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Children's Coverage: What Matters Most to Parents Results from Focus Groups in 6 Cities

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Executive Summary

The Children's Health Insurance Program (CHIP) was enacted in 1997 to provide affordable coverage to lowincome uninsured children who lived in families with incomes above the eligibility limits for Medicaid, but unable to afford private coverage. Medicaid and CHIP have helped to significantly reduce the number of lowincome uninsured children nationally by expanding eligibility levels and simplifying enrollment procedures. CHIP now covers nearly 6 million children, building on Medicaid's coverage of 28 million children.¹

The passage of the Affordable Care Act (ACA) as well as debate about extending funding for CHIP has meant that policy makers are considering options for the future of children's coverage. Congress has extended funding for CHIP for two years (through 2017), but longer-term there will be additional debate about how best to ensure coverage to children in low and moderate income families. Specifically, would private coverage (either employer sponsored coverage or Marketplace) or Medicaid work for children who currently are enrolled in CHIP? To help inform policy makers about what matters most to parents with regard to children's coverage, the Kaiser Family Foundation contracted with John Snow Incorporated (JSI) to conduct focus groups with parents with moderate incomes enrolled in private coverage who had children in public (primarily CHIP) or children with private coverage (generally the same coverage as the parent). Key findings include the following:

- Affordability was a primary concern for parents with moderate incomes who are struggling financially despite recent improvements in the overall economy. Parents thought the cost of private coverage for their children was too high and often unpredictable but CHIP coverage was affordable.
- Across private and CHIP coverage, families valued comprehensive benefits and were generally satisfied with providers available through their coverage; however, parents in both groups said they had some problems accessing selected specialists. Parents reported that children with private coverage and CHIP had access to vision and dental coverage and that these services were highly valued.
- When asked about their own private coverage, parents reported that the costs of coverage were high and they frequently delayed or avoided seeking care because of costs. Parents reported high (up to \$10,000) deductibles and high out of pocket costs for copayments or coinsurance. In addition, parents reported gaps in coverage and periods when they were uninsured when they were in between jobs.
- Coverage under the same plan as their children was not a priority for parents. Parents with children in private coverage were willing to have children in a separate plan for lower costs. Parents with children in CHIP did not want children in private coverage (generally due to costs).

• Parents were largely unaware that a debate had been going-on in Congress. Parents of children with CHIP as well as parents of children with private coverage were worried about the future of CHIP noting that the program provided a role as a safety-net for those who need it. Nearly all parents with children enrolled in CHIP as well as those with children who had private coverage said they would enroll in Medicaid if their current coverage were no longer available. Parents with CHIP coverage said there would be serious financial consequences for their families if CHIP were no longer available and they had to enroll their children in private coverage.

Introduction and Background

Ensuring affordable coverage has long been a priority for policy makers. Over time, Medicaid had been expanded to provide coverage and comprehensive benefits to children 0-6 with incomes up to 133% FPL and for older children up to the poverty level. The Children's Health Insurance Program (CHIP) was enacted in 1997 to provide affordable coverage to low-income uninsured children who lived in families with incomes above the eligibility limits for Medicaid, but unable to afford private coverage. Formerly known as the State Children's Health Insurance Program (SCHIP), the program was established as Title XXI of the Security Act as part of the Balanced Budget Act of 1997 and reauthorized as part of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA). The Affordable Care Act provided additional funding for the CHIP program through September of 2015. Together with Medicaid, CHIP has helped to significantly reduce the number of low-income uninsured children, building on Medicaid's coverage of 28 million children.²

The passage of the Affordable Care Act (ACA) as well as debate about extending funding for CHIP has meant that policy makers are considering options for the future of children's coverage. In the near term, Congress passed the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) which was signed by the President into law on April 16, 2015. Under MACRA, CHIP funding was extended for an additional two years (through 2017) without making other changes to the program.

This report is based on based on focus group discussions with parents with moderate incomes enrolled in private coverage (employer sponsored or Marketplace) who had children in public coverage (primarily CHIP) or children with private coverage. The purpose of the groups was to gain insight into what low and middle-income families value in their children's coverage, their experiences with CHIP and private insurance, and on parents' perspectives on the future of CHIP. The information gathered can help inform policy questions such as would private coverage (either employer sponsored coverage or Marketplace) or Medicaid work for children who currently are enrolled in CHIP?

