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NARRATIVE MATTERS

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To Cover Their Child, One Couple Navigates A Health Insurance Maze In Pennsylvania

Two graduate students fight the bureaucracy to gain coverage for their son under the Children's Health Insurance Program—and hope that provisions of the Affordable Care Act will cut the red tape.

BY ARI B. FRIEDMAN AND TARA MENDOLA

Our son, Erik, was born in Philadelphia in April 2012. Two days after his birth, we applied for coverage for him through the Pennsylvania Children's Health Insurance Program (CHIP), which covers children whose families do not qualify for Medicaid but cannot afford to buy health insurance. Under CHIP rules in our state, he should have been covered within four to six weeks. In fact it would be six months before he was covered. Changes coming under the Affordable Care Act are designed to make it easier for parents like us to navigate the CHIP and Medicaid programs, but it remains to be seen whether they will have the intended effect.

Both of us are graduate students living in Philadelphia, and our universities provide us with health insurance as part of our stipends. But adding a dependent to our coverage is prohibitively expensive—60 percent greater than even unsubsidized CHIP. So we applied for CHIP, grateful that it was one of the few entitlement programs still available to students.

CHIP is designed to cover families who fall in the gap between Medicaid and private coverage. As of March 2013 the program covered 187,755 children in Pennsylvania. In most states CHIP enrollment rules require all children to be uninsured—often called "going bare"—for six months before they are eligible for the program. In Pennsylvania, policy makers fought to exempt children under age two from the go-bare requirement, making them eligible from birth. With that in mind, we applied just days after Erik was born.

We first called Independence Blue Cross, one of several private insurers in Pennsylvania that use state and federal CHIP funds to cover eligible children. The private insurer referred us to the state Medicaid program, explaining that Medicaid had to reject our application and forward it to CHIP.

After we applied for Medicaid through the state's online system, we called our Medicaid district office to check on the status of the application, only to learn that it had been lost. We were told to reapply. About a week later, we tried to check on our second application. Getting through was a challenge: The system would put us on hold and then cut us off after five to ten minutes. We tried calling the Pennsylvania CHIP office, finally reaching a representative after multiple dropped calls, but this person was unable to check the status of our application.

In late May, more than a month after our son was born, we received a letter indicating that Erik was not eligible for Medicaid, as anticipated. But the rejection letter made no mention of passing the application along to CHIP. After

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dozens of phone calls, we learned that our documentation had been lost in the Medicaid system for a second time and had not reached Independence Blue Cross. We were told to fax the documentation to Medicaid for a third time and request reconsideration—effectively resetting the clock and beginning the entire process anew. We never learned why the application hadn't been passed on originally, or why the only way to correct the problem was to start again.

Mounting Expenses

By this point Erik was forty-four days old. Our own insurance provided partial coverage for only his first thirty days. Unwilling to go without some form of insurance, we bought catastrophic coverage for Erik for $90 per month with a $2,500 deductible and a $5,000 out-of-pocket maximum. Our expenses began to pile up: $600 from the hospital for the delivery, $500 in well-baby visits and vaccinations, and $400 for a minor surgical procedure, all of which we paid out of pocket. These were all relatively routine expenses for a healthy, full-term baby; had Erik been premature or sick in any way, the cost would have been much higher. We were lucky. Angry, discouraged, and scared, but lucky.

Our next step was to call the district Medicaid office again and ask to speak with Erik's case worker. We were told that she had up to forty-eight hours to return our call, and that the reconsideration of our application would be complete by the end of the week. The call was never returned. We called again and asked to speak to an office manager. Again we were told that someone would call back within two days. No one did.

In early July we received a second rejection letter from the district Medicaid office, which did not indicate whether our file had been forwarded to Independence Blue Cross. A state Medicaid representative told us that our file had been flagged with the rejection code "69." She noted that this was odd, as that code did not exist in Medicaid's internal regulations. Concerned about our situation, she sent a ticket to the district office giving them three working days to resolve the case.

Three days passed. Then seven. More calls. No results.

A Chance Encounter

With Erik nearly ninety days old and still without CHIP, we tried to visit the county Medicaid office, which supervises the district offices. When we went to the address listed on the state website at the time, however, we found only a demolished building. After finding the correct address, we met a caseworker for another district in the elevator who pointed us toward the city's Office of Community Services, which assists residents with questions about city services. Because the district Medicaid office was run by the city, she explained, the community services office could help us.

