers would likely result in higher enrollment among children who are currently eligible but not enrolled.

Background

In 2002 the Robert Wood Johnson Foundation began the Covering Kids and Families initiative, a \$55-million initiative to support outreach and enrollment efforts in over 140 local community-based projects in 45 states and the District of Columbia. The evaluation of CKF included research to explore the relationship between parents' perceptions about access to care in Medicaid and SCHIP and enrollment decisions for their children.

In 2005 researchers from the Urban Institute and HMA conducted 13 focus groups with parents in five geographically and racially/ethnically diverse cities to study the relationship between access to care and enrollment in public programs (Hill et al., 2005). Access to primary care was generally good for children enrolled in either Medicaid or SCHIP. However, many parents reported problems with access to dental and specialty care. Few parents indicated that problems accessing care discouraged them from enrolling their children in these programs or from renewing their children's enrollment in these public coverage programs.

In contrast, parents of uninsured children reported difficulty accessing both primary care and dental and specialty care. In most cases, however, these parents were able to obtain care from safety-net clinics, hospitals, or physicians with whom they had an existing relationship. This finding raised questions about how parents' perceptions of the availability of or satisfaction with free or subsidized care for their uninsured children might affect their motivation to enroll them in public coverage. Frequent disruptions, or churning, in children's coverage are well documented (Summer and Mann, 2006). Parents' experiences with the administrative aspects of public coverage could also be a factor in their enrollment decisions (Federico et al., 2007; Sommers, 2007).

Building on the results of the 2005 focus groups, researchers conducted face-to-face interviews in four cities with 80 low-income parents whose children were eligible for Medicaid or SCHIP and were either enrolled or uninsured. The interviews explored parents' experiences seeking health care for their children; their perceptions of access, quality and cost, with and without coverage; and their beliefs about the value of public coverage. The research goal was to determine whether parents' experiences with, or their perceptions of, access problems in Medicaid or SCHIP deterred them from enrolling or re-enrolling their children in these programs.

Methods

In February and March 2008 the Urban Institute and Health Management Associates (HMA) conducted face-to-face interviews with 80 parents or guardians in four geographically diverse cities (Columbus, Ohio; Dallas; Denver; and Little Rock, Ark.). Community-based organizations that serve low-income families in each city helped the evaluation team identify parents eligible to participate in the interviews. A semi-structured interview protocol was developed to engage parents in conversation about their perceptions of the cost, quality, and availability of care for their children under four hypothetical medical scenarios (fever, toothache, behavioral/emotional/speech problem, and preventive care). Parents were asked about perceptions or experiences from the perspective of their current situation (insured or uninsured), and then were asked to talk about how having their children insured (if currently uninsured) or uninsured (if currently insured) would affect the cost, quality, and availability of care under the same hypothetical scenarios. Parents with a child currently uninsured were asked how their child lost coverage and what attempts they had made, if any, to regain coverage, and whether they planned to try to re-enroll their child in a public program. Parents with insured children who had ever lost coverage were also asked about those circumstances and how they regained coverage for their children. More detail on development of the interview protocol, site selection, screening of participants, and characteristics of the interviewed parents and their children can be found in Appendix A.

Findings

This section describes the findings from the interviews with parents. First, it presents their general perceptions about insurance. It then discusses the perceptions of health care for uninsured children, followed by perception of care for publicly insured children. For each insurance status, consideration is given in turn to cost of care, availability of providers, dental and specialty care, and quality of care, followed by parents' overall satisfaction with care and coverage. Finally, parents' experiences with enrollment and re-enrollment are discussed.

Parents' Perceptions of Insurance Coverage for Their Children

Medicaid/SCHIP Compared With Uninsurance

Parents strongly believed that having Medicaid or SCHIP coverage was far better than being uninsured, regardless of their child's current insurance status. Public coverage eliminates parents' exposure to medical bills and keeps out-of-pocket medical costs low. Parents feel more secure and less worried about unexpected medical needs (illness, injury, or ongoing conditions) when their children have Medicaid/SCHIP coverage compared to when they are uninsured.

"For me, it's very important to have insurance, because with insurance, one feels, for example, safer."

—Mother of uninsured child, Dallas (translated from Spanish)

"I'd be a lot balder and a lot more broke [if my child didn't have insurance]!"

—Father of publicly insured child, Columbus

Private Insurance Compared with Medicaid/SCHIP and Uninsurance

Several parents in each city had experience with, or opinions of, employer-based coverage and made comparisons with their Medicaid or SCHIP experiences. Many of them thought their children would get better care with private insurance. In particular, they believed they would have better access to name-brand prescriptions rather than being restricted to generics, particularly for psychiatric or chronic conditions.

"[The care is] second-class with Medicaid. First class is...private insurance."

—Father of publicly insured child, Little Rock

"You get better care when insured, but even better on private coverage. With private coverage, you can pick your doctors. With [Medicaid HMO], you get a list... Sometimes with [Medicaid HMO], they won't pay, or they make you have to get a generic even though your doctor prescribed a brand-name drug."

—Mother of publicly insured child, Columbus

"[Medicaid] beats being uninsured. But I see the difference between the therapy offices where people have good insurance and where my kids are going; it's like night and day."

—Mother of publicly insured child, Denver

Parents' Perceptions of Medical Care Access

Access to Medical Care Without Insurance

Although parents worried about finding providers who would see their children, cost considerations dominated the conversations about getting health care without insurance. The financial options parents thought they would face in a particular medical scenario shaped whether, how quickly, and where they would seek care. While affordability and availability of providers were the first consideration in seeking care, parents also weighed the quality of care available at the price they could afford. Parents' chief concerns about getting health care for an uninsured child were specifically:

- Having enough money to pay up-front for the total cost of care;
- Having the option to get billed later, or worrying about the long-term consequences of a medical bill; and
- Where to find good-quality, free or very low-cost care if the first two options seemed unattainable.

Cost of care. The ability of parents to obtain care for their uninsured children is severely limited by the cost of care. Cost was the main reason parents cited for wanting to enroll their children in coverage. Parents of uninsured children must often weigh their tolerance for the medical risk of delaying medical attention against the financial risk of obtaining care. They often reported that they would wait as long as possible or see if the condition would clear up on its own before seeking care.

“[I would say,] ‘Can you deal with it for a little while, and see what happens?’”

—Father of uninsured child, Columbus

“Depending on how bad it was, if they had really bad pain, then I would have to find the money and get them to the doctor. But if they could deal with it, I would probably put it off [if they were uninsured].”

—Mother of publicly insured child, Little Rock

This strategy was particularly prevalent in the case of seeking preventive care. Many parents could not justify the cost of a preventive care visit because it was not viewed as an urgent need. Instead, they would seek free care through clinics, churches, and schools, if they sought care at all.

“He had to get shots—through a school program that was free. I don’t have a place to schedule annual visits for him. So, no, I don’t take him for that.”

—Mother of uninsured child, Denver

When immediate care was needed, many parents concluded that without insurance they would rely on the emergency room, even if the situation were not a true emergency. Although other providers are available, and less expensive, most parents reported being unable to pay the entire bill up front, as required at private clinics. Even though it would be more expensive to seek care at the ER, the emergency department could set up a payment plan and “can’t turn you away” if parents lack the means to pay the bill in full. One mother described her thought process this way:

“If [my child] were uninsured and it came down to my child being sick like that, I would have to take them to the emergency room. That’s my only resort. I don’t have any cash—you know, some doctors charge us \$200, so I don’t think I could afford a doctor. I would have to take them to the emergency room...to tell you the truth it’s more expensive [at the emergency room]...”

—Mother of publicly insured child, Little Rock

Several parents who had medical debt or experience with unpaid bills for their own, or their children’s, care while uninsured expressed concern that people with unpaid bills may not get seen the next time they visited a provider to whom they owed payment for earlier care.

“I took my daughter to Children’s Hospital for her vomiting. The care was good. The staff treated us well, and she didn’t have to wait too long. But now we owe them \$1,000, so they might not accept her.”

—Mother of uninsured child, Dallas

Availability of providers. Low-cost clinics in public or children’s hospitals, local universities, and community-based organizations seemed to provide a medical home for many uninsured children. However, these clinics are limited in the number and scope of services they offer, and access is often restricted to those who live in a certain geographic area or to a certain number of visits. Parents also reported that many private providers “don’t want to mess with” uninsured patients, leaving few options for uninsured children. There was a general perception that if one had the money to pay for services in cash, uninsured children could have the same access to care as those with public insurance. Access to care was thus an issue of affordability rather than insurance explicitly.

“I think if you have the money, anybody will see you. But I’ll never have that.”

