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Living Without KidsCare

Insights from Parents of Children Who Lost Their Health Coverage When Arizona Scaled Back Its Children's Health Insurance Program

Fourteen thousand children in Arizona lost their health insurance at the end of January 2014 when the state ended its KidsCare program for low-income children. This made Arizona the only state in the country without an active Children's Health Insurance Program (CHIP). As many as 37,000 children were enrolled in KidsCare at the time the program ended. About 23,000 of those children were transferred to Arizona's Medicaid program (the Arizona Health Care Cost Containment System or AHCCCS). The remaining 14,000 children lost their health coverage.¹ These families were sent notices referring them to the new federal health insurance marketplace created by the Affordable Care Act where some of them could potentially purchase health insurance.

There is no current information about how many of these 14,000 children have obtained health insurance since KidsCare ended. This study does not substitute for the need to gain a more detailed look at what happened to the 14,000 children who were referred to possible marketplace coverage. Rather, it is intended to shed light on the experiences of these and other children previously covered by KidsCare when the program ended.

¹ T. Brooks, M. Heberlein, & J. Fu, "Dismantling CHIP in Arizona: How Losing KidsCare Impacts a Child's Health Care Costs," Georgetown University Center for Children and Families and Children's Action Alliance (May 2014), available at <http://ccf.georgetown.edu/wp-content/uploads/2014/05/Dismantling-CHIP-in-Arizona.pdf>.

About the Study

Georgetown University's Center for Children and Families sponsored two focus groups and three interviews with Arizona parents, most of whom had children enrolled in KidsCare within the past year. PerryUndem Research and Communication conducted the focus groups and interviews. Joseph Fu, Director of Health Policy at Children's Action Alliance, a children's advocacy organization in Arizona, helped identify and recruit families who had lost coverage.

The focus groups were held in Phoenix in October 2014. One group was conducted in Spanish with five Spanish-speaking Latino parents; the other group was held with five English-speaking parents of mixed racial and ethnic backgrounds. The three additional interviews were conducted in November. Eight of the thirteen families had children enrolled in KidsCare when it ended January 31st, 2014 while the others had lost KidsCare coverage before that time.

The families in this study represent an array of post-KidsCare health coverage situations. Ten of the parents have children who are currently enrolled in AHCCCS. However, two of these parents only enrolled in AHCCCS after months of having no health insurance for their children. Another parent had initially enrolled in a marketplace plan, found it too expensive, and subsequently dropped the plan and successfully enrolled her child in AHCCCS.

The remaining three parents have children who could not qualify for AHCCCS when their KidsCare coverage ended. As a result, two currently have uninsured children and one enrolled her child in her employer plan.

Research is still needed for a more complete understanding of what happened to the 14,000 children who lost KidsCare. A comprehensive survey of these families would be necessary to paint a full picture of whether children were able to access marketplace coverage and how their experience in new plans compares with KidsCare. This study, however, does help to better understand what the loss of KidsCare has meant for families whose children benefited from its coverage.

Background

Low-income children in Arizona have faced challenges obtaining and keeping affordable health coverage for many years. In 2013, the last year data is available, nearly 191,760 children in Arizona lacked health insurance, which amounts to 11.9 percent of the state's children (only Texas and Nevada had higher rates).²

Arizona's rate of uninsured children has fluctuated along with KidsCare policy changes. While the rate of uninsured children has significantly decreased since 2008 in Arizona, it actually increased between 2009 and 2012. A main reason is that KidsCare, Arizona's version of the Children's Health Insurance Program (CHIP), froze enrollment in December 2009 as part of the state's widespread budget cuts in response to the economic downturn.³ Children who would otherwise be eligible for the program were put on waiting lists instead of being enrolled.

KidsCare II began in May 2012 as a time-limited alternative program for some children up to 175 percent of the Federal Poverty Level (FPL). The eligibility level was increased to 200 percent FPL in 2013. Federal authority for the program ended December 31, 2013 but an extension was granted until January 31, 2014. About 23,000 children families with incomes between 100 to 138 percent FPL were sent notices and were transitioned to Medicaid effective January 1, 2014. Another 14,000 children in families over 138 percent FPL were notified that they would need to apply for private coverage.