When we got there, the guard at the front door tried to turn us away, stating that the office was for rental assistance only, but we asked to speak with someone anyway. The employee who finally met with us flagged Erik's file and promised to make it her business to see that things were finally resolved. The next day we received notice that Erik had been rejected for Medicaid again, but this time his file had finally been sent to Independence Blue Cross for CHIP consideration. If not for that chance meeting in the elevator, we might never have known on which office door to knock.

Nearly a month later an employee of Independence Blue Cross called to tell us that our application was stalled because the company didn't have a copy of Erik's Social Security card—although the district Medicaid office had insisted early on that a Social Security number wasn't necessary. Fortunately, we had recently received Erik's card in the mail, and we faxed a copy to the insurer the same day.

Erik's file was then sent to the Pennsylvania Insurance Department to verify that he was uninsured—the only apparent role that this department plays in CHIP enrollment, adding another player to an already complicated process.

Since we had purchased Erik's catastrophic insurance on a month-to-month basis, we asked Independence Blue Cross if we could continue to maintain his coverage until his CHIP insurance came through. We assumed that would not be a problem because Pennsylvania exempts infants from the go-bare requirement, but the representative believed that any insurance coverage would very likely jeopardize Erik's application. He told us that approval should take only a week longer and recommended that we let Erik be uninsured.

Reluctantly, we allowed the monthly coverage to lapse, praying that we were now past the worst delays and that nothing would happen to our son in the meantime. It felt as though the one concrete way we had to protect our son's health and our financial security was being taken away.

At the beginning of this process, we would not have worried too much about what was promised to be a brief period of uninsurance. Now we were afraid that it might be weeks or months before Erik eventually received CHIP. Believing that the system had failed, we sent letters explaining our situation to every local official who we thought might respond, including the mayor of Philadelphia, the governor of Pennsylvania, and our congresswoman.

We'd read somewhere that putting a face to our son's name would make him harder to ignore, so we took a picture of him lying on our green terrycloth bathmat and printed out a sheet of wallet-size photos, mailing one with each letter. Within a week a representative of the governor's office called us. She promised to do what she could. Although we were grateful for her kindness, the fact that we needed political intervention signaled that something in the system was profoundly broken.

Three days after the governor's office called, we received a letter from CHIP. It began, "You recently contacted Gover-

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Policy Checklist

The issue: Complex and fragmented enrollment procedures for Medicaid and the Children's Health Insurance Program (CHIP)—the two major public insurance programs for children—create significant obstacles to getting coverage. As a result, millions of children eligible for coverage are not enrolled.

National initiatives to improve Medicaid and CHIP enrollment procedures:

- Provisions in the 2009 Children's Health Insurance Program Reauthorization Act (CHIPRA): http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Childrens-Health-Insurance-Program-CHIP/CHIPRA.html
- Federal incentives to improve states' enrollment procedures: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Childrens-Health-Insurance-Program-CHIP/CHIPRA-Awards-and-Performance-Bonus.html
- Proposed single streamlined application: http://www.kff.org/medicaid/upload/8409.pdf
- Connecting Kids to Coverage Challenge: http://kidscoverage.challenge.gov/

Related reading:

Jennifer E. DeVoe, Carrie J. Tillotson, and Lorraine S. Wallace. "Insurance Coverage Gaps among US Children with Insured Parents: Are Middle Income Children More Likely to Have Longer Gaps?" Matern Child Health J. 2011;15(3): 342–51.

Martha Heberlein, Tricia Brooks, Joan Alker, Samantha Artiga, and Jessica Stephens. "Getting into Gear for 2014: Findings from a 50-State Survey of Eligibility, Enrollment, Renewal, and Cost-Sharing Policies In Medicaid And CHIP, 2012–2013." Washington (DC): Kaiser Commission on Medicaid and the Uninsured; 2013 Jan [cited 2013 Apr 1]. Available from: http://www.kff.org/medicaid/upload/8401.pdf.