—Mother of uninsured child, Columbus

“Everything that has to do with health care costs so much; and if you have nothing, they really have nothing for you.”

—Mother of publicly insured child, Little Rock

A few parents indicated that seeking medical care without insurance would open an opportunity for enrollment, and this was indeed the way some children got enrolled.

“If you take [an uninsured child] to the doctor, they’ll tell you to take him to the ER at Children’s Hospital, and then they’ll try to get him signed up.”

—Father of publicly insured child, Columbus

The special cases of dental and specialty care. Parents without insurance find access to affordable dental care or other specialty care challenging. While many parents said they “didn’t have a clue” where to seek care, others described programs for uninsured children to obtain dental care or counseling through a local school, safety-net clinic, or church. Still others thought they would try to find such a place if their child was uninsured. Some parents said they would have to go to the ER for a toothache if their child was in pain, but that it would be very expensive. Others said they would delay getting care until their child regained insurance coverage.

Few parents had experience with a child with a behavioral, emotional, or cognitive development problem. The three parents who had sought behavioral or mental health care for their uninsured children managed to find support through a school or a low-cost counselor. Nearly all parents emphasized the high cost of caring for chronic conditions or dental emergencies and acknowledged that they would not be able to obtain care for an uninsured child in that circumstance without help.

“I never took my daughters to the dentist before they got insurance, because they had it through school. You fill out a permission slip and they take kids to a dentist group to go get their teeth cleaned. If they had a toothache and had to be seen right away, I’m not sure I’d know what to do—whether a dentist would see you without insurance. If they would bill me, I’d take them in, and then just deal with the bill.”

—Mother of publicly insured children, Little Rock

A mother finds a way to pay cash for her uninsured son's mental health care.

Selma* and her husband live in Dallas with their youngest child, age 5, recently enrolled in Medicaid, and two older children, ages 7 and 9, who are uninsured. When she applied for Medicaid in November 2007 for all three of her children, only her youngest child qualified. She didn't understand why her two older children were denied coverage and was never offered any explanation. She thinks there may be another program for them, but she is not sure.

Her oldest son is "special," "very slow," and "depressed." She took him to Mexico for treatment. Upon returning to Dallas, she had him evaluated at school but was told he "didn't qualify." Luckily, she was able to find a psychologist to see her son who accepts "whatever money I can bring him, say \$20 a week. He would take insurance, if [my son] had it. The care is good and it's helping him a lot," she said, "but it has been hard." (translated from Spanish)

*Name has been changed

Quality of care. Discussions about quality of care typically raised issues about having a regular source of care and the value parents place on a provider who knows their child's health history. For a child lacking coverage, the loss of a regular provider and continuity of care were the greatest concerns for parents after affordability.

"If I had to go to a free clinic, I would have to start over every time I went in; unless I went over and over, but then I'd have to start paying for each service, each shot, each visit."

—Mother of publicly insured child, Denver

"When my kids were uninsured, I didn't feel the doctors knew my children well enough to do a good job diagnosing them."

—Mother of publicly insured children, Dallas

The importance of follow-up care was also a recurring theme. While many parents perceived the quality of care provided at emergency departments as high in cases of urgent care, several parents commented that the ER does not serve uninsured children well as a regular source of care.

“In the emergency room they usually tell you to follow up with your doctor, and if you don’t have one, you don’t get followed-up.”

—Mother of publicly insured child, Little Rock

“Emergency room doctors are great if it’s really an emergency, but if it’s just a sick child, I think they don’t do as well as a personal care physician would do for that child...They are very limited in what they can do at the hospital...as far as follow-up care, as far as knowing the background of that child, the medical history. I think they’re just working in the dark. And they don’t have time to do all the tests that that child might need done.”

—Guardian of publicly insured child, Little Rock

Many parents felt that the quality of care available to uninsured children at some free or low-cost clinics was lower than that at clinics or doctors’ offices that accept Medicaid/SCHIP.

“In my opinion, when you don’t have any type of insurance, it’s like you don’t get the best care. They put you on the back burner; they put you off for the people who do have insurance because they don’t [think] they’re going to get paid.”

—Mother of publicly insured child, Little Rock

“[The doctors] don’t do additional tests that they might like to do, because it would cost more, and since you’re paying for it instead of the insurance, they don’t do the test.”

—Mother of uninsured child, Dallas (translated from Spanish)

Parents of children with a usual source of care had more confidence they could take their child to the same place, regardless of insurance status, to maintain continuity. However, they acknowledged that they would not be able to go to that provider indefinitely because cost would become an issue. They generally thought the quality would be the same whether or not their child had insurance.

“ [Without coverage] I wouldn’t be able to afford a private pediatrician. I think I could still take them to Children’s. You can really go anywhere once or twice and work it out, but not on a regular basis.”

—Mother of publicly insured children, Columbus

Satisfaction. Parents of uninsured children were overwhelmingly dissatisfied with their lack of coverage and the attendant financial and medical insecurity. One mother summed up the concerns of most parents with an uninsured child:

“ No, I’m not satisfied with the care he can get uninsured. I always worry about it, that he might get sick.”

—Mother of uninsured child, Dallas

Access to Medical Care With Medicaid or SCHIP

Overall, parents were satisfied with the care available through public programs, but many expressed several types of concerns. Many of the issues were peculiar to Medicaid and SCHIP. Others, however, reflected the problems that parents, particularly working parents, have with managed care or the health care delivery system generally.

Cost of care. A sense of financial security was central to parents’ discussion of seeking health care for a child with Medicaid/SCHIP, in stark contrast to the situation with an uninsured child. Many parents said that with coverage they could take their child to see a doctor at the first sign of illness, an option parents of uninsured children could not afford.

“ [When we were insured], we went to the doctor any time we needed to... if we had to go, we knew it was there.”

—Mother of uninsured child, Columbus

“ If you don’t have any insurance, you can’t go see a doctor if you can’t afford it, and a lot of times if you don’t have health insurance, you can’t afford it. So without the [Medicaid], they wouldn’t be able to get the services they need.”

—Mother of publicly insured child, Little Rock

Three of the states we visited charge co-payments for office visits and prescription drugs in their Medicaid (Arkansas) or SCHIP (Colorado and Texas) programs, but few parents reported that these co-payments limited their access to care.

Availability of care. Nearly all parents perceived availability of care to be greater and more convenient for children with public coverage compared with uninsured children. While parents said they would take their child—with or without coverage—to the emergency room in the case of sudden illness such as a high fever, parents were more likely to say that they would take their child to see a doctor at the first sign of illness, and for preventive care, if their child had public coverage.

Parents reported that when their children are publicly insured, they have better access to information about providers they can contact for primary, dental or specialty care. Parents with children in managed care often mentioned they could refer to a “guide” or “book” to help them locate a particular type of provider, or they could ask the child’s primary care doctor. Numerous parents also reported having access to a nurse hotline for medical advice or a 24-hour, urgent care center, often affiliated with a children’s hospital. Many parents said they would call the nurse hotline if their child fell ill outside of normal office hours to learn whether the situation warranted a trip to the emergency room. Unlike when children are uninsured, with coverage for their children, parents have more flexibility to make choices about when and where to seek care for their child, without fearing that a bill will follow.

“I would call the 24-hour hotline for nurses. They’ll give me the advice I need. I might have to go to the ER. [My children] have a regular doctor, but there’s no walk-in. Depending on the situation, the nurse might tell me to go to the urgent care clinic at [Children’s Hospital].”

—Mother of publicly insured children, Columbus

As a consequence of greater availability of care, and also because of the requirements of Medicaid managed care, parents said their children have—or could have—a regular source of care. Few parents had concerns about obtaining preventive care for a child with public coverage because they could make an appointment with their child’s regular provider. Parents generally placed a high value on their children’s access to preventive care with public coverage. Some parents mentioned receiving reminders about check-ups, immunizations, or dental cleanings. Parents who said their children did not have a regular provider because, for example, their Medicaid/SCHIP coverage was recent or they were new to the area, often mentioned their child’s school either as a source of preventive care or information about preventive care.

While many children on Medicaid or SCHIP saw the same provider at their usual place of care, many others did not, a distinction that appeared to depend on the particular office or clinic the child attended. Still, most parents reported that they were able to see another doctor at the same practice if their child's primary care physician was unavailable. Parents had mixed feelings about seeing the same provider: while many noted the convenience of the doctor knowing the child and his or her medical history, others expressed frustration at having to wait until their provider was available to see their child.

“If you can’t get an appointment with [the primary care physician] on a certain day, you might have to wait a week before you can get your child seen because he has to see that particular doctor.”