Methodology

This report is based on 14 focus group discussions conducted by the Kaiser Family Foundation and John Snow, Inc. in six cities during February and March 2015. Sites included Birmingham, AL, Chicago, IL, Denver, CO, Philadelphia, PA, and Tampa, FL. Each of these states operate separate CHIP programs. An additional 4 focus groups were conducted in Los Angeles, CA (two in English and two in Spanish).

Each focus group consisted of 5-14 parents for a total of 113 participants representing 208 children ages 18 or under. Half of the groups included parents of children currently enrolled in CHIP. (In Los Angeles, children were enrolled in Medicaid (Medi-Cal) because California ended their CHIP (Healthy Families) program and transitioned children to Medicaid.) The other half included parents of dependent children enrolled in private health insurance, either through an employer or through the Health Insurance Marketplace. All parents included in the groups were enrolled in private health insurance through their employer or the Marketplace. Most participants were in families with incomes between 139% and about 300% FPL (the CHIP income range for the state). A small number of parents of children with Marketplace coverage had incomes above the CHIP income range for the state, but below 400% FPL and were receiving tax credits to obtain Marketplace coverage. (See Table 1 for details about income and participation in the focus groups).

Most focus group participants had at least one child under the age of ten because younger children tend to utilize more health care services. Participants also included a mix of gender, age, race and ethnicity, educational attainment, and health needs.

State	CHIP Name	CHIP Income Eligibility	ESI Coverage for Parents and Children		Marketplace* Coverage for Parents and Children		Total Private Coverage Parents	Total Private Coverage Children	Parents with Private Coverage and Children with CHIP**	
		6-18 Years	Parents	Children	Parents	Children			Parents	Children
Birmingham, AL	ALL Kids	147% - 317%	8	12	0	0	8	12	11	18
Denver, CO	Child Health Plus	148% - 265%	8	16	1	1	9	17	6	12
Chicago, IL	All Kids	148% - 318%	3	4	8	19	11	23	7	17
Philadelphia, PA	CHIP Name	139% - 320%	7	9	2	7	9	16	8	14
Tampa, FL	Kid Care	139% - 215%	7	10	1	4	8	14	7	11
Los Angeles, CA English	Healthy Families / Medi-Cal	139% - 266%	3	6	5	9	8	15	8	15
Los Angeles, CA Spanish	Healthy Families / Medi-Cal	139% - 266%	3	5	2	2	5	7	8	17
Total			39	62	19	42	58	104	55	104

*Marketplace income ranged up to 400% FPL to get families that had parents and children in marketplace coveage.

**CHIP includes those in Medi-Cal in California

FINDINGS

WHAT IS THE FINANCIAL SITUATION AND HEALTH STATUS OF LOW AND MODERATE INCOME FAMILIES IN THE STUDY?

Most participants were working or were in working families, but many still felt the pinch of the recent recession. Parents included in the focus groups were working in a range of jobs, including as researchers, truck drivers, construction workers, retail clerks, and in the health care and social services sectors. A few were self-employed. While some had been in the same job for a number of years, others had changed jobs recently or had been unemployed for periods of time.

Several participants indicated that they had recently been laid off from career positions during the recession and while many had found new jobs, their new positions did not pay as well or offer similar benefits. Many had not seen large pay increases in recent years and noted that while the news points to improvements in the economy that was not their experience. For example, one woman from Philadelphia commented that wages at her job had been stagnant for the past three years and after her husband was laid off five years ago, he has been working as a self-employed carpenter but had difficulty finding work. She felt like unemployment had gone down but most jobs were minimum wage and it was difficult to make a living. Cathy, a mother from Birmingham with children in CHIP, had taken an early retirement until her husband was disabled and required substantial care. She lost her savings during the recession, had to file bankruptcy, and had gone back to work.

As a result, many parents, particularly those with children covered by CHIP, indicated that they were living on tight budgets. While most parents said that they were managing, several explained that they needed to monitor their monthly expenses closely, could not afford much beyond the basics, and feared unexpected costs. For example, Jeff, in Chicago, who was a father of three young kids, said that even with his full-time job as an electrician, his financial situation changed monthly and some unexpected expenses like car repairs could change everything. Susan, from Philadelphia, explained that her income has stayed the same but insurance and other costs have increased, forcing her and her family to cut back expenses in other areas of their lives. Consequently, they worried about the cost of health coverage.

