

Fulfilling Pennsylvania's Promise to Cover All Kids

A Collection of True Stories from
Families with Children Who are
Uninsured

True Stories from our recent report
on Children's Health Insurance Status
in Pennsylvania

June 2015



Pennsylvania has the distinction of being the birthplace of the nation's Children's Health Insurance Program (CHIP). The federal government modeled the national program in its image, bringing free or low-cost health care coverage to millions of children. We are a state with a long history of bipartisan support for ensuring children have access to health care so they can have healthy childhoods and grow up to become healthy adults, productive citizens and contributing members of society. While Pennsylvania has nearly reached its goal of covering all kids, we've fallen short by categorically excluding 24,000 undocumented immigrant children.

Public Citizens for Children and Youth (PCCY) interviewed 53 parents of children like Maria's, and our investigation found that 85% of parents said they had to delay or forego care for their child due to lack of insurance. Among these families we found:

- + 100% of parents stated that they did not seek care for their child because they could not afford it;
- + 91% of children received delayed care or went without care for a serious medical need requiring the expertise of a specialist;
- + 67% of parents reported their child was harmed by delaying or foregoing care;
- + 42% of parents reported that delaying or foregoing care negatively affected their children at school causing absences, lower grades and behavioral problems;
- + 28% of children required emergency room care because a neglected problem worsened.

These findings are consistent with years of academic research that shows uninsured children have worse health and life outcomes than insured children. In addition, uninsured and/or under-insured children cost the system more on average. CHIP costs an average of \$2,500 per child per year – almost half the \$4,600 that a leading Pennsylvania pediatric hospital spent per child in the last fiscal year in uncompensated care – expenses which are financed largely with public dollars.



Researchers have found that undocumented and uninsured children have more preventable hospitalizations and higher childhood mortality rates. Ayanian (2009), found that these children are 6 to 8 times more likely to have unmet health care needs, and Mohanty et al. (2005), found they have hospitalization costs that are 3 times higher compared to insured children largely because they have decreased access to preventive health services.



The good news is that there is ample precedent for states to cover kids regardless of their immigration status. Five states – California (36 counties), Illinois, Massachusetts, New York, Washington – and the District of Columbia have adopted reforms to make undocumented immigrant children eligible for public health insurance.

Collectively, at least 202,000 children have gained access to health care in these states by enrolling in public health insurance.

Pennsylvania can and should join these states by allowing undocumented immigrant children to enroll in CHIP. Based on the experience of other states, we estimate that approximately 6,000 children are likely to enroll in the program in the first year. To support this essential program expansion an additional \$15.4 million in state spending would be required annually.

Public support is growing for closing the gap in universal health care coverage for every child as evidenced by the broad-based and ever expanding Dream Care - Cover All Kids Coalition.

It's time to realize the true potential of the state's 'Cover All Kids' program by making the 24,000 children eligible for health care coverage.

Nearly 9 Out Of 10 Children Received Delayed Or No Care At All For A Medical Concern. Among These Children:	
100% Of Parents	Did not seek health care for their child because they could not afford it.
91% Of Children	Received delayed or no care for a serious medical condition requiring the expertise of a specialist.
67% Of Children	Were harmed by delaying or foregoing health care according to their parents.
42% Of Children	Were absent, earned lower grades or had behavioral problems in school because of an unmet health problem.
28% Of Children	Required emergency room care because a neglected health problem worsened.

True Stories

Miguel - Age 11



Miguel sits at the table pushing around the rice and beans on his plate with his fork. "Eat something, hijo," his mother pleads. "I can't," he replies, wrapping his thin arms around his skinny frame. "My stomach hurts too much." It's been this way every night and a good part of most days for more than six months. Miguel,

once an active, cheerful 11 year old who loved sports, has lost a startling 30 pounds and turned into a listless homebody. He rarely goes outside to play with his friends for fear of an urgent attack of diarrhea. He's missed more than 30 days of school, causing his grades to drop as he falls behind the rest of his class.