—Mother of publicly insured child, Dallas

Despite the generally high level of satisfaction expressed by parents, there were some complaints about access to care for publicly insured children. A number of parents said that it was often difficult to get an appointment with their child's physician, particularly in the case of sudden illness, or that the physician's hours were not convenient for them because they overlapped with work and school hours. The wait for a sick care appointment could range from a few days to several weeks, and if the child happened to fall ill outside of normal office hours, many parents reported that the ER would be their only option for seeking care. While parents acknowledged that there would likely be a long wait at the ER, they were confident their child would eventually be seen.

“[For a fever,] I wouldn’t take my kids to the doctor because it’s hard to get an appointment when it’s not deadly.”

—Mother with publicly insured children, Little Rock

A few parents expressed frustration about a long process or not knowing how to switch their child's primary care provider if enrolled in a Medicaid health plan. Parents gave a variety of reasons for wanting to change their child's primary care physician, including wanting an office with more convenient hours, a doctor who is also an asthma specialist, or a doctor who shares the mother's religious beliefs.

“You have to always take them to the same clinic, and if you want to change, it takes a long time; it’s a process. So if you’re not happy, you have to wait for them to switch you before you can go to another clinic.”

—Mother of publicly insured child, Little Rock

The special cases of dental and specialty care. After cost and affordability, the biggest difference between uninsured and publicly insured children's access was seen in the area of dental and specialty care. Parents of publicly insured children were generally positive about access to dental and specialty care for their children and the quality of care available to them. In each city where we conducted interviews, a number of parents mentioned the availability of a Medicaid-only pediatric dental clinic. Parents praised the service, quality, and appointment availability. Only a few parents mentioned difficulty finding a provider that accepted Medicaid, long waits for an appointment, or a long travel distance required to see a dentist that accepts Medicaid. Several parents had not attempted to seek dental care over the period their child has been or was on public coverage but thought they could ask their regular provider for a referral or consult a provider directory.

“There are more options with Medicaid. If you need to go to the dentist, there he is. If you need an eye doctor, there he is.”

—Mother of uninsured child, Denver (translated from Spanish)

A mother is grateful for a new dental clinic that serves children on public coverage.

Nadia* lives in Little Rock with her four children, three of whom are on Medicaid; she is separated from her husband. She is very pleased with the dental care now available to her children. “We just found somebody because it was televised...They only see kids on Medicaid. We’ve been going there for a year, but before that it was really hard because any place that accepts Medicaid, it took three to four months to get an appointment. [This dental clinic] is awesome. Totally child-friendly. Everybody greets you, and after one to two visits they know who your child is.” On the first visit, she said, “Parents can go back and there’s a window where you can see where everything is set up and how they do things...They have TV screens on all the seats so the kids can choose what show they want to watch while they’re in the chair. If their favorite dentist is available, the kids get to see that one.”

*Name has been changed

Several parents described how their children had obtained speech or language therapy or behavioral health services organized through schools or day-care centers that Medicaid covered. Schools appear to play an important role in testing and arranging care for children with special needs who are enrolled in Medicaid.

“A lot of times the schools have programs that can help, and I ended up getting my daughter into a program at her school...They have counselors that meet with them [in school], but the main thing was the parent and child get to meet with a psychiatrist and the child gets evaluated, and Medicaid pays for it...She was on it for a year.”

—Mother of publicly insured child, Little Rock

At the same time, the topic that generated the strongest expression of dissatisfaction with Medicaid or SCHIP concerned challenges obtaining a referral for specialty care. Among the frustrations parents described were:

- A primary care provider who lacked interest in a parent’s concerns;
- Difficulties with prior authorizations for treatment;
- Long and complicated process of documentation across multiple agencies or providers;
- Several-months wait for a specialty appointment; and
- Concerns about the quality and appropriateness of care, particularly regarding psychiatric medications.

“In order to get help for behavioral problems, you have to get a referral. But my son doesn’t talk to the doctor enough for him to understand the problem, so he doesn’t give him a referral. The teacher says he needs to be seen by a specialist, but we just can’t get through the referral process.”

—Mother of publicly insured children, Dallas

Quality of care. Most parents were pleased with the overall quality of care available to their children on public coverage. Having a usual source of care and continuity of care were important aspects of quality to parents. In contrast to when children are uninsured, having public coverage virtually assures that a child will have a usual source of care, typically a clinic or private doctor’s office.

“My kids are healthy, but if I have to take them to the doctor, they’re getting the best care, and that’s why they’re [staying] healthy.”

—Mother of publicly insured child, Little Rock

“I’m just glad they have a good doctor. That makes a big difference, versus a doctor that doesn’t know you.”

—Mother of publicly insured child, Little Rock

Some parents qualified their assessment of public coverage relative to its cost: it’s “good for what I can afford.”

“There’s no charge for anything. But the drawback is that you have to go to busy clinics. The clinics aren’t the best; they’re set up for poor people. Waits can be long in crowded waiting rooms full of sick people, and the quality can be bad. You might not get good follow-up on test results.”

—Mother of publicly insured child, Denver

Satisfaction. Most parents, regardless of their child’s current insurance status, were satisfied with Medicaid/SCHIP for providing their children access to good, quality care at no, or low, cost.

“It’s a great program for children and parents who don’t have insurance through a job. I would recommend that parents sign their kids up; put aside whatever pride you have and sign them up.”

—Mother of publicly insured children, Dallas

Parents’ Experiences With Enrollment and Renewal

The stories parents shared with interviewers about their children’s enrollment and re-enrollment in Medicaid or SCHIP were a mix of positive and negative experiences. In all four cities, we spoke to parents whose children had always been on public coverage, or had experienced only brief disruptions, but many more expressed frustration over the difficulties of trying to regain coverage for their children after it was terminated. About one-third of the parents who participated in the study reported having at least one child who had been continuously insured.

Positive Experiences With Enrollment and Renewal

Enrollment. In each location, some parents reported no or few concerns about enrollment, describing enrollment as “easy.” Children were most often enrolled in Medicaid at birth, and parents often credited the assistance of hospital staff with a smooth enrollment process. Other parents had sought public coverage when their children were previously ineligible for it, after they had recently moved, or had lost a job with health benefits, as one parent described:

“I signed them up first thing for [Medicaid]. It’s not as important for me, but it is for my kids. I always try to make sure, if I do nothing else, ma’am, I’ll get them insurance.”

—Mother of publicly insured children, Columbus

Renewal. Similarly, in each city, there were parents who described the renewal process as “straightforward” or “simple” and indicated that it was not a burden. The children of these parents were more likely to have never had a disruption in coverage. Continuous enrollment was more frequent in Arkansas and Ohio, where the SCHIP program is an extension of the Medicaid program and eligibility for children’s coverage extends to 200 percent of the federal poverty level (FPL) for all age groups. In Colorado and Texas, SCHIP is a separate program, and income eligibility limits for Medicaid are much lower and vary by age (Table 1).

“No problems signing up, just asked for my income. Once a year they ask you a few questions about your income.”

—Mother of publicly insured child, Little Rock

Parents who described little trouble keeping their children covered were often single and not working. It may be that non-working parents have incomes well within income eligibility limits and therefore are less likely to fluctuate above the income cut-off, making it easier for their children to maintain eligibility. They might also have more time available and more familiarity with or acceptance of the eligibility requirements and demands of public insurance programs. As one mother explained, it takes a certain amount of responsibility to stay on Medicaid:

“If you stay on top of things, take care of your business, then everything will fall into place. It’s when you don’t go to your appointments or don’t certify when you’re supposed to that you run into problems.”

—Mother of publicly insured child, Dallas

TABLE 1

Summary of Eligibility and Enrollment Policies in the Study States

	Arkansas	Colorado	Ohio	Texas
Medicaid Program Name	ARKids	Family Medicaid	Healthy Families	Texas Medicaid
SCHIP Program Name	ARKids	CHP+	Healthy Start	CHIP
Income Eligibility Thresholds (Percentage of FPL)				
Medicaid Infants (less than 1 year old)	200	133	200	185
Medicaid Children (ages 1–5)	200	133	200	133
Medicaid Children (ages 6–19)	200	100	200	100
Separate State Program (ages 0–19)	a	200	a	200
Waiting Period (in months)	6	3	0	3^b
Enrollment Simplification Policies (Yes or No)				
Joint Application	a	Y	a	Y
Administrative Income Verification	Y	N	N	N
No Face-to-Face Interview	Y	Y	Y	Y
No Asset Test	Y	Y	Y	N
Presumptive Eligibility	N	Y	N	N
Renewal Simplification Policies (Yes or No)				
Joint Renewal Form	a	Y	a	N
Administrative Income Verification	Y	N	N	N
No Face-to-Face Interview	Y	Y	Y	Y
Frequency of Renewal (in months)	12	12	12	6 (Medicaid) 12 (SCHIP)
12-Month Continuous Eligibility	Medicaid Expansion only	SCHIP only	N	SCHIP only^c

Source: Adapted from Cohen Ross D, Horn A, and Marks C. *Health Coverage for Children and Families in Medicaid and SCHIP: State Efforts Face New Hurdles*. Washington: Center on Budget and Policy Priorities and Kaiser Commission on Medicaid and the Uninsured, 2008.