I listen to the TV and hear these stories about the unemployment has come down and everything. I believe that it has, but the jobs that are out there I think are minimum wage and maybe slightly better, and the benefits with them are next to nothing. Donna, Parent of a Child with Private Insurance (Philadelphia, PA)

With the economy getting better the cost of living is getting higher. It's costing more to buy gas and groceries and everything of that nature. Therefore, the little extra income that you would have to afford medical care that's kind of wiped out by some of the other things. Lakeisha, Parent of a Child with Private Insurance (Birmingham, AL)

I think the numbers don't lie. The economy is better but if the economy is set up to work for the wealthy, then it's working great for them. But it's not working great for everybody else. Scott, Parent of a Child with CHIP (Philadelphia, PA)

Many children were healthy, although some had on-going health needs. Most participants

described their children as overall very healthy. Several had asthma that required ongoing care and medication. Others had severe food or environmental allergies. A few had children with more serious conditions, including one mother in Birmingham with a child who needed multiple surgeries for a tumor on her ear that also caused hearing difficulties and a parent from Denver whose son had behavioral health needs. More commonly, parents described sports-related and other injuries, fevers, cough or flu. Some of these injuries or illnesses resulted in a trip to urgent care or to the emergency room. Many parents also had children with glasses or who had dental needs, including cavities and a need for braces.

My kid has food allergies. Besides that I haven't dealt with broken bones yet, I'm surprised...I guess just having that safety net knowing that I have coverage and they know that they can be taken care of ... I don't know, it makes me feel better. Scott, Parent of a Child with Private Coverage (Philadelphia, PA)

Ours was behavioral health. Ashley, Parent of a Child with CHIP (Denver, CO)

My two-year-old has a defective heart valve. That could cause complications later...We have to get it checked every year just to make sure that it's functioning properly. Michelle, Parent of a Child with Private Insurance (Birmingham, AL)

WHAT DO PARENTS VALUE IN HEALTH COVERAGE FOR THEIR CHILDREN?

Parents of children in both CHIP and private coverage valued similar features in health coverage for their children, including broad benefits and low costs. When looking for health coverage for their children, they wanted the security of knowing that the services that their children would need would be covered and that they would be able to access benefits with little hassle. In particular, they indicated a desire to be able to see their child's preferred physician and hospital, visit emergency rooms, have coverage for prescriptions and a wide array of specialty services, including dental and vision care. Some parents also stressed the need to be sure that if their children were sick or injured, they would be able to access all the services they needed at a reasonable cost, without worrying about whether services were in or out of network or that they would receive bills they would not be able to pay. Services parents valued most for their children were similar to those they looked for in their own coverage, though most parents indicated that it was much more important to have comprehensive coverage for their children. A few parents, particularly of children in CHIP also expressed concern about ensuring that their older children would have a source of continuous coverage after age 18, when they were in college or living on their own.

It should be good quality and the price should be affordable. Olga, Parent of a Child with Private Insurance (Denver, CO)

Just good coverage that covers stuff. Tests, stuff to check on them, how their health is. It's very important. Male, Parent of a Child with Private Insurance (Chicago, IL)

That you're able to choose your own doctor or dentist. Howard, Parent of a Child with Private Insurance (Chicago, IL)

With my daughter being 18, I'm concerned about what we're going to do next year. She won't be eligible for All Kids any more. I will have to go to the Marketplace to find insurance for her. Now, my employer offers family coverage but in all honesty, it's too expensive for me to afford because it's around 450 dollars a month for family coverage as opposed to maybe \$25 per pay period for myself. That's one of my concerns. Erica, Parent of a Child with CHIP (Birmingham, AL)

DO PARENTS THINK THAT INSURANCE COVERAGE FOR CHILDREN IS AFFORDABLE?