His mother, a well-groomed, bright woman with short brown hair, is at her wit's end with frustration. No matter how hard she tries to do the right things, she hasn't been able to get her son the expert care she is well aware he needs. If Miguel were documented like her eight year old child, he would have gotten to a proper G.I. doctor months ago who'd have ordered the necessary tests to get to the source of his pain. What he's had instead are occasional visits to a general clinic or health center where they prescribe medications that have done little to alleviate his chronic cramps and loose bowels. With expenses for rent, food and clothing, the family can barely afford to pay for these repeated visits. A few times, when his pain was really severe, there were trips to the emergency room, resulting in \$4,000 in unpaid medical bills. Ultimately, it's not just Miguel who is suffering. His unmet medical issues have affected the whole family, creating an atmosphere of constant stress. It's a vicious cycle: the costs mount; the pain goes untreated; the anxiety increases.

"All the time I'm worried," says his mother. "All the year he's sick and I am feeling so terrible because we can't afford to see a specialist. I know something is wrong with my son and I know his health is important, but what can I do? There is only so much money we have. If only he had insurance, I could get him to the right place."

Miguel is not his real name. He lives in Bucks County. The image in this story is not Miguel because he is undocumented.

Luis - Age 12

Luis is a tall, beefy 12 year old with spiky brown hair, clear brown eyes and badly discolored teeth. He hasn't seen a dentist in two years and complains of toothaches, likely from unfilled cavities. His school attendance is spotty due to frequent bouts of asthma. His mother lives in fear of the kind of acute attack that would necessitate a rush to the ER, saddling her with an enormous bill she could never pay. If Luis had health insurance like his documented asthmatic baby sister, he'd have a maintenance inhaler on hand that he could use regularly to prevent an emergency – but it's been months since his mother filled that prescription. Although she works six days a week from 6 am to 2 pm in the kitchen of a diner, it's often a struggle just to pay the rent, let alone buy medication. The best she can offer Luis is an occasional nebulizer treatment using his sister's medication. Hers is covered by insurance because she's an American citizen.



School used to be a refuge for Luis. That was before a gym teacher publicly humiliated him before practice by announcing he could no longer play on the basketball or football squad because he didn't have health insurance. After that the bullying started—taunts, name-calling, threats on the way to school, beatings in the bathroom where there are no cameras—all because the kids say he is a Mexican, not a real American. Bullying turns its victims into bullies and Luis has begun to live out that prophecy. His grades have plummeted and he has angry outbursts in the classroom.

“Luis is very depressed. He needs help,” his mother says desperately. She managed to find a counseling center that would treat him on a sliding scale and tried three times to make an appointment, only to be told repeatedly that there were no openings. With insurance there would have been alternative choices. Without insurance the options dried up. “Luis, he was a good boy,” his mother says with a hopeless shrug. “This bullying is destroying him. He has to have help with his emotions, but I can't get it for him.”

Luis is not his real name. He lives in Chester County. The image in this story is not Luis because he is undocumented.

True Stories

Victor - Age 15



Victor, who is 15 years old, had the misfortune to be born two months before his mother emigrated here from Mexico to find work. In the intervening years she gave birth to three more children who had the advantage to be born American citizens. The family lives in a very tiny house used by mushroom workers in

Chester County; a cramped, box-like structure with a curtain separating their sleeping quarters. While all the siblings share the deprivations of poverty, Victor alone suffers from the deprivation of not having health insurance.

Consequently, his medical care all too often consists of an aspirin and what his mother believes to be a nutritious meal—although she knows neither is sufficient. “I never know when he’s sick enough to need a doctor or maybe he’ll just get better on his own,” she says remorsefully. “It’s not like with the other kids. If something is wrong with them, I can always take them for help.” But aspirin rarely meets Victor’s needs. It’s not enough to handle the pain from a tooth he broke in a sport’s accident and the several unfilled cavities found by a dentist he saw six years ago. It’s not enough to quell the constant knee pain that has plagued him since he tripped and fell off a treadmill at school. His mother knew he should have gone to the ER but she had no money and hoped he’d heal on his own. And she was petrified that someone at the hospital would report him for deportation. Unrealistic as those fears are, they are common among immigrants who frequently know little about the law and have no one to explain things to them.

“Whenever Victor is sick or hurt, he wants to go to the doctor,” says his mother as tears flood her careworn face. “Over and over he asks me, ‘Why can’t I go to the nice places you take my sister and brother?’ All I can tell him is, ‘You wouldn’t understand.’ How can you explain this kind of unfairness to your child? I feel so helpless and worried all the time. It’s so terrible for a mother to see her child in pain and know that you can’t do anything about it.”

Victor is not his real name. He lives in Chester County. The image in this story is not Victor because he is undocumented.