Genevieve M. Kenney, Victoria Lynch, Michael Huntress, Jennifer M. Haley, and Nathaniel Anderson. "Medicaid/CHIP Participation among Children and Parents." Washington (DC): Urban Institute; 2012 Dec [cited 2013 Apr 1]. (Timely Analysis of Immediate Health Policy Issues). Available from: http://www.urban.org/UploadedPDF/412719-Medicaid-CHIP-Participation-Among-Children-and-Parents.pdf.

nor Corbett's office regarding your struggle in obtaining health care for your newborn son," and told us that the application process was finally complete. "Eric was found eligible for Full-Cost CHIP," the letter continued, misspelling our son's first name.

We went from exhausted relief to renewed anxiety in a matter of sentences—at $241 dollars a month, the premiums for full-cost CHIP were far more than we had expected, based on our income. We soon discovered that CHIP's representatives were basing their decision on a calculation error that tripled our reported income, and we were told to resubmit our most recent paystubs along with a request for reconsideration.

In the third week of August we were told that we were eligible for a subsidized rate of $30 per month. By that time CHIP enrollments for September were closed, so we waited one more month, officially enrolling Erik in October 2012.

He was six months old.

Looking Forward

In the final count—and, yes, we did count—obtaining coverage for Erik had taken eighty-six phone calls to the Medicaid district office, the state Medicaid office, the Blue Cross insurer, and the CHIP hotline. One call still stands out in both of our memories, nearly a year later. Erik was crying, and the woman on the other end of the line heard him and kept asking us if he was all right, if someone was with him, if he needed food.

At the time the questions seemed judgmental and intrusive, coming from someone who couldn't even tell us the status of Erik's application. In retrospect, we realize that she probably just wanted to help. Perhaps asking if the baby was all right was as much as she felt she could do. This woman's concern was typical of our experience as a whole: Throughout our months of waiting, no one was uncaring. But the system's inefficiency and lack of transparency stymied everyone's efforts to get us the service we needed.

Fortunately for parents who find themselves in our position, the system is poised for change. Under provisions of the Affordable Care Act, beginning in 2014 CHIP, Medicaid, and the new health insurance exchanges will be able to request application data directly from other government institutions, such as the Internal Revenue Service and Social Security Administration. These three groups will be required by law to share with each other the information needed for eligibility determinations. Assuming that the process unfolds as it should, this electronic transfer of information, coupled with the law's virtual elimination of paper income verification, should eliminate what turned out to produce the greatest delay in our application process: the repeated loss of our application forms within the Medicaid system.

In Pennsylvania, Medicaid determines parental income and eligibility, while private insurers administer CHIP's subsidized insurance. This disconnect has hamstrung CHIP in any effort to guide the process or even check application status. If CHIP were empowered to coordinate the process and provide up-to-date, accurate information to parents at each stage of that process, enrollment barriers could be reduced. The information sharing provisions of the Affordable Care Act will improve CHIP's access to that information, although ensuring that the program's representatives communicate with parents is another matter. It doesn't matter if the person on the other end of the line knows the status of your application if he or she doesn't pick up the phone.

To get Erik enrolled, our family needed greater transparency and integration between the CHIP and Medicaid application procedures, as well as accurate, community-level information and outreach to help new parents with enrollment procedures. For example, our pediatrician's office had CHIP fliers prominently displayed at the front desk, but nobody there knew much about how to navigate the system.

The Affordable Care Act will make hotlines and patient "navigators" available to help people understand their coverage options on the exchanges. These forms of assistance are promising, but

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CHIP already has a hotline in Pennsylvania. The problem is that it is difficult to reach anybody at that phone number or to get help in checking the status of an application.

In other words, the provisions of the Affordable Care Act sound great on paper, but additional incentives may be required to reduce wait times and improve customer service.

There is also a renewed focus on outreach in the health care law. It provides $40 million in federal funding to improve CHIP and Medicaid enrollment, building on $80 million in grants provided under the 2009 CHIP reauthorization. Some of these grants support the enrollment and retention of vulnerable populations, such as American Indians and Alaskan Natives. Others focus on helping states use technology more effectively in the enrollment and renewal process, engaging schools in community outreach, and ensuring that eligible teenagers stay on the rolls. Yet none of the Affordable Care Act grants appear to specifically address the issue of CHIP enrollment delays.