Most thought the costs of private coverage for families were too high. While nearly all families valued the benefits and coverage provided to their children, many worried about the costs. Those with employer coverage (ESI) thought that the costs were high and most felt like there were multiple costs for insurance. Those with ESI noted that the premium amounts come directly out of their paychecks, so they were not making direct premium contributions. However, most also had other out of pocket expenses including deductibles, copayments and coinsurance. A number of parents with ESI had a choice of paying lower premiums with higher deductibles or a plan with higher premiums and lower deductibles. Some cited plans with very high deductibles (up to \$10,000). In addition to high costs, some noted that the costs of ESI were increasing and to mitigate costs parents had to choose the plan with the higher deductible or move from a PPO to an HMO with less choice in providers. Some who had their children on private coverage had switched them to CHIP because they could no longer afford the costs.

Parents were somewhat mixed on the costs of coverage through the Marketplace. Some thought Marketplace coverage was affordable, others thought it was expensive. Similar to employer coverage, parents with Marketplace coverage often were making choices and trade-offs between premiums and other out-of-pocket expenses. A few with Marketplace coverage also noted recent increases in premiums.

Those with private coverage for their children also complained about the lack of predictability and difficulty managing costs associated with their children's coverage. In addition to high premiums and deductibles, many said they received bills for portions of service that might not be covered in network. Unexpected medical costs would have severe financial implications. Some said costs were not always clear – especially if the plan only covered a percentage of the costs. For example, costs were very unpredictable if the plan covered 80% of the costs of a service. An MRI that costs thousands and is covered by private insurance could still result in substantial out of pocket expenses for the family. A small number of participants with Marketplace coverage noted that the increases in costs for services were also not predictable.

Most families with children in CHIP valued the affordability of coverage. Families noted that the premiums, fees or copayments were affordable and most services were covered and paid for. Families generally knew if they had a single enrollment fee (CO) or co-pays, premiums, etc. Most noted that the costs were generally predictable. When asked what they liked most about their children's CHIP coverage, many indicated that the affordability, as well as coverage, was a significant benefit.

Issues Around Affordability

Private (ESI or Marketplace) Coverage

Our plans have gone from just a simple copay with deductible to the higher copays and the higher deductible. From 20-percent to 30-percent on other procedures, that we pay out-of-pocket. Even if it's a \$10,000 dollar procedure, you still pay 30-percent of that. ... Quite a lot of our salary goes into insurance. Gwen, Denver, CO

For me, I wouldn't say that it was affordable. What I would say is I have learned how to work it in. You don't plan on having kids. They come. You work them in the budget, so that is how that worked. Rotanda, Los Angeles, CA

When I had my third kid, it just skyrocketed. The cost of it was just absolutely atrocious. My employer's plan was taking so much money out of my paycheck, I barely had a paycheck. Jeff, Chicago, IL

I feel like collectively we make it happen but we're riding it out. To me it's just a responsibility I have. If it wasn't affordable or if it is I'm still going to do it somehow, someway. It's not something like, no thank you. Habib, Philadelphia, PA

We had a really significant increase [on the Marketplace] and I don't know why. I didn't change anything. Susan, Philadelphia, PA

The price went up and we got a little bit less...You're just paying this thousands, and thousands of dollars and you're thinking, well, is anybody going to get sick so we can use some of it. I want to get some of it back. Mark, Philadelphia, PA

I [had] more money in my pocket on kidcare – only \$20 premium.....[there is] nothing better about employer coverage, it is just more expensive to have private coverage" Collette, Tampa, FL I would say, with the regular insurance you're looking at a copayment of 30 dollars versus 13 dollars. Yes, it does make a difference, especially if you've got three doctors with two kids, which I've done in the past. In a week, it makes a significant difference. Kathy, Birmingham, AL

CHIP Coverage

When I first got the job that I work at now, I did some math to determine would it make more sense to just do the family plan at work or to do the individual plus the All Kids premium? I saved like 150 bucks. Shamiqua, Chicago, IL

Yeah. My wife's insurance is a \$3,000 deductible so by the time they get that, I mean, you could be paying full prices for the kids. That's why we picked up All Kids Insurance. Art, Chicago, IL

The number of follow ups specialist visits that I had when my son broke his thumb, that would have devastated my family. I couldn't imagine the kid going, paying a percentage of the visits in addition to the out-of-pocket costs. There's no way. Brenda, Denver, CO

When they transferred her from the ER to [Children's Hospital], not once did I have to worry about the insurance part because of her CHIP That was a comfort to me because I know she was there for the eight Mondays in ICU. Diana, Philadelphia, PA

My son, he's getting intensive care, intubated with his asthma weeks and weeks. I never had any problem with the bill or anything. Diane, Philadelphia, PA

ARE PARENTS SATISFIED WITH BENEFITS AND ACCESS TO CARE FOR THEIR CHILDREN?