Delores - Age 14 and Juan - Age 16

Fourteen year old Delores and her 16 year old brother, Juan, have lived in the United States for most of their lives, yet neither was born here. Consequently they've never had health insurance and meeting their medical needs puts a huge financial and emotional burden on their parents. Delores attends a special school because she is intellectually disabled and developmentally delayed. Small for her age with a tiny face and soft curls that dust her shoulders, she looks and acts like a cheerful pre-teen who hasn't entered puberty, although she's already a teenager. Her mother has had to stop working to take care of her as well as her mentally unstable brother.



Delores gets her basic primary care for \$30 a visit at a community health center which means at the minimum her chronic asthma is being treated. Her other health issues are not. She hasn't seen a dentist for over a year because it's too costly. Her vision is poor, and while she should wear glasses all the time, she doesn't. When she broke her last pair, her teacher thought it would be advisable to keep at school her one pair of free glasses because they'd be safer there. Their budget is already stretched to the limit by Delores's recurrent monthly expenses: \$30 for asthma medicine for her nebulizer; \$10 for her hearing aid batteries and \$100 for the pampers she must wear at night because she's incontinent.

As if Delores's needs weren't enough to manage, Juan also has serious problems. He was recently hospitalized for a mental breakdown that the psychiatrist initially diagnosed as a bi-polar episode but later changed to an anxiety disorder. The ambulance that rushed him to the hospital and his subsequent stay totaled \$4,300 which the family is trying to address through a payment plan that will only stress them farther. Juan seems calmer now that he's on medication and has returned to school for half days. "I don't know how much longer we can pay for his medication," his mother says, shaking her long pony tail. "He needs more than pills. He needs mental health treatment. No way can we afford that." Without therapy, who knows what Juan's future will be?

These are decent people who go to bed every night guilty and frustrated knowing that their children would receive the health care they deserve if they only they had insurance. They want to do the best for their kids – but they can't do it on their own.

Delores and Juan are not their real names. They live in Chester County. The image in this story is not them because they are undocumented.

True Stories

Alma - Age 14



Alma is the oldest of four children, a strikingly pretty girl with soft brown curls and lovely manners. Unlike her three younger siblings who were born in the United States, she was born in Honduras and is the only child in the family who is undocumented and uninsured. Her parents live in fear that she will get sick and need emergency care

that they won't be able to pay for. This happened two years ago. Alma had a stomachache that didn't respond to over the counter medication. One night she awoke writhing in pain. There was no choice but to take her to the emergency room at CHOP where she was admitted, kept overnight and released when the symptoms subsided. All that remained was an \$8,000 hospital bill. Fortunately, the family qualified for CHOP charity care. "We were lucky that time," her father says, "but who knows what might happen if there were another emergency."

Alma's parents are all too aware that ignoring small health issues eventually makes them much harder to treat. That's why they are so diligent about scheduling doctor visits for their insured children. The fact they can't do the same for Alma is heart-wrenching. "It's so hard for me not having insurance for Alma," her mother says tearfully. "I can take my other kids for health care whenever they need it. I should be able to do that for Alma, too. Children born outside the US are just as worthy as children born here. They should all have health insurance." She reaches in her bag for a tissue, her shoulders heaving with sobs. Alma gently pats her hand. She understands why her mother is upset but she doesn't understand why it has to be the way it is.

Alma is not her real name. She lives in Delaware County. The image in this story is not Alma because she is undocumented.

Gloria - Age 15

Mercedez, a pleasant woman with a long brown pony tail, was thrilled when her daughter who lived with her parents for over a decade in Honduras finally came to live with her family in America. But Mercedez barely recognized the 15 year old girl who stepped off the plane.

Gloria was painfully thin with the bloated, extended belly of a starvation victim. Because Gloria is an undocumented immigrant, the task of restoring her health fell solely to Mercedez, who couldn't possibly afford the services of a nutritionist or a doctor.



Dental care is another. Gloria is so embarrassed by her badly discolored front teeth that she covers her mouth with her hand when she speaks and almost never says anything in school. "I tell her when I finish paying for her trip here from Honduras I will get her teeth fixed," Mercedez says, "but there is no dentist I can take her to now because she's uninsured."