Bold values indicate changes to policies in 2007 or later.

a. Medicaid-expansion state; no separate state program

b. In 2007 Texas removed the requirement that children be uninsured for three months after the date of eligibility determination. Children who have had private coverage in the three months prior to enrolling in SCHIP are still subject to the three-month waiting period.

c. Administrative renewal is conducted at six months for children between 185 percent and 200 percent FPL to ensure income has not exceeded 200 percent FPL.

d. Arkansas obtained a waiver to charge co-payments for Children's Medicaid.

FPL=Federal Poverty Level

Children with health issues were also more likely to have had continuous coverage, which appears to increase parents' motivation to keep them insured and connected to a regular provider. Very few children with ongoing health problems were uninsured.

*“ [My daughter] had health struggles the first few years of her life...
I fall short on other things, but [health insurance]—I’m on top of it.”*

—Mother of publicly insured child, Denver

Parents with positive renewal experiences also frequently reported having good communication with the Medicaid program. In Dallas, a number of parents appreciated that the Medicaid program sent a monthly letter to inform them of their child's status in the program and let them know if their child needed a well-child visit or a dental checkup. When it was time to renew, a different letter would arrive with instructions about how to complete and submit the application. Frequent communication with Medicaid appeared to help some parents maintain coverage for their children.

“ First thing I did...I made sure I had him covered...They do a review at the agency every six months; it’s not a hassle. I get a notice a month ahead of time.”

—Father of publicly insured child, Columbus

Challenges Parents Face to Keep Their Children on Public Coverage

For many parents, enrolling or renewing Medicaid/SCHIP coverage was not easy. With one exception, all of the currently uninsured children represented in the interviews had previous experience with coverage on Medicaid or SCHIP, and most of their parents had made at least one attempt to regain that coverage. Many parents whose children were on Medicaid or SCHIP at the time of the interviews had recently regained this coverage, often only after several attempts. Once a child was terminated from public coverage, parents typically faced significant bureaucratic hurdles—often made more challenging by everyday responsibilities—to regain that coverage. This section elaborates on the various barriers to re-enrollment that parents described.

System Terminations. In all four cities, the most common reason children became uninsured was a system termination of coverage during a renewal period, typically after one year of continuous coverage, but sometimes more frequently. A number of parents reported not knowing that their child was uninsured until making a visit to a doctor's office. The most common reasons for system terminations that parents cited were administrative barriers such as:

- Lost application, renewal forms, or other paperwork the parent reported sending in;
- Not receiving notice about the need to renew or not being able to understand the contents of a notification due to language barriers; and
- Not being able to produce the required documents.

“Someone misplaced the paperwork, so my child became uninsured. I didn’t have a job. I had no income...I took her to the doctor and that’s when I found out she was uninsured. So I had to leave the doctor’s office because I didn’t have \$100 to pay for the visit.”

—Mother of uninsured child, Denver

“Once they sent me something, but only to say that [the coverage] was going to expire...Since I didn’t understand the letter, I just left it alone...The next time I went to the clinic, they told me that the kids didn’t have insurance.”

—Mother of uninsured children, Little Rock (translated from Spanish)

“Many employers don’t want to give the paper that shows you work for them [so we can’t qualify for Medicaid].”

—Mother of uninsured children, Dallas (translated from Spanish)

Parents in Denver and Dallas spoke with great frustration about wrongful terminations associated with changes to the computerized eligibility systems in their respective states. While interviewers were in Denver, advocates were planning a rally called “Fix it or Ditch it” to bring further attention to the Colorado Benefits Management System (CBMS), which makes automated determinations of an applicant’s eligibility for each of the state’s public assistance programs. Many parents in Dallas complained about problems associated with the Texas Integrated Eligibility Redesign System (TIERS), which was intended to streamline eligibility for multiple assistance programs.

Recertification of one-year-olds. A surprising number of parents in each city mentioned how their child became uninsured after their first birthday. This milestone triggers recertification when the child was enrolled at birth or shortly thereafter. In some cases, recertification problems included not being able to show an original birth certificate even when the child had been enrolled in Medicaid at birth, in a hospital within the state. The loss of coverage varied from several months to several years before parents regained coverage for their children.

“They cut him off as soon as he turned 1. I had to get him recertified with his birth certificate. I gave them a copy, but they wanted the real one, and I didn’t have it; I didn’t have money to pay for it.”

—Mother of publicly insured child, Columbus

In other cases, parents were not sure why their 1-year-old had lost coverage or what programs the child might be eligible for. A Dallas mother explained that her child lost Medicaid at age 1; now age 6, and in excellent health, he has been uninsured for five years.

Income eligibility limits. A number of working parents described how their children lost public coverage because their income exceeded eligibility limits at the time of renewal. Children of seasonal workers appeared to face frequent disruptions because of fluctuations in parents’ income. Working parents felt that the system was “punishing” them for having some economic success, for trying to do the right thing. In some cases, parents enrolled their children in private coverage but found that, in the long run, it was not affordable or high-quality. Their children would end up back on public coverage or uninsured.

“My husband earns about \$500 a week, which is too much for the program, but he doesn’t always get work.”

—Mother of uninsured child, Dallas (translated from Spanish)

“I don’t make that much. But they are denying me based on my income. I am living from check to check...Instead of pushing me to be self-sufficient, it is pushing me back [to welfare] so I can get the health care for my kids.”

—Mother of uninsured child, Denver

“When it was time for my renewal, I had been working overtime. So when I took my pay stubs in I made too much money, and so I lost all my benefits... I put my daughters under my insurance at work. Only thing was because it was a part-time job, it was kind of challenging to meet the deductible, so after that first year, I went and applied for [Medicaid] again, and they got on it.”

—Mother of publicly insured children, Little Rock

In Denver and Dallas—where income limits for children’s eligibility for Medicaid are relatively low and decrease as the child ages—parents were more likely to say their children were uninsured because they made too much money for them to remain eligible. Coordination between Medicaid and SCHIP, despite joint applications, frequently did not assure continuity of coverage nor address the disruptions in coverage due to income fluctuations. Most parents with uninsured children in Denver and Dallas said they were not told about their state’s SCHIP program when they learned that their income disqualified their children for Medicaid. Most parents whose children were on SCHIP said they found out about the program through informal channels.

“After my mother-in-law told me about [SCHIP]...I called a number and they sent an application. I filled it out, made copies and sent it in. I found out we did qualify. It’s kind of confusing. I still don’t understand it, but my kids have coverage now.”

—Mother of publicly insured children, Denver

Other rules. The inability to meet non-income related program requirements also kept parents from enrolling their children in public coverage. Parents in all four cities described instances in which they could not, or would not, “play by the rules” established by Medicaid to ensure that only eligible children are enrolled in public coverage. Some children lost coverage after their parents reached their time limits on Temporary Assistance for Needy Families (TANF) or failed to follow TANF participation rules. Other parents were anticipating that they and their children would lose coverage when they completed their one year anniversary off TANF.

Child support and immigration issues also disqualified some children. In Columbus, a mother said her newborn son was not allowed Medicaid coverage because she refused to name his father. The baby remained uninsured for months, until she agreed to identify his father. A father in Little Rock was unable to enroll his children in public coverage because he and his family were legal, permanent residents but had not completed the five-year waiting period required before they could receive public benefits.² A Denver mother said that when she married a man who was an illegal alien, she and her son, a U.S. citizen, had to get off Medicaid because the father would not “get his papers” unless he could show they were his dependents and not dependent on any public assistance.

A father caught between welfare and work made a decision that left his son uninsured.

Matt,* a single father in Denver, enrolled in TANF and began job training classes when he got custody of his 8-year-old son, whom he enrolled in Medicaid. Frustrated over a lack of job referrals, he quit the program and got a part-time job. The state terminated health benefits for him and his son for lack of compliance. His son has been uninsured since and has a decaying tooth and needs speech therapy, which he receives through a school-based program.