Families of those 14,000 children were able to shop for replacement health insurance on the federal marketplace under the Affordable Care Act. But the plans available through the marketplace generally cost more than KidsCare and tend not to cover as many health services. A recent study conducted by

² J. Alker & A. Chester, "Children's Coverage at a Crossroads: Progress Slows," Center for Children and Families (November 2014), available at <http://ccf.georgetown.edu/ccf-resources/childrens-coverage-crossroads-progress-slows/>

³ M. Heberlein, J. Guyer, & C. Hope, "The Arizona KidsCare CHIP Enrollment Freeze: How Has it Impacted Enrollment and Families?" Kaiser Commission on Medicaid and the Uninsured and Georgetown University Center for Children and Families (September 2011), available at <http://ccf.georgetown.edu/ccf-resources/1403/?issue=chip%2F>

Georgetown University's Center for Children and Families and Children's Action Alliance found that health care costs for kids would increase between two and eight times on marketplace plans compared to KidsCare, even with available tax credits to help purchase coverage.⁴ Some of these families may be locked out of tax credits to help pay for their children's marketplace coverage, due to the "family glitch," which bases affordability of available employer-sponsored insurance only on the cost of individual coverage rather than family coverage. Some experts worry that the additional costs of the marketplace plans discouraged many parents from enrolling and that a number of the 14,000 children have remained uninsured since KidsCare ended.

Key Findings

Following are highlights from the two focus groups and three interviews with parents whose children lost KidsCare.

- **All parents in this study were highly satisfied with KidsCare.** They appreciated their easy access to doctors, specialists, medications, surgical procedures, and the benefits available to their children. Most felt the costs with KidsCare were reasonable and affordable.
- **Parents were frustrated by the frequent changes to KidsCare.** They felt the program had undergone many changes in recent years that made it difficult to keep their children enrolled. For example, some children were moved between KidsCare and AHCCCS as eligibility rules changed. Other children temporarily lost coverage during these changes and were uninsured – and could not be re-enrolled due to caps on KidsCare enrollment. These changes led to disruptions in care for their children and periods of being uninsured. This frustrated parents.
- **They were unprepared for the end of KidsCare.** Most of these parents wanted to keep their children enrolled. Most felt the state did not effectively communicate to them why their coverage was ending and what their options would be for affordable coverage. Some recalled receiving notifications in the mail but other parents say they did not receive any notifications. None seemed prepared for KidsCare to end.

⁴ *Op. cit.* (1).

- **When KidsCare ended, many parents floundered.** Some children were transferred directly into the AHCCCS program without any gaps in coverage but others were not so lucky. These children became uninsured on February 1, 2014 and their parents had to scramble. Most applied for AHCCCS coverage in the hopes their children would qualify. Parents looked into the marketplace plans and their employer's plan but most found these options too expensive. Four of the children were uninsured for at least some time period after their KidsCare ended and two have remained uninsured as their parents continue to search for affordable coverage.
- **There were disruptions in care for many children.** When KidsCare ended, some of the children went without needed health services and medications for at least a short time period. In one case, a child with Lupus and heart and respiratory ailments was hospitalized because her family could not afford the doctor visits and medications she required. Other children did without medications for their asthma or ADHD. A parent that could no longer afford ADHD medication saw behavior changes in her daughter that have, among other big challenges, made school more difficult. The end of KidsCare adversely affected the health of some children who could no longer obtain the same services and care they had received while enrolled in the program.
- **Parents who were able to enroll their children in AHCCCS seem most satisfied.** Many were able to keep their children's same health providers, which was important to them. Most also see the coverage as comparable to KidsCare and all appreciate that the costs are lower with AHCCCS. The big worry for these parents is keeping their children enrolled in AHCCCS – they are anxious that changes in their income or rule changes with the program could cause their children to lose their coverage.
- **Parents with children who did not qualify for AHCCCS are under financial stress.** Two of these parents currently have uninsured children and are putting off healthcare services because they cannot afford them. The parent with employer-sponsored coverage says her plan costs too much, puts a strain on the family budget, and that she avoids taking her children to the doctor because the plan has a high deductible and she cannot afford to pay. These children are going without needed health services.

- **All want KidsCare to be reinstated.** They feel the program was affordable and offered high quality care for their children. They believe the program filled an important niche – it offered affordable health coverage to children in families who make slightly more than the AHCCCS income limit. Without KidsCare, some parents feel vulnerable and without a safety net for their children.

Detailed Findings

Parents were highly satisfied with KidsCare.

Parents in this study say they were pleased with the coverage, care, and costs of KidsCare. They liked their children's doctors, felt they had an array of providers to choose from, and believed the care their children received was of high quality. They also appreciated the breadth of coverage offered through KidsCare. "[KidsCare] took care of everything basically," explained one parent.

Most found the costs of KidsCare to be affordable – with a low monthly premium (often \$15-\$30 according to these parents). Some had shopped around for health insurance before and knew this was a good deal.