Parents reported they were satisfied with the benefits for their children in both private and CHIP coverage. Parents felt that their coverage (private and CHIP) fit their children's health needs. In particular, parents of both sets of children liked that a comprehensive array of services were covered, including wellness visits, prescriptions, and emergency care were, and that their children could visit their choice of providers. Parents of children in both CHIP and private coverage used their health coverage for well-child visits, including annual checkups, sports physicals, and other routine services. Several also used their providers for specialty services, including allergists, chiropractors, mental health specialists, dermatologists, oncologists, etc. In all states, families with children in CHIP noted that they could obtain prescription drugs and care from primary doctors and specialists for low or no copayments. Families enrolled in CHIP indicated that they were also using mental and behavioral health services, including therapy, medication. For example, Ashley in Denver, whose son had ADHD was able to have weekly able to obtain weekly therapy sessions.

Most parents said they had a primary care doctor whom their children used for ongoing care in private and CHIP coverage. Many chose their children's primary care doctor, and as noted, they selected their plan to ensure that their children's providers were covered. Others were assigned a provider, but were able to change. Most indicated that they visited their primary care physicians when their children were sick or injured. Others used urgent care settings.

Across CHIP and private coverage, most children were able to access care, but both groups mentioned problems finding specialists. A majority of participants with children in both CHIP and private coverage indicated that they had no problem finding primary care physicians for their children and rarely encountered long wait times. Most also indicated that they were able to access services from specialists. However, participants in both groups indicated some trouble finding convenient locations for or getting timely appointments. For example, a woman with private coverage in Tampa said it was very difficult to find a psychiatrist for her 12 year old. If she could fine one, the location was not convenient or it was hard to get an appointment. Some with CHIP mentioned having to wait for an appointment with a specialist. For example, one parent said that she needed to wait 3 months to see a dermatologist. Problems accessing specialists are often related to supply and can have implications for those with both public and private coverage.

Parents also indicated that they had obtained dental and vision care for their children in CHIP or through private coverage. Parents with children in private coverage and those with children in CHIP highly valued dental and vision benefits. Children in CHIP had access to vision and dental services. Most parents in our focus groups also reported that children with private coverage had access to dental and vision services; however, in a number of cases, these benefits were covered under separate plans. While both children with CHIP and private coverage had access to dental benefits, the out of pocket expenses for these services was lower for children with CHIP coverage. In both CHIP and private coverage, parents noted that often there were caps or limits on coverage for dental or vision (i.e. one pair of glasses per year or a set dollar limit for dental expenses) and costly orthodontia care was generally not covered.

ARE PARENTS' SATISFIED WITH THEIR OWN HEALTH COVERAGE?

Many parents were satisfied with the benefits provided by their own private health insurance. All parents in the groups were enrolled in private health insurance through their employer or through the Marketplace. They believed that most services they would need were covered, although some did not have vision or dental coverage, and did not purchase those benefits separately. While some of the parents complained about limited plan choices, particularly among those offered through their employers, many indicated that they had chosen a plan that could meet their needs, and had a broad network of providers.

However, parents were anxious about the high costs of their coverage and said they frequently avoided seeking care for themselves. Many parents in the groups complained about the high costs of coverage including premiums as well as out of pocket expenses such as deductibles, copayments and coinsurance. Some participants cited deductibles as high as \$10,000. Many parents in the study said that they would never delay care for their children, but they often delayed care for themselves due to cost. High deductibles as well as copayments of \$30 to \$40 for a doctor visit and unpredictable levels of coinsurance were all cited as barriers to accessing care. A number of parents relied on home remedies for their ailments because of the cost of obtaining care. In addition, while all parents in this study had coverage, many parents indicated that they had experienced periods when they were uninsured in recent years. They lost coverage as they moved between jobs or could not afford to pay their employers' premiums and therefore chose not to enroll.