Unlike Mercedez's other two children who were born in the United States and have access to health care, Gloria's medical and emotional needs must be paid out of pocket—and the family's pockets are empty. She is a sad, lonely girl who after two years is still deeply mourning her grandfather in Honduras whose death led to her moving here. She's had difficulty adjusting to life in a new country, makes no friends at school, rarely leaves the house and is clearly depressed. Being uninsured, the only therapy the family can arrange is an occasional visit from a compassionate friend from church.

What worries Mercedez even more than Gloria's depression is her obsession with cleanliness. "She is always looking for something to clean," her mother says. "I have to hide the broom and mop so I can relax in my own home and get a break from her constant scrubbing and making neat. She always has a sponge in her hand, wiping this, sweeping that. It's endless. She can't have a speck of dirt on her clothes or she goes crazy. I know there is something wrong with her and she needs help. I am upset all the time from this." Mercedez was finally able to find a counselor at an agency targeting Spanish speakers who are uninsured. She is praying the counselor will work with her daughter until the obsession calms down. Given the agency's limited resources for staff salaries, who knows.

Gloria is from Delaware County. The image in this story is not Gloria because she is undocumented.

True Stories

Maria - Age 4



Maria is the kind of child who crawls into your lap and into your heart. She has a bright, playful smile and a round face adorned with wispy bangs. What she doesn't have is health insurance because she was born in Honduras, not in the United States. Before they left Honduras, a doctor told her parents that she was malnourished. She is small for her four years, and according to her mother, she is never hungry and has to be forced to eat. After driving an hour from their home to get her an annual check-up at a Spanish-speaking Montgomery County public health center, her parents were advised to take her to a specialist to explore why she's not growing. When they learned the fee was \$150 they never made an appointment. Instead they just worry.

Anxiety is also the only treatment they can afford for a skin rash around her ankle that Maria scratches constantly. When they tried to see a dermatologist, the office asked what kind of health insurance they had. At their response, "none", suddenly the doctor was no longer available. Dental care is also on hold. After scraping up enough to take Maria to a dentist, they were told she had three cavities and it would cost \$1,200 for the fillings. That was \$1,200 more than they could even begin to lay out. To make matters worse, a friend incorrectly told them that Maria couldn't be accepted in pre-school with cavities, so they didn't even try to enroll her. Misinformation like this is rampant in immigrant communities, particularly when there is no health provider to counteract with the truth.

Of all their anxieties, what Maria's parents dread the most that their little girl may need emergency care and they wouldn't be able to afford to take her to a hospital. A while ago Maria had a very high fever that peaked at 4 am. In a frenzy, her mother called a relative who recommended an over the counter remedy, and her father drove all over town in the middle of the night to find an open pharmacy. The memory of that night haunts them. What would they do if something like this happened again and the medicine didn't work?

Maria is typical of so many undocumented children whose parents are victimized by ignorance. Not only are they petrified of the expense of an emergency room visit, many believe their child could be deported. Without the guidance of a primary care doctor in a health center, there is no one to allay their misconceptions or direct them to places that can address their child's needs. Without health insurance, families make mistakes and children suffer unnecessarily.

Maria is from Delaware County. The image in this story is not Maria because she is undocumented.

Tony - Age 16

Tony's Emotional Well-Being Worries Mom, Ana.

The agony of dealing with the health issues of an uninsured child is written all over Ana, a petite, wiry woman whose face is a mask of exhaustion and concern. It takes her a long time to loosen up and talk about her anguish and then the tears start to flow and it all pours out: how inept she feels that she cannot get health care for her son Tony, an overweight 16 year old with a bad case of acne; how bad she feels not being a fit mother who takes proper care of her child; how after missing 15 days on her job, she had to cut back from full-time to half-time work to have more time at home to deal with Tony's emotional eruptions and his physical problems; how her other three children cringe at his angry outbursts; how Tony has withdrawn from his friends and how he acts out and gets in trouble at school over and over; how frustrated she feels not being able to afford to get him an x-ray to find out why his back hurts or to see a specialist about his persistent nose-bleeds; how Tony was calmer for a while after she somehow wrangled him a year of free therapy at a social service agency, but that's used up now and he's always in a bad mood, either mad or sad at something and she never knows why; how she looks at her seven year old who is documented and has access to health care and then looks at Tony who really needs it, and wishes it were that easy for him.