“I probably could get him back on, but I don’t have time, with my job, the driving. I work in Brighton. I’d have to take a day off, and it’s just hard to do that...I called to get an application for [SCHIP], but it never came, and then I moved...I don’t want him to get an abscess, so I will try to get him back on. I could go in at 8 a.m. but I could be there till 1 p.m. with a case worker. Then I have to pick up my son from school. It’s time-consuming to do all that...It would be better if I could just send in my pay stubs.”

*Name has been changed

Lost in transition. Life transitions often intensified the struggles of parents trying to prevent a child’s loss of coverage. A number of parents described major life events such as separation or divorce, turmoil getting out of an abusive relationship, a change in parental custody, the death of a spouse, or a move to a new county or state, as the reason their children lost their coverage. In some cases, the children remained uninsured; in others, parents were able to enroll or re-enroll in public coverage.

“I became homeless when I left my abusive husband. Even though I was pregnant and had two small children, I didn’t qualify (for Medicaid) because of my husband’s income, and because I had no address. You can’t get coverage without an address.”

—Mother of publicly insured children, Denver

State-to-state transfers of Medicaid coverage also proved difficult for some parents. Barriers included a lack of assistance from the previous Medicaid program to cancel coverage, a lack of assistance to facilitate the new enrollment process, and difficulties proving residency and income to the new program, perhaps without a permanent residence or job. Moves were particularly challenging for Spanish-speaking parents (see *Issues Specific to Spanish Speakers*, below).

Some states, such as Colorado and Ohio, administer eligibility determinations for benefits programs at the county level. Parents in Denver and Columbus experienced confusion and gaps in coverage when they moved from one county to another.

“You have to start over and get on a waiting list for two to three months... They’ll backdate things if you have care during that period, but you still have to pay out-of-pocket and then submit those claims to get reimbursed.”

—Mother of publicly insured child, Denver

Problems encountered at the eligibility office. Mailing in documents or calling state offices did not ensure a successful outcome for some parents. Despite official elimination of requirements for face-to-face interviews for enrollment or renewal in all four study states, and the option to complete the renewal process by mail or by phone, a number of parents said they had no choice but to schedule an appointment, or simply show up, at a local welfare office because case workers did not return phone calls. Missing an appointment or coming with incomplete information means “starting over.” Overcrowded offices, long waiting times, and disrespectful and/or indifferent case workers were frequent complaints. Inconvenient hours of operation were an impediment to working parents.

“The application is not bad, but DHS [Department of Human Services] staff can be snotty. They do not return phone calls. I have to go there to get their attention, and the DHS hours are the same as my working hours so it’s difficult to get there.”

—Mother of publicly insured child, Little Rock

“Telephone interviews are possible, but if you miss the call, then you have to start all over... The office here is horrible; the staff attitudes are bad. They either lose applications or they just disregard them.”

—Mother of uninsured child, Dallas

“It feels like [eligibility workers] want to keep people from applying. You get treated like you are trash or something when you get there. It is humiliating.”

—Mother of uninsured child, Denver

“So many people show up at the office. You could be waiting from 7 a.m. till noon, and still be waiting for your case worker to see you.”

—Mother of publicly insured child, Columbus

Role of Parents' Attitudes Toward Coverage

What seemed to make some parents more successful in overcoming bureaucratic challenges or personal circumstances in regaining coverage for their children was sheer determination. Some parents were highly motivated to obtain insurance coverage for their children, either because the child had a health problem or other special health need, or because of the high value they placed on insurance. These parents reported that no amount of effort was too much.

“I know it’s OK to advocate for my kids and get them what they need. You’ve got to know tricks. You’ve got to keep calling until it goes through. Part of your job [as a parent] is to fight for your services.”

—Mother of publicly insured children, Denver

“I heard that sometimes they take Medicaid away, but I didn’t believe it because in the time my children didn’t have Medicaid, I insisted and insisted until they gave it back to them. But I guess if I hadn’t insisted so much, they might not have given it to us again.”

—Mother of publicly insured child, Dallas (translated from Spanish)

Some parents who put forth great effort to obtain insurance were nonetheless unsuccessful. For these parents, the administrative challenges proved insurmountable for the time being. They clearly wanted their children to be covered and were unhappy that their children were uninsured. But they were taking a break from trying and hoping that “nothing bad” happened.

“Between divorce and debt, I’m really stressed out. I don’t have time, or gas money. I tell my son to be careful because we don’t have insurance... Maybe if I could do it on the computer. Maybe if they could mail me the application and I could mail it back that would be great.”

—Mother of uninsured child, Denver

“I’ve applied four times...It almost doesn’t matter anymore. I’m about to throw in the towel.”

—Mother of uninsured children, Dallas (translated from Spanish)

After multiple unsuccessful attempts to re-enroll her daughter in Medicaid, a mother gives up for a time, but plans to try again.

Because Julia,* a single mother from Columbus, had recently moved and never received notification about renewing her daughter’s Medicaid coverage, it was terminated. She knew something was wrong when she didn’t get her food stamps, so she brought a pay stub to the welfare office to get her food stamps reinstated. She was told she could not get her child back on Medicaid, however, without coming back with a rent receipt. She told the caseworker that she had not been informed in advance she would need that. A few weeks later she returned with the rent receipt. This time she was told her child could not get back on Medicaid without a birth certificate, which she would have to retrieve from New York City, where her daughter was born. At the time of the interview, four months after her last visit to the eligibility office, she said she had given up. “I’ll go back up there before the week is out. Certain days are intake days. I’ll just go early and sit and wait.”

*Name has been changed

Parents who were *not* concerned about their child’s lack of coverage, and therefore had chosen not to try to re-enroll them after a coverage termination, were the exception. Among parents whose children had been uninsured for a year or longer, good health and a lack of need, or a previously negative enrollment experience were the primary influences behind their decision not to re-apply.

“Well, it’s been a year, and I just haven’t applied...I just haven’t... and she wasn’t sick so I said I’ll just wait.”

—Mother of uninsured child, Little Rock

“I haven’t re-applied for her. For now, I just pay cash.”

—Mother of uninsured child, Little Rock

“Lately, no—it’s been a while since I applied. They put too many barriers in the way...They ask such questions, like ‘Why did you get pregnant?’ or ‘Why didn’t you take care of yourself?’ Very personal questions.”

—Mother of uninsured child, Denver (translated from Spanish)

Parents’ Perspectives on Why Some Children Are Uninsured and How to Improve Coverage

When asked why some parents might not have their children enrolled in Medicaid or SCHIP, parents whose children were continuously insured most often replied that such parents were “lazy” and had “no excuse.” As one parent summed up, “They’re too occupied with life unless something tragic comes up.” This explanation was common in all cities except Denver, where parents were sympathetic about system barriers that might make a parent give up trying. Another frequent assertion was that parents did not like other people “getting in their business” and thus were reluctant to provide all of the information and documentation necessary. In Little Rock, parents said that people simply did not have enough information. In Columbus, several parents thought transportation might be a barrier to enrollment.

Parents of both insured and currently uninsured children had many suggestions about how to make it easier for parents to get and keep their children enrolled in Medicaid or SCHIP. Their ideas highlighted three general themes: the programs provide too little information to parents; the programs ask for too much personal information from parents; and income eligibility does not account for families’ medical needs.

Lack of program awareness or understanding of potential eligibility. Parents may not know what is available for their children or may not understand the qualifications for coverage. Some parents suggested sending materials home through the school so parents could become more aware of the programs that are available. Making information more accessible through the Internet has not necessarily facilitated enrollment, however.

“A lot of people automatically think that you have to be below poverty in order to qualify for health care. They don’t know that with \$30,000, you can still have a child qualify for one of their services.”

—Mother of publicly insured child, Little Rock

“Even on the Web sites it is not very accessible or user-friendly. You have to go through a lot of information to see how to apply.”

—Mother of uninsured children, Denver

Several parents also mentioned needing more information about when their children’s coverage was about to be terminated. Since Medicaid/SCHIP cards do not show an expiration date, families may be confused about when and how to renew their coverage if they did not receive information in advance or could not understand information they had received.

“When they’re born, they get [Medicaid], but you don’t know if it’s going to last a year, or what, and you don’t know when you have to do something. You just go, and find out they don’t have it!”

—Mother of publicly insured child, Little Rock

“If you find out the second day of the month your child is off, you can’t get back on until the first of the next month.”

—Mother of publicly insured child, Denver

Amount of required personal information. A number of parents, particularly in Little Rock, suggested that parents may resist government programs to protect their privacy. Parents whose children have been continuously insured said that, for them, the burden of information required was acceptable and not a reason to keep a child uninsured. Other parents, however, questioned the necessity of having to provide information so frequently for renewals.

“I can understand if they ask for your income, but that should be enough. But they got to know all this other stuff.”