I mean, we definitely put the wants on the back burner. Just from a medical standpoint, because I need to go to the eye doctor. I can't see at all. I'm not going to the eye doctor because I would rather my kid go to the doctor when they're sick.-Phoebe, Parent of a Child with CHIP (Birmingham, AL)

Oh yeah. That's one of my sacrifices because ... Even if though my health and my health is important but I have opted for other healthier things for my lifestyle to off-set the cost of having to taking their medication. Lataya, Parent of Children with CHIP (Tampa, FL)

Parents of children with CHIP thought their private coverage might be adequate for their children's needs but that the additional costs of putting their children on their coverage would be too much. Those with insurance through their employers indicated that they had not added their children to their coverage either because it was not available or because it would be too expensive. One woman said that while the benefits would be available, she would never be able to take her child to the doctor because the copayments were prohibitive.

WHAT WAS THE EXPERIENCE FOR CHILDREN IN CALIFORNIA WHO TRANSITIONED FROM CHIP TO MEDICAID?

Parents in California were generally happy with coverage when children were transitioned from Healthy Families (CHIP) to Medi-Cal (Medicaid). California began transitioning children from the Healthy Families Program (HFP) to Medi-Cal in January 2013. Throughout 2013, the state transitioned approximately 875,000 HFP enrollees. Most parents said that the benefits were comparable, they were able to maintain the same doctors and that costs were better. Some families with incomes above 150% FPL are still required to pay premiums, but participants in the focus groups noted that their premium and copayment amounts were reduced.

Most families in this study had no issues with the transition from CHIP to Medicaid; however, some families had temporary gaps in coverage. Families were notified about the transition via mail. While coverage was supposed to be transitioned without gaps in service, parents still needed to continue to pay premiums and respond to the annual eligibility review notice. While most families in this study managed the transition well, a few families had gaps in coverage. It is unclear if the gaps were related to the transition from CHIP to Medicaid or if there were other issues with renewal. Some families may not have received or responded to renewal notifications on time. Some noted that in-person or onsite enrollment helped parents maintain or reinstate coverage. One family said they were informed that their coverage was not current when they went to the doctor and then re-enrolled in Medi-Cal at that point.

Policy Discussion

HOW DO PARENTS FEEL ABOUT HAVING THEIR CHILDREN IN THEIR OWN HEALTH PLAN?

Parents enrolled in family plans with their children said it was easier to manage one plan, but almost all said they would be willing to have their children in a different plan for lower costs.

Nearly all of the participants with children enrolled in private health insurance through an employer or the Marketplace had children enrolled with them in the same plan. When asked whether they liked being covered under the same policy, most indicated that they did. They cited the convenience of having one set of benefits to manage, of being able to obtain care from the same family practitioners within the same network, and being able call a single number for customer services or assistance with claims for the entire family. However, for most families, the providers used by their children (pediatricians and other specialists) were not the same as those used by the parents. In addition, nearly all of the participants also indicated that they found their plans to be very expensive and would be willing to have their children in separate coverage if it meant they would have lower costs and could maintain similar benefits and providers. A number of parents said that they would gladly put up with a few headaches or hassle of dealing with separate plans for their children to save money.

In contrast, most of those with children in CHIP noted lower costs far outweighed any issues with having children in separate plans. Most parents with children in CHIP indicated that they had few difficulties managing their children's coverage separately from their own, and several indicated that they found CHIP coverage to be much less complex and burdensome than their own private plans because there were fewer bills to track compared to private coverage. In fact, one participant in each CHIP group noted that they would rather be in CHIP than have their children move to their private coverage.

I'll go through forms and forms just to save 10 bucks. - Ashley, Parent of Child with Private Coverage (Denver, CO)

If we could be on CHIP would be great. Scott, Parent of Child with CHIP (Philadelphia, PA)

It's not difficult for me to manage the two only because All Kids is so easy to me. I mean, I feel like everything ... I feel like everything that my kids need is covered. My insurance gets a little complicated. I'm on the phone with them a lot. If All Kids

was a plan like that, then it'd be difficult to keep up with both, but it's pretty easy. I feel like I mostly just deal with my own. - Candice (Chicago, IL)

HOW DID PARENTS FEEL ABOUT THE CHIP REAUTHORIZATION DEBATE?