The 2009 CHIP reauthorization rewarded states with bonus payments for taking certain steps to streamline enrollment, providing larger bonuses if enrollment improved after those steps were taken. In 2012 Colorado received $43 million in bonus payments. But Pennsylvania—along with twenty-three other states—has yet to receive a single performance bonus. Although the additional CHIP funding provided by the Affordable Care Act will help, we believe the issue must be addressed at the state level. Specifically, we believe that our state would benefit from a new performance measure: the proportion of Medicaid and CHIP applicants receiving an eligibility decision within thirty days.

Another promising policy measure, outlined in the 2009 reauthorization, is presumptive eligibility. In some states' CHIP programs, a child is temporarily covered from the day his or her parents apply. Presumptive eligibility eliminates coverage gaps and long wait times.

In Iowa, for instance, parents start with a visit to a "qualified entity," such as a school, pediatrician's office, or hospital. An outreach worker puts the child's information into the system and immediately receives a determination of eligibility. Since implementing presumptive eligibility, Iowa has seen a 27 percent increase in CHIP enrollment.

Sixteen states, including Connecticut, California, and Colorado, have implemented presumptive enrollment for CHIP. But although the Affordable Care Act allows all US hospitals to presumptively enroll patients in Medicaid, presumptive eligibility for CHIP remains available only in certain states.

A majority of states still require that infants "go bare"—be uninsured—for six months before becoming eligible for CHIP. We believe that this requirement is ultimately counterproductive. Periods of uninsurance are bad for children and families, and it is parents just barely holding their heads above water who are hurt most by existing go-bare laws.

Without coverage, one hospital visit can lead to financial catastrophe and even greater dependence on all forms of government aid. For many lower-middle- and middle-class families, medical costs are the key obstacle that has put financial security out of reach: Medical bills cause 17–28 percent of all bankruptcies.

These required periods of uninsurance are designed to prevent what is known as "crowd-out"—that is, they discourage parents from dropping private insurance to enroll their children in the less expensive CHIP. Yet there is contradictory evidence on whether waiting periods reduce crowd-out or increase it.

Given the lack of certainty, we believe that policy makers should look to alternative solutions that do not enshrine into law mandatory periods of uninsurance for children. One such solution might involve a penalty for employers that don't offer family coverage at a price competitive with full-cost CHIP. If such a penalty were implemented, employers would no longer have an incentive to push their employees toward an outside insurer by raising the cost of adding dependents.

Postscript

After receiving a letter we had written in August, CHIP's director of policy and planning in Harrisburg, Pennsylvania, called us to apologize and offered to backdate the insurance policy to August 1. Although the bulk of our expenses for Erik had occurred prior to August, every bit of assistance made a difference.

As instructed, we made out a check to Independence Blue Cross for the August and September premiums. However, when we called to check, no one at the insurer knew that they were supposed to backdate the policy. Everything was ironed out eventually, but it took another two months.

Throughout these eight months, the individual caseworkers and employees we reached were empathetic and kind. The breakdown lies within the system itself. To blame the failures of that system on the myth of the governmental employee as recalcitrant and incompetent is to take the easy way out of a greater problem. And when we ignore this problem, when we write off the rabbit hole of lost paperwork, demolished buildings, and endless phone calls as the price to pay for a government handout, we are complicit in allowing vulnerable children and families to fall through the cracks of that system, leaving them without the services designed to help them.

The passage of the Affordable Care Act ensures the survival of CHIP for now and builds on the improvements already made through the 2009 reauthorization. Whether or not CHIP in Pennsylvania will realize the full potential of those improvements, however, depends on our collective refusal as voters to tolerate programs which only look good instead of being good. We must believe not only that the gross inefficiencies of entitlement bureaucracies should be reformed, but also that such reform is both possible and necessary. ■

Ari B. Friedman (arib@alumni.upenn.edu) is a fifth-year medical-doctoral student in health economics at the University of Pennsylvania's Perelman School of Medicine and Wharton School. He hopes to complete a residency in emergency medicine by 2020. **Tara Mendola** is a sixth-year graduate student in comparative literature at New York University, specializing in medieval Arabic and French literature. The authors live with their son in Philadelphia. The authors gratefully acknowledge Genevieve Kenney, George Hoover, Daniel Polsky, and Karin Rhodes for their insightful comments on earlier drafts of this article.

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