—Mother of publicly insured child, Little Rock

“Trying to keep the insurance when you’ve got a job, going to class, taking care of your kids—it takes too much time to get away. You’ve got me in the system, what more do you need? If I don’t change my job, why do I need to go back? We’ve got lives to live.”

—Mother of publicly insured child, Columbus

Families’ unique situations and needs. Parents in all four cities, especially those whose children had lost coverage, felt that income alone was not necessarily the best way to make coverage decisions for children and their families. Some parents suggested higher income eligibility limits as a way to help families get their children insured.

“If they evaluated the cost of living, they would have better guidelines and cover more people. I make \$1,000 per month and don’t qualify for Medicaid, and my daughter doesn’t qualify because I make too much.”

—Mother of uninsured child, Denver

“It’s hard when you’re right on the income break...It would be good to raise the income limit. If you’re dependent on child support, and that doesn’t come through, you’re really stuck. I want [my kids] to be insured just in case those emergencies come up.”

—Mother of uninsured child, Columbus

Issues Specific to Spanish Speakers

Spanish-speaking parents reported additional barriers to getting health care services or maintaining public coverage for their children as a result of limited English proficiency, perceived discrimination, and concerns about immigration status. Results mirrored those reported in focus groups (Hill, et al., 2005).

Language barriers. Parents frequently mentioned difficulty finding Spanish-speaking doctors, understanding official communications from Medicaid/SCHIP, and navigating the process of enrollment or renewal. Many expressed frustration at having to wait for a translator at a clinic, and one mother reported using hand signals to describe to her doctor what was wrong with her child. Language barriers also added confusion to enrollment and renewal procedures when parents could not read letters they had received about how and when to renew coverage.

The intensity of the language barriers varied across study sites, with parents in Dallas reporting the fewest problems and those in Little Rock reporting the most.¹ In Dallas and Denver, where the Spanish-speaking communities are large and well-established, parents often cited friends, family, or local organizations as resources in learning to navigate the system. In contrast, Spanish-speaking parents in Little Rock, where social and community networks may be weaker because of more recent arrivals of immigrant families, parents were less likely to report having community, social, or family connections they could turn to for translation assistance. Several Spanish-speaking mothers who had recently moved to Little Rock from another state described language barriers with their case manager as a contributing factor in the delay in the transfer of their children's coverage to Arkansas's Medicaid/SCHIP program; their children were uninsured at the time of the interviews.

Perceived discrimination. Infrequently, parents described receiving differential treatment in a medical setting or welfare offices based on their ethnicity or limited English. Two mothers who had trouble getting the help they needed from administrative staff attributed the problem to discrimination:

“If they are a racist then they won’t help you...I took my daughter [to the clinic] because she was suffering from depression. And the [receptionist] told me that if we weren’t a part of the [school] then she couldn’t get care. I was a student at that school. So the woman was a racist because she didn’t even want to try to understand me. Since I didn’t speak the language right, they didn’t want to help.”
—Mother of uninsured child, Denver (translated from Spanish)

Recognition of discrimination was not limited to Spanish-speaking parents. One English-speaking mother said that it can be difficult to learn how the system works, but her background and ethnicity helped her:

“...All the hoops they make you jump through make it off-putting and if you are not used to it—like myself, I’ve spent years figuring out how to get through the system. And I have an advantage because I am Caucasian and I am educated.”
—Mother of publicly insured child, Denver

Immigration status. Spanish-speaking parents also faced barriers to enrollment because of factors associated with their immigration status. In some mixed-status families, children who are U.S. citizens and eligible to receive benefits were uninsured because their parents were unable to provide all the necessary documents. Precarious employment and housing situations often compounded the difficulties immigrant parents had producing documents. While these problems were not unique to immigrant parents, they reported them more frequently than other parents. Citizen children with immigrant parents may be denied coverage because of their parents' inability to prove income or place of residence.

Immigrant parents have been unable to get their children back on public coverage without an employer's cooperation in providing a pay stub for proof of income.

Maria,* a married mother in Dallas, said her four children lost Medicaid coverage two years ago when her husband could no longer produce a pay stub from his job to document the family income. They also moved to a trailer on land for which they pay rent, but the landlord won't give them a written record of how much they pay, which they also need in order to apply.

"I keep after the owner to get the proof of rent payments, but he always says, 'No, tomorrow, tomorrow.' If my husband had a stable job where they paid him with a check—a pay stub—we wouldn't have much trouble." (translated from Spanish)

*Name has been changed

Conclusions

States have made significant progress in reducing the stigma associated with public health insurance programs. They have adopted a variety of strategies to increase parents' awareness of the programs and to simplify enrollment and renewal processes. Nevertheless, from the perspective of many low-income parents, getting and keeping their children on Medicaid/SCHIP is much harder than it should be. Parents' life experiences, children's health needs, personal challenges, coping skills, and risk aversion may all have contributed to whether their children were insured or uninsured at the time of the interviews. For the vast majority of children who were uninsured, or had experienced a time uninsured, the cause was an administrative termination or life transitions rather than dissatisfaction with Medicaid/SCHIP coverage or a preference for paying out-of-pocket.

Although more than half of the parents interviewed were themselves uninsured, they thought of having health coverage for their children as part of being a responsible parent. Parents whose children were enrolled in Medicaid/SCHIP appreciated the medical and financial security that public insurance offers. Parents of uninsured children would like to have that security as well. Without coverage, they saw their choices as primarily: going to the ER, where they could not be turned away but would get a bill; going to a private clinic, where they would have to pay in advance; or delaying care. While some parents faced barriers to care in public coverage, most were satisfied with the care available. The cost barriers to health care without coverage far exceed access problems with Medicaid or SCHIP.

While other research has found that cost-sharing in children's Medicaid and SCHIP reduces access to and use of care (Kaiser Commission on Medicaid and the Uninsured, 2003; Kenney, Hadley and Blavin, 2007; Kenney et al., 2007; Hadley et al., 2007), the interviews in this study provide little evidence that co-payments for office or ER visits or prescriptions reduce enrollees' access to care. Most parents seemed willing and able to pay the required nominal amounts.

Churning was highest where administrative and eligibility barriers were greatest, namely, in Denver and Dallas. Colorado and Texas were the two study states that operate separate SCHIP programs, which have been shown to be associated with higher rates of disenrollment and lower retention than Medicaid expansion programs (Kronebusch and Elbel, 2004; Sommers, 2005). Of the six parents interviewed whose uninsured children have ongoing health problems, four reported administrative issues as the reason their children were not enrolled in Medicaid or SCHIP. All six live in Denver or Dallas. In all four cities, parents' sheer willingness to keep trying seemed to be the strongest factor in explaining why children were insured after a disruption in coverage.

Our findings suggest that policy and procedural changes in several areas could help reduce both the number of children who are eligible for, but not enrolled in, Medicaid or SCHIP and the frequency of coverage disruptions.

Simplify enrollment and renewal requirements. The study states all waive the requirement of an in-person interview for application and renewal in Medicaid/SCHIP, instead allowing parents to apply electronically, over the phone, or by mail. However, when these approaches fail, as they did for some parents interviewed, parents find that they must make an in-person visit in order to successfully complete their children's enrollment or re-enrollment. This was an enormous burden, especially for working parents. Many feel that these administrative barriers undermine their incentive to work. Making these processes more passive for parents, by reducing and shifting the burden of documentation of eligibility from parents to Medicaid/SCHIP agencies could reduce churning (Howell et al., 2006; Wolfe and Scrivner, 2005).

Several states are adopting “ex-parte” renewal to improve retention. Ex-parte renewal procedures make use of third-party data sources (such as the National School Lunch Program, food stamps, tax returns, the National Vital Statistics System, and motor vehicle departments) to assist in determining eligibility or citizenship/identity documentation (Dorn, 2007 and 2008). Such efforts could also change the perception of some parents who are deterred from enrolling their children because they feel the application process is too difficult or an invasion of their privacy. In a few cases, states are allowing parents who refuse, or are unable, to provide proof of income, to enroll their child in SCHIP if they are willing to pay the full premium (even if, with proof of income, the child was eligible for free coverage). Similarly, telling parents why the information is needed and providing assurances about its confidentiality could help allay privacy concerns.

Improve coordination between Medicaid and SCHIP. While both Colorado and Texas have a common application for their Medicaid and separate SCHIP programs, the systems to link applications and coordinate eligibility determination and transitions between the two programs do not appear to work well. Working parents were disproportionately affected because of frequent income fluctuations. States with separate SCHIP programs could mitigate these problems by instituting automatic transfers of children from Medicaid to SCHIP as they age or as family income increases (Summer and Mann, 2006).