Parents who have children with chronic health conditions were particularly thankful for KidsCare.

These parents explained that their children were able to receive consistent treatment for conditions like asthma and mental health needs under the care of highly trained specialists. One Phoenix mother has a daughter with serious asthma and explained that her doctor's visits and prescriptions were expensive but with KidsCare, she was able to afford it. Another mother has a daughter with Lupus and heart and respiratory ailments; these conditions required weekly doctor visits and frequent stays in hospitals, all covered by KidsCare with little costs passed on to her.

While they valued the care, costs, and coverage of KidsCare, many parents were frustrated with policy changes to the program.

Some parents had experience with their children losing KidsCare in the past year and having to reapply. One or two whose children lost coverage during this time period could not immediately obtain coverage again because the

"[KidsCare] covered everything. I used to take my daughters to their appointments and I never really had a problem. I was really happy."

Latina, Spanish-Speaking Parent

state had put a cap on KidsCare’s enrollment. Some also explained that their children moved between KidsCare and AHCCCS, causing disruptions in care that they found frustrating and alarming. These parents were not always clear on why their children lost KidsCare or moved between the two programs but believe the state made changes to eligibility requirements and this caused the problems. They explained that the state had a history of tinkering with the KidsCare program, which made it hard for them to keep their children enrolled.

Many parents had heard KidsCare was ending but were nonetheless unprepared when it happened.

Some parents said they received a notification from KidsCare telling them the program was ending and explaining their options for health coverage for their children. Other parents do not recall receiving a notification.

Most say that no reason for ending the program was ever offered. Some assume the program was cut because of “politics” and to save the state money. One parent suggested the program was “too popular” and that too many families were enrolling their children in it. Others agreed this could be the case – that state politicians did not want so many people getting help through KidsCare.

Many feel disheartened the state would cut a health coverage program for children. “As a working American citizen who pays taxes, I feel that I should qualify for the service...I don’t feel that they should’ve taken it away from us that work hard and pay taxes,” said one mother. These parents take health coverage for their children very seriously – particularly those with children who have chronic health conditions. None wanted their children to become uninsured – even for a short period. These parents recall feeling stressed and worried about the future when KidsCare ended.

“I think it was just extremely irresponsible to take other people’s lives and use them as political pawns in a game because that’s essentially what happened.”

Father of Formerly Enrolled Child

Many parents floundered.

Even many parents who received notifications from the state had to scramble when KidsCare ended in January 2014. These notifications indicated if the child was to be transferred directly to the AHCCCS program or if the child was going to lose health coverage. Those families with children deemed ineligible for AHCCCS were directed to the health insurance marketplace to find affordable health coverage for their children.

Those who had children transferred directly into AHCCCS seemed to struggle the least during this period. While they worried they might lose their children's providers and that the coverage may be different, they were thankful to still have coverage for their children.

Five of the parents in the study say their children lost health coverage once KidsCare ended and that this was a tumultuous time. One went to the health insurance marketplace and enrolled in a health plan. Another enrolled in her employer's health plan. The three other parents applied for AHCCCS coverage for their children (one eventually enrolled).

"It was hard when [my children] were without health insurance."

Latina, Spanish-Speaking Parent

Some children went without needed care.

For some children who became uninsured when KidsCare ended, there were negative effects on their health. For example, a mother of a teenage daughter who has Lupus as well as heart and respiratory ailments explained that she had to cancel doctor appointments and could not fill prescriptions while her daughter was uninsured. She had applied for AHCCCS for her daughter when KidsCare ended (her daughter was not transferred automatically) and was denied. Over a period of five months, her daughter's condition worsened and she ended up in a hospital ER. Her daughter's hospital stay lasted many days and resulted in a large medical bill that she was unable to pay. Shortly thereafter, AHCCCS found a paperwork error with her

application and provided her with retroactive coverage for the previous three months.

Another mother explained that her daughter had to stop taking her ADHD medications when KidsCare ended. She said she just could not afford the medication without insurance. She applied to AHCCCS for her daughter but was denied. She also looked into her employer's plan but discovered it would cost her \$300 a month just for herself and \$650 if she added her children. These costs were too high for her to afford. Doing without the ADHD medication has negatively affected her daughter. Her daughter's behavior has changed and school has become more difficult. "It has affected everything," said the mother.

"[My employer's plan] would be another rent for me and I just can't afford it."