"If something terrible happened to Tony, I think I could take him to the hospital," she muses aloud. "But they'd charge me a lot for that wouldn't they? Maybe I could get him some private health insurance, like car insurance you pay for every month. That would be really expensive though. I've even thought about sending him back to Mexico. He'd be seen by a doctor there for free. But no, I am keeping my child here with me, with his mother and his brothers and sister. Hopefully with the grace of God we can move forward."

Tony is from Montgomery County. The image in this story is not Tony because he is undocumented.

True Stories

Santiago - Age 15



As might be expected from a 15 year old boy who was born and raised in Mexico (until he came to the US eight years ago), soccer was always Santiago's favorite sport. Not any more. He's had to give up his passion since he hurt his ankle and his knee on the playing field. Each time his mother knew she should have the injuries x-rayed. But that was not an option because Santiago is undocumented and has no health insurance – and she has no money for unbudgeted expenses. Now Santiago hangs around the house doing nothing because it's hurts too much for him to kick the ball.

Worse than the leg pain are his constant earaches. Usually, when the pain gets so unbearable that Santiago can't go school, his mom takes him to a pharmacy clinic, knowing full well that what he really needs is an ENT specialist, but that is beyond her means. The medication prescribed by the clinic is, at best, palliative and doesn't address his underlying ear problem. It's also expensive – more than \$200 a month – and he often skips doses because the family till is empty. Santiago is on a merry-go-round that never stops—can't see a doctor, can't see a specialist, can't pay for medication. And the ride has taken its toll. He now has hearing loss in one ear that could easily progress.

"All I do is worry about his health care," says his mother despondently. "Sometimes I can't pay attention at my job, and I've already missed five days this year because I need to take care of him. There are so many times I just feel I don't have the energy to push for help for my son. It's hard for me not to give up."

Santiago is from Philadelphia County. The image in this story is not Santiago because he is undocumented.

Jose - Age 8 and Marco - Age 4

Elena has two sons. Jose, the eight year old, is a constant source of worry because he is an undocumented immigrant with multiple health issues and no insurance. By contrast, Marco, who is four, was born in the United States and as a citizen does have insurance. Elena never worries about him because she doesn't have to. As luck would have it, insured Marco never gets sick and uninsured Jose always has something wrong.



Thankfully, a school nurse picked up Jose's poor vision in a routine screening because he'd never been seen by an eye doctor. Although he liked school, he struggled in class and his grades suffered because he couldn't see the words on the blackboard. Consequently, the teacher kept him inside during lunch or recess to practice his spelling lessons. That meant missing out on important playtime breaks and embarrassing him in front of the other kids. The day he got his glasses through a program that distributes them free to kids who can't pay, he ran into the house, screaming with excitement, "Mama, Mama – I can read the letters!"

Elena arranges to get Jose seen from time to time at a local clinic, but when the doctor heard a heart murmur and told her he needed an EKG, she waited months and months to make the appointment until she saved enough money for the bill. When Jose complained of mouth pain, likely caused by cavities, she put off taking him to the dentist until there was money to pay for a visit. When he fell out of his bunk bed and injured his right shoulder, there was no emergency room visit to diagnose the injury because there was no money. Months later Jose is still complaining that his shoulder doesn't feel right; not like the other one. Elena is sure it hasn't healed properly and berates herself for failing him. There is a strong possibility Jose may have sleep apnea because he makes dreadful breathing noises at night. That hasn't been looked into either for the obvious reason: no money! Health care delayed is health care denied and only makes small problems into bigger ones.

"We do everything in our power to make sure our child gets taken care of," Elena says passionately. The round dark eyes that dominate her pretty face get even larger. "My husband has to work extra hours and overtime. We can't spend time together as a family as much. My son has two eyes like every other kid. He is no different. Citizen or not, he deserves to have health care."

Jose and Marco are from Philadelphia County. The image in this story is not them because they are undocumented.

Public Citizens for Children and Youth (PCCY) serves as the leading child advocacy organization working to improve the lives and life chances of children in the region.

Through thoughtful and informed advocacy, community education, targeted service projects and budget analysis, PCCY watches out and speaks out for children and families. PCCY undertakes specific and focused projects in areas affecting the healthy growth and development of

children, including child care, public education, child health, juvenile justice and child welfare.

Founded in 1980 as Philadelphia Citizens for Children and Youth, our name was changed in 2007 to better reflect our expanded work in the counties surrounding Philadelphia. PCCY remains a committed advocate and an independent watchdog for the well-being of all our children.

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