Conduct pre-termination reviews. Some states make several attempts to contact families by mail and/or phone rather than automatically terminating coverage when renewal requirements have not been met (Duchon, Ellis and Gifford, 2008). Other states, including Ohio, have recently implemented automatic, pre-termination reviews of cases to try to avoid wrongful terminations that might arise when a family or parent loses TANF or other types of public assistance. Pre-termination reviews and similar techniques could reduce disruptions in coverage that may result from a change of address, missing documents, missed appointments, recertification at age 1, end of TANF benefits, or other circumstances, particularly in the absence of passive or ex-parte renewal procedures. Frequent communication with parents by mail about preventive care and renewal dates, as parents in Texas described, could also serve as a reminder to parents to update contact information to Medicaid, SCHIP, and/or their health plan before a renewal date.

Revise training and performance incentives for eligibility caseworkers. Poor staff-client relations were evident in all four cities, transcending structural differences in program design. Negative perceptions of caseworkers and lack of confidence in their follow-through contributed to some parents' decisions to give up, or at least suspend, their efforts to pursue public coverage. A "cultural" reorientation away from compliance with rules toward customer service could be fostered through education and training, and reinforced through employee recognition and evaluation criteria that emphasize enrollment and retention goals.

Expand health literacy and language assistance efforts. Many parents expressed uncertainty or confusion about how to navigate the health care system with Medicaid or SCHIP. Medicaid and SCHIP programs have authority to institute performance standards for communicating this information and to periodically review how their health plans or internal member service functions communicate with their members, including those with limited English proficiency. While simply offering a provider guide is sufficient for many parents, others need additional help in order to understand their provider and service options. Efforts to support and train community-based organizations to provide enrollment and benefits information that is culturally sensitive, as well as application assistance, to racially and ethnically diverse families could improve enrollment success rates.

Expand enrollment assistance in schools and school-based health clinics. Schools are a source of trusted information for parents and so offer an additional opportunity for outreach to parents about enrollment in Medicaid/SCHIP, particularly where Medicaid-reimbursable services are offered.

Endnotes

1. Only one parent was interviewed in Spanish in Columbus, so it is not possible to characterize the experience of the Spanish-speaking community there.
2. The Children's Health Insurance Program Reauthorization Act, signed into law February 4, 2009, gives states the option to eliminate the five-year waiting period for legal immigrants.

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Appendix A: Detailed Methodology

Interview Protocol

The Urban Institute-HMA team developed semi-structured, interview protocols from which interviewers asked parents open-ended questions about health care options for their children with and without coverage. To study perceptions, we asked parents to draw on either their own or others' experiences. The interviews also explored parents' experiences with the process of enrolling and re-enrolling their children in public coverage. Because the 2005 focus group findings (Hill et al., 2005) suggested that access differed by type of care—primary, specialty, and dental—the questions posed different health care scenarios designed to encourage interviewees to talk about different types of care they might have experienced or might face in the future:

- fever
- toothache
- behavioral, emotional, or speech problem
- preventive or well-child care.

Two protocols were developed: one for parents with at least one child uninsured and one for parents with children enrolled in Medicaid or SCHIP (see Appendix B). Each protocol included questions about where the parent would obtain care, the perceived quality of care, and the out-of-pocket cost for each scenario, given their child's current health insurance status. Each protocol then asked parents to draw on their own experiences and perceptions, or the experiences of people they knew, to describe where they would go for care, the expected quality, and expected cost of care for each of the same scenarios if their children had the opposite health insurance status (enrolled in Medicaid/SCHIP or uninsured).

Parents of uninsured children with previous experience on Medicaid or SCHIP were asked how the child lost coverage and about what barriers kept them from re-applying for Medicaid/SCHIP. They were also asked about any concerns they might have had about quality or access to care when their children had public coverage, and whether any such concerns were reasons that caused them not to renew coverage for their children. Parents of insured children who ever had a break in coverage were asked about their most recent enrollment or re-enrollment experiences and what they perceived might be reasons that keep parents from applying for Medicaid/SCHIP. All parents were asked about the most important changes that their state's Medicaid or SCHIP program could make to encourage parents to sign up their children for coverage.

The interview protocol included questions about the respondent's current employment and marital status, own insurance coverage, and information about children, including age, health status, insurance status and history of any disruptions in coverage. We conducted a pilot study of our interview protocol and participant recruitment methodology in Washington, D.C. The interviews were conducted in English and Spanish.

Site Selection. Six key criteria guided our selection of locations to conduct interviews. The first was the structure of the SCHIP program in a state (Medicaid expansion or separate SCHIP) since we planned to interview parents of children eligible for either Medicaid or SCHIP. Other criteria were community health needs, as measured by child uninsured rates and poverty rates; health care capacity or access, as measured by physician-to-population ratios, Medicaid payment rates, and managed care penetration; regional diversity and urban setting. Finally, we gave preference, for logistical reasons, to those cities where the Urban Institute or HMA had offices or good contacts with children's advocacy groups. Data that supported our choices of Dallas and Denver—selected among states with a separate SCHIP program—and Little Rock, Ark., and Columbus, Ohio—selected among states where SCHIP is an extension of Medicaid—are shown in Appendix C.

Recruiting Participants. We relied on referrals from our local contacts and CKF coalition members as well as Internet searches of prominent local organizations to identify two to three community-based organizations (CBOs) in each city. Our criteria for selecting CBOs were that they serve families likely to be eligible for our study, and that they be able to provide office space to conduct private interviews on the days of our visits. In order not to bias the sample toward parents who were seeking health care for themselves or their children, we chose CBOs that provided primarily non-health care services, such as food and clothing distribution, emergency assistance with utilities, and family-based social support services (see Appendix D). Although some of the CBOs did provide health care services, we only recruited clients who were not seeking health-related services.

We actively sought Spanish-speaking parents in two cities, Denver and Dallas, where we worked with CBOs whose clientele included a relatively large share of Hispanic families. We also interviewed, but did not seek out, Spanish-speaking parents in Little Rock and Columbus who were eligible and interested in participating. While most of the interviewees were a convenience sample of parents (or guardians) seeking services at the CBO on the day of our visit, some CBOs called parents ahead of our arrival, pre-screened them, and scheduled their interview.

Eligibility to Participate in the Study. We sought a sample of parents in families with at least one child under age 18 who was eligible for public coverage. Parents were eligible to participate in an interview if they met the following criteria based on voluntary answers (we did not require any documentation of eligibility):

- Adult parent or guardian of at least one child age 18 or younger living in the household;
- Family income below 200 percent of the federal poverty level;
- An ability to show copies of children's social security card (as a proxy for eligibility based on immigration status);
- At least one child who is currently uninsured or enrolled in Medicaid or SCHIP.

We sought to interview parents of three groups of children:

- Long-term uninsured: children without any insurance coverage for more than six months;
- Recently uninsured: uninsured children who were on Medicaid or SCHIP within the last six months;
- Recently re-enrolled: children with Medicaid or SCHIP coverage who had re-enrolled in public coverage within the last six months (for comparison purposes).

We used a screening instrument to identify parents who met our eligibility criteria. Eligible parents who consented to participate were interviewed immediately by one of two project interviewers stationed at the site, one of whom was fluent in Spanish. Each interviewed parent gave permission to have their interview recorded and was promised anonymity. We paid each participant a cash stipend upon completion of a private interview that typically lasted 30 minutes.

Interview Participants. We interviewed 80 parents or guardians representing a total of 164 children (Table A-1). Single parents (no spouse or partner in household) comprised nearly two-thirds (50) of our sample. About one-third (29) of parents were part of a household with no full- or part-time worker. The rest of the parents were either employed themselves or had an employed spouse, although their employment was often tenuous. Many parents reported working part time while attending school or having a spouse with temporary or seasonal employment. More than half of parents interviewed (44) were uninsured themselves. A number of parents (23) had public coverage (mostly Medicaid, but also Medicare, Indian Health Services, and VA disability) and 10 had job-based coverage; for three, insurance status was not determined. About one-quarter of interviews were conducted in Spanish, primarily in Dallas and Denver. Most interviewees were women; six were men.

More than one-quarter of parents (25) described their children's health status as "fair" or "poor," or volunteered information about a child's disease or disability. Our sample included 26 parents or guardians with at least one uninsured child in their household and 54 with all children in the household insured (and at least one child on public coverage). While we did not find as many parents of currently uninsured children as we originally sought, more than half of parents with all children currently insured reported having at least one child that had experienced a time uninsured. In total, two-thirds of parents interviewed (54) reported having at least one child that was currently or previously uninsured. Fifteen of the 26 parents of currently uninsured children reported that they were planning to try to enroll their child or children in public coverage.