At the time that these groups were conducted, Congress was debating the future of funding for CHIP. Parents of children in both CHIP and on private health insurance were told about the CHIP reauthorization discussion occurring in Congress this year and asked to share what they knew and their perspectives on the program. Parents of children currently enrolled in CHIP were then asked to comment on what they would do for coverage for their children if the program no longer existed.

Most parents were not aware of CHIP policy discussions in Congress. Across all study sites, few parents had heard about the CHIP reauthorization debate. They asked if the debate was part of ongoing discussions around the Affordable Care Act, whether the changes would also apply to Medicaid, and whether CHIP programs in states other than their own were also part of the discussion. Several participants did not realize that CHIP was a national program, particularly in the states where CHIP was called by a state-specific name, like ALL Kids.

Many parents with children currently enrolled in CHIP were worried about the possibility of losing their children's coverage and having to pay more for insurance. Most of these parents were very satisfied with CHIP's benefits, services, and affordability, and felt that it provided financial security, and wanted to maintain those benefits. Several parents asked whether there were actions they could take to help keep their programs running.

For me, personally, just to be quite honest, it would be a financial disaster. ... Chances are real good I would be looking for a good bankruptcy attorney. Greg, Parent of a Child with CHIP (Birmingham, AL)

In all honesty, with my daughter, we may have to take that penalty. It'll be cheaper to take that penalty once a year, which will be about 95 dollars or however much it is, rather than for me to pay 400 dollars a month. Kim, Parent of a Child with CHIP (Birmingham, AL)

I think a lot of people just wouldn't have coverage for the kids. I can't say that for myself because I have to weigh everything out and see what we would give up. I'm sure so many people couldn't afford it. People will be taking their kids to the emergency room and not be covered by insurance and it just raises costs for everyone. It will create the exact opposite of what they're trying to do. Lisa, Parent of a Child with CHIP (Philadelphia, PA)

While most parents said they would try to enroll their children on their own plans if CHIP ended, they indicated that doing so would have serious negative financial consequences for their families. A majority of parents with children currently enrolled in CHIP indicated that they felt it was important to keep their kids insured, even if the program ended, and would search for coverage on the Marketplace or add their children to their own plans if they had to. However, many parents expressed concerns about the high cost of adding their children to their plans. In particular, they worried about having to pay higher premiums and copayments for every visit, and about the deductibles. Parents worried that these additional out of pocket costs would mean they would potentially delay or go without services for their children. They also indicated additional expenses for their children's insurance would cause substantial stress force them to sacrifice in other ways by cutting back on food, clothing, and family entertainment, taking their children out of sports and other activities, or working additional jobs, which would take them away from their children more often.

I would try with one of those health clinics and hope that he doesn't get sick ... I mean really bad that I need to go to an emergency room. It's going to be too high to put him on my plan. I just can't afford it. Female, Parent of a Child with CHIP (Tampa, FL)

Most parents of children in CHIP also indicated that they would be willing to enroll their children in Medicaid if they were eligible. This is particularly true among parents who had previous experience with Medicaid for their children and felt that the coverage was affordable and benefit and services would meet their children's needs and were equivalent or better than CHIP. A number mentioned they had Medicaid coverage when they were pregnant or that kids were covered by Medicaid when the parents were unemployed or laid-off from a job. Some that had previously been covered by Medicaid preferred Medicaid to CHIP coverage. A few mentioned lower costs and fewer limits on Medicaid compared to CHIP (i.e. no premiums and no limits on eye glasses for children). A smaller number of parents had negative impressions of Medicaid, including a belief that it did not provide benefits that were as comprehensive as those in CHIP or that they would not have as broad a network of providers.