Mother of Formerly Enrolled Child

Parents who have children now enrolled in AHCCCS seem most content, although some have faced problems. Many parents say their children were able to keep the same doctors and other health providers when their children moved into the AHCCCS program. This was important to them. Many also found the coverage similar to KidsCare, which helped with the transition. Finally, all of the parents appreciate the lower costs of AHCCCS compared to KidsCare – they are finding the program more affordable. These are the positive aspects of the transition.

But a few have struggled. One parent experienced additional challenges accessing her son's mental health counselor and more difficulty accessing his medication after the transfer to AHCCCS (though based on policy these benefits do not appear to differ between programs). She feels her son was doing better with KidsCare coverage than he is with AHCCCS and worries his depression will worsen.

A few parents, particularly the Spanish-speaking Latinos, also had negative experiences with AHCCCS caseworkers that stayed with them. One participant also feels that the

program has a stigma and wishes her child was still enrolled in KidsCare, which she felt had no stigma.

Finally, a number of parents are worried about keeping their children enrolled in AHCCCS. They are anxious that their income will disqualify their children or that the state officials will tinker with the program like they did with KidsCare.

Two parents with uninsured children and one parent with employer coverage are struggling since KidsCare ended. All three say they put off medical care for their children to avoid costs they cannot afford. These parents say they looked for affordable coverage options but could not find any.

The parent with employer coverage says adding her children to her plan was expensive and that the premiums are hard to afford and these monthly costs are straining her family budget. She is not sure how long she can keep it. She says she avoids using her coverage because the deductible is so high.

At least one of the parents with uninsured children looked for a plan on the health insurance marketplace and found the plans to be too expensive. Both parents with uninsured children also applied for AHCCCS but were denied.

The parents with uninsured children are experiencing stress and anxiety. They fear something bad will happen to their children and often worry about the worst-case scenario. They fear a large medical bill they cannot afford. Their children are receiving no care currently. These parents feel vulnerable in a way they did not when KidsCare was in place. They will try applying to AHCCCS again and hope their children will finally qualify.

“There are clinics where you can apply for a discount. That will be the solution [when you don’t have insurance]. Having a child with asthma like me, I have to have insurance.”

Latina, Spanish-Speaking Mother

In the meantime, these parents are trying to find workarounds for their children's health care. They know of low-cost health clinics that they plan to use if their child is sick or needs medications.

All parents wish their children were still enrolled in KidsCare.

Even those parents with children enrolled in AHCCCS feel this way. They found the program to be a good balance between high quality care and affordable costs. While they did not like some aspects of program administration – notably frequent rule changes and poor communication – they were happy with the care and their children's doctors.

Also, a few parents felt KidsCare did not suffer from the same stigma as AHCCCS – they felt more comfortable with their children participating in a program they paid for.

Some also felt KidsCare offered an important safety net for children in families that earned slightly too much to qualify for AHCCCS. They feel there is no affordable option now if their children do not qualify for AHCCCS.

Conclusion

While this study is based on the experiences of 13 families, it gives insight into the kinds of challenges that other families likely faced as their children lost health coverage when KidsCare sunset in January 2014. Several common themes emerged from conversations with these parents and caretakers.

Families needed better communication about the ending of KidsCare and information about affordable health coverage options. This includes more advance notice so families could plan ahead, and improved assistance in helping families find alternative coverage for their children.

“KidsCare used to be the option before if [my child] did not qualify for AHCCCS. But now what?”

Mother of Formerly Enrolled Child

Families whose children do not qualify for AHCCCS face financial constraints finding affordable health care.

What also emerged is a realistic picture of the financial constraints many of these families face. If their children could not qualify for AHCCCS, parents found their other health coverage options to be too expensive. Those who tried to stretch to afford coverage ended up struggling – one dropped her marketplace plan and another is contemplating dropping her employer’s plan because of the high premiums and large deductibles. The costs of KidsCare were affordable for these families – private insurance is not.

When children lose health coverage – even if only temporarily – it can have adverse effects on their health.

One child in this study was hospitalized. Two struggled with behavioral and mental health challenges when their care and medications ended or changed. One child with asthma went without needed medications and risked her health. How many of the 14,000 children who lost coverage have faced similar health challenges since the program ended? As programs change, helping families maintain coverage and health care for their children during the transition is critical to the child’s health and wellbeing.

The experiences of these families are relevant to other states as the expiration of CHIP funding draws closer. As the only state without an active CHIP program, Arizona’s experience can serve as a cautionary tale of what to expect if federal CHIP funding is not renewed in time for states to keep their programs running smoothly. This study raises important questions about what could happen to children and families nationwide if CHIP funding is not extended.