TABLE A-1

Characteristics of Interviewed Parents and Their Children

	Columbus	Dallas	Denver	Little Rock	Total
Parent/family information					
Parents/guardians interviewed	18	17	21	24	80
Children represented in interviews	39	40	38	47	164
Only one adult in household*	13	7	15	15	50
No full- or part-time worker in household**	11	3	4	11	29
Currently uninsured	8	12	12	12	44
Language used in interview was Spanish	1	10	6	4	21
Children's information					
Any child in family in fair/poor health or with a chronic disease or disability	4	9	7	5	25
All children in family continuously insured	8	4	3	11	26
One or more children currently or ever uninsured	10	13	18	13	54
One or more children in family <i>currently</i> uninsured	3	6	11	6	26
Parent plans to obtain coverage for an uninsured child	2	5	3	5	15

* Includes parent/guardian that is separated from spouse; excludes parent/guardian living with a partner or other adult relative

** Excludes seasonal, temporary workers

Strengths, Limitations, and Implications of the Chosen Methodology. We used private interviews as a data collection technique to explore how the interplay of experiences with, and perceptions of, health coverage—and unique family circumstances—influence parents’ enrollment decisions for their children—within the context of different public program structures and rules. Although more time-consuming, this method was chosen over focus groups so that researchers could gather “stories” that reveal how children became uninsured, and why uninsured children were not enrolled in Medicaid or SCHIP.

The difficulty that we encountered finding parents of uninsured children at community-based organizations and local government agencies was instructive. We found that most of the sites with which we partnered made a point of signing up their clients for any services for which they were eligible, including Medicaid/SCHIP, regardless of the type of services they were seeking. This diligence is a tribute to the voluntary and local government sectors but may have limited our ability to find and recruit low-income parents whose children were uninsured. Parents who turn to community-based organizations are more likely than others to be “plugged-in” to the health and social services for which they qualify.

We found no parents who had never heard of Medicaid. Parents we interviewed may be more proactive about enrolling, or trying to enroll, their children in public programs than parents who do not visit local service providers. Reaching these types of parents—whose children are eligible but not enrolled in public coverage—would have required a different research methodology.

By interviewing low-income parents in states with different program designs, we were able to observe how some policies and procedures appear to reduce coverage barriers, and thus better enable parents to keep their children enrolled, while other programs impose barriers that require parents to exert a greater effort to maintain their children’s coverage or reinstate it.

Appendix B: Interview Protocol

Interview questions are summarized below for parents of uninsured and insured children.

Uninsured Children:

Overall impressions of quality and access to care for uninsured children

Publicly insured Children:

Overall impressions of quality and access to care for publicly insured children

- Q1.1 If your child/one of your children came down with a fever, what could you do to get care for that child?
- Probe for where they would go, quality, cost
- Q1.2 With/without insurance, do you think you would be able to find good care for your sick child?
- Q1.3 Would your family have to spend much money to get care for your child with a fever?
- Q1.4 What if your child had a toothache and needed to see a dentist? What could you do to get care for your child?
- Q1.5 What if your child had speech problems or an emotional or behavioral problem? For example, what if your child was having trouble learning to speak? Or if you had a teenager who was depressed? Would you be able to get your child care for such problems?
- Q1.6 What if your child needed preventive care, like well-child visits? What would you do?

Uninsured Children:

Overall impressions of quality and access to care for publicly insured children

Publicly Insured Children:

Overall impressions of quality and access to care for uninsured children

- Q1.7 OK, we've been talking about what it might be like getting care for your child with/without health insurance. I'm wondering now whether you think it would be different if your child or other children in your community did/did not have Medicaid/SCHIP.
- How would having/not having Medicaid/SCHIP affect getting care for a sick child with a fever, or would it have no effect?
 - Would having/not having Medicaid/SCHIP affect the cost of care for a sick child? Why?
- Q1.8 What about a child that needed to see a dentist?
- Q1.9 What about a child with a speech problem or an emotional or behavioral problem?

Q1.10 What about a child that needed a well-child visit?

- Would having/not having Medicaid/SCHIP affect whether a family always sees the same doctor?

[If Medicaid and SCHIP have different program names, ask:]

- How about SCHIP, compared to Medicaid? In your opinion, are SCHIP and Medicaid pretty much the same? Or is one better than the other? Are there certain types of care that are different (dental, preventive, etc.)? Why?

Uninsured Children:

Previously Enrolled in Public Insurance: Impressions of/Experiences With Public Program Enrollment

Q1.11 Why or how did your child lose health insurance coverage (Medicaid/SCHIP)?

Q1.12 Were there any concerns you had about your child's coverage when your child had Medicaid or SCHIP? If YES: What were they?

Q1.13 Did any of these experiences cause you to decide to *not* renew your child's coverage under Medicaid/SCHIP?

Publicly Insured Children:

Impressions of/Experiences With Public Program Enrollment

Q2.11 How long has your child been on Medicaid/SCHIP? Would you say that has been six months or less? More than six months?

Q2.12 What made you decide to sign your child up for Medicaid/SCHIP?

Q2.13 Did you have any problems getting her enrolled?

Q2.14 Do you have any concerns about your child's coverage? If YES: What are they?

All Children:

Barriers to Public Program Enrollment/Satisfaction with Health Care

Q1.14 At this time, what are some of the reasons that keep you/other parents from applying for Medicaid or SCHIP for your child?

Q1.15 What would be the most important thing that programs like Medicaid or SCHIP could do that might persuade you/other parents to sign your child up for coverage?

Q1.16 Overall, how satisfied are you with the health care you can get for your child with/without him/her having health insurance coverage?

Appendix C: Site Selection Data

TABLE C-1

Interview Sites and Key Selection Criteria

	Little Rock	Columbus	Dallas	Denver
SCHIP Structure	Medicaid Expansion		Separate	
Access				
Uninsured Rate	14.4%	11.6%	18.2%	18.2%
Safety-Net Capacity	Fair/Poor	Fair	Poor	Good
Medicaid Managed Care Penetration*	81.7%	69.5%	67.3%	94.1%
Region of U.S.	South	Midwest	South	West
Total Metro Area Population	184,053	728,432	1,208,318	557,478
Medicaid Expenditures per Child**	\$1,620	\$1,548	\$1,583	\$1,590
Medicaid Payment Ratio**	1.24	0.97	0.99	1.06

* Denotes county rate

** Denotes state rate

Sources: 1) U.S. Census Bureau, Current Population Survey (CPS), 2003. Available at <http://quickfacts.census.gov/qfd/>

2) U.S. Census Bureau, CPS, 1999.

3) U.S. Census Bureau, Model-Based Small Area Health Insurance Estimates for Counties and States (SAHIE), 2000.

Available at www.census.gov/hhes/www/sahie/index.html

4) 2000, 2005 Area Resource File: Dentists; Physicians and Surgeons.

5) Kaiser Family Foundation, State Health Facts Online, Medicaid Payments per Enrollee, FY2005.

Available at www.statehealthfacts.org/profileind.jsp?rgn=1&cat=4&ind=183

6) Zuckerman S, McFeeters J, Cunningham P, Nichols L. "Changes in Medicaid Physician Fees, 1998-2003:

Implications for Physician Participation." *Health Affairs*, Web Exclusive, 2004.

7) Kaiser Family Foundation State Health Facts Online, *Medicaid Managed Care Enrollees as a Percent of State Medicaid Enrollees, as of June 30, 2007*. Available at www.cms.hhs.gov/MedicaidDataSourcesGenInfo/Downloads/mmcer06.pdf.

Appendix D: Community-Based Partners

TABLE D-1

Organizations That Assisted in Recruiting Interviewees, by Interview Site

Columbus, Ohio

March 17–18, 2008

- Columbus/Franklin County Community Action Agency (utility assistance program)
- Lutheran Social Services, South Food Pantries (private food and clothing bank)
- Lutheran Social Services, West Food Pantries (private food and clothing bank)

Dallas, Texas

February 7–8, 2008

- North Dallas Shared Ministries (private food and clothing bank)
- Metrocrest Social Services (private food and clothing bank)

Denver, Colo.

March 10–11, 2008

- Project Wise (private program of support services for women transitioning from welfare to work)
- Sisters of Color United for Education (private organization of health education and wellness for underserved and under-insured families)

Little Rock, Ark.

February 25–26, 2008

- University of Arkansas for Medical Sciences (Head Start program)
- Central Arkansas Development Council (utility assistance program)

Washington, D.C.

Pilot interviews

- Bread for the City—two locations (private food and clothing bank and health care services)
-



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