I would push as hard as I could to get back in Medicaid. ... I would do that before my job. Christine, Parent of a Child with CHIP (Tampa, FL)

Many parents with children in private coverage were also concerned about the CHIP program ending. Nearly all parents with children currently enrolled in private insurance said that they would try to enroll their children in CHIP if they lost their employer or Marketplace coverage. Many said that they felt their financial situation was precarious and appreciated that CHIP existed as a safety net coverage option for their children if they lost their current coverage. For example, Lakeisha, a mother from Chicago with children enrolled on her employer plan indicated that she appreciated the security of knowing that CHIP was there to provide a backup coverage option for her child if her employer coverage were not available. Her son needs medications to manage his asthma. A few parents also expressed that they did not think it was a good idea to have children uncovered and believed that if the program ended, low-income families may not be able to obtain other coverage, and their children would become uninsured. In addition, parents thought it was not fair to take away CHIP coverage and then have lower income families subject to the penalty for not having insurance. Most parents with private coverage said they would enroll their children in Medicaid if they were eligible.

I think they shouldn't discontinue it. I think everybody's here, probably, just blessed to have really great insurance with great jobs. What about those who don't have? What are you going to do with them? I just feel for them. Lakeisha, Parent of a Child with Private Insurance (Birmingham, AL)

Definitely. Because I took advantage of it at a time where we needed it. It was like I said, for preventive care, it's awesome. It's just those outside circumstances that didn't. I think something should be there....I'm grateful that I am employed to where I can have insurance. I think something needs to be there. There are a lot of people that fall in that

place where you need something to cover you until you can get back to where you're able to have your private insurance. Phoebe, Parent of a Child with Private Insurance (Birmingham, AL)

I need a backup plan if I ever lose my job I need to know there's something out there. Diane, Parent of a Child with Private Insurance (Birmingham, AL)

For me, to take away a program that is helping people and then on top of that, you're taking away a program that's helping with insurance and then you're going to charge because the child doesn't have insurance when obviously the parent is not able to afford it because they haven't enrolled in this program, it's like you're hitting the person when they're down twice. Tiffany, Parent of a Child with Private Insurance (Tampa, FL)

Most parents said they would want to learn about changes to CHIP through multiple avenues, especially mail. Participants stressed the need to learn about future changes to their children's coverage as early as possible and through multiple means, including by mail, online, through the media, from providers and schools, and especially mail. Many stressed that they did not always trust television for information about health coverage and explained that they would want something in writing, with information for a website and phone number where people could call to have further questions answered. The need for multiple avenues to learn about changes in coverage was highlighted by parents in California experienced gaps in coverage because they did not receive or respond to renewal notifications.

Conclusion

The passage of the Affordable Care Act (ACA) as well as debate about extending funding for CHIP has meant that policy makers are considering options for the future of children's coverage. Congress has extended funding for CHIP for two years (through 2017), but longer-term there will be additional debate about how best to ensure coverage to children in low and moderate income families. Specifically, how would private coverage (either employer sponsored coverage or Marketplace) or Medicaid work for children who currently are enrolled in CHIP?

This study examined what parent's value in children's coverage. Affordability was a primary concern often followed by broad coverage. Most thought the costs of private coverage were too high and often unpredictable and that CHIP was affordable. Across private and CHIP coverage, families valued comprehensive benefits (including dental and vision coverage) and were generally satisfied with providers available through their coverage. When asked about their own private coverage, parents reported that the cost of coverage was high and they frequently delayed or avoided seeking care for themselves because of costs. In addition, parents often reported gaps in coverage and periods of being uninsured when they were in between jobs. Coverage under the same plan with their children was not a priority for parents. Parents with children in private coverage were willing to have children in a separate plan if it would lower the costs they faced. Parents with children in CHIP did not want children in their private coverage (generally due to costs). Nearly all parents with children enrolled in CHIP and private coverage said that they would enroll their children in Medicaid if their current coverage were no longer available and they were eligible. While funding for CHIP was extended for two years, these issues, particularly about affordability, are key in thinking about the longer term priorities for children's coverage.

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Endnotes

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¹ Vernon Smith, Laura Snyder, Robin Rudowitz, *CHIP Enrollment Snapshot: December 2013*. (Washington, DC: Health Management Associates and Kaiser Family Foundation,) January 2014. <u>http://kff.org/medicaid/issue-brief/chip-enrollment-snapshot-december-2013/</u>

² Vernon Smith, Laura Snyder, Robin Rudowitz, *CHIP Enrollment Snapshot: December 2013*. (Washington, DC: Health Management Associates and Kaiser Family Foundation,) January 2014. <u>http://kff.org/medicaid/issue-brief/chip-enrollment-snapshot-december-2013/</u>