

CHIP/Medicaid Family Stories

LISTEN TO THEIR VOICES

November 13, 2006

Children with Chronic Health Needs Wrongfully Cut from Coverage

DEVANTE is a 13 year old boy with cancer of the kidneys who went without any health coverage for four months while his mother attempted to renew his Medicaid coverage. Although the mother submitted at least three renewal applications beginning in February, 2006 - one through the financial counselor at Texas Children's Hospital - and called the CHIP/Medicaid hotline dozens of times - there was no record of the child's case in the system when advocates contacted the call center on his behalf on August 25, 2006. **Meanwhile, Devante went without any health insurance at all from May through August. He depended on clinical trials for care, and his tumors continued to grow.** Devante's mother wanted to transfer him to M.D. Anderson for care, but without health insurance, was unable to cover the cost of care. Texas Children's Hospital had applied for the "Medicaid spend down" program, but the deductible was \$1,743 a month, and out of the family's reach. Devante is now at MD Anderson and the radiation therapy is taking away the pain that he was in, but he suffered needlessly for months while his paperwork was caught up in red tape. It was only through personal intervention and extensive follow up with the highest levels of the Texas Health and Human Services Commission that his coverage was reinstated.

"**JANE**" contacted advocates on Friday, October 13 frantic that her children had lost their CHIP coverage because her son's mental health medications were running out the following Sunday. Without the medication, he would not be able to function in school on Monday. This mother had initially had problems with CHIP starting in November, 2005. Paperwork was lost, her children were denied for being non-citizens when they are citizens, and her seven year old daughter was coded as being pregnant. Advocates intervened to restore coverage, but then the family lost coverage again when attempting to renew in June. The mother submitted the renewal application two days after receiving the notice in the mail. She found out that her coverage ended when she took her daughter to the doctor for an ear infection in September. She immediately called the CHIP/Medicaid hotline and was told that an error had been made and that her coverage would be reinstated in October. In mid October, when her coverage had not been reinstated, she again called the hotline and was told that coverage would be restored in November. **It was later discovered that a computer glitch had prevented at least 1,000 children from completing the cycle of enrollment.** The error caused the system to not recognize a family's health plan selection or payment of an enrollment fee, and as a result, Jane's children were wrongfully disenrolled. It was only when advocates intervened that her coverage was restored and her children's prescriptions filled.

JOEL is a 9 year old child with Crohn's disease whose mom discovered lost his CHIP while trying to schedule a specialty appointment for October 17 at Children's Medical Center in Dallas. Joel had had surgery in March, 2006 to remove a disabled section of his large intestine and since then had been in chronic pain. Because of the pain, he has undergone many procedures and requires ongoing medication. His mother re-enrolled in CHIP effective September 1, 2006 and paid the enrollment fee as required, but when she called the health plan on September 30, the child had been disenrolled. The system had not registered payment of the enrollment fee, and the data entry worker listed the family as living in Dallas County instead of Smith County. The mother was told that the problem had been solved, but then, when she tried to confirm the appointment with the specialist, she was told that her son still had no health

coverage. Call center staff had never reactivated her coverage, and when she called on Friday, October 13 to try to correct the matter, operators transferred her around, told her to file a complaint or left her on hold. It was only by appealing to the highest levels of the Texas Health and Human Services Commission that coverage was restored in time for the specialty visit.

Children Caught Up in Red Tape and Unable to Renew Coverage

MARGARET tried for months to get her child re-enrolled in CHIP. Her son's coverage was set to expire in April, 2006 and so she submitted his renewal application in March, 2006 and paid the necessary enrollment fee. When she had not heard anything back in April about his coverage, she called the CHIP hotline and was told that they had nothing on file. She filled out a new application and faxed it in on April 27th. She was then told that he would be re-enrolled by June as soon as they received the paperwork. She called back around the first of May and was told that they had not received anything for her son. She was very frustrated and appealed to a local outreach worker at a health fair in late May, who contacted administrators of the Texas Health and Human Services Commission. The outreach worker looked into her case and was told that they did receive the application but needed proof of child support. Margaret faxed the required information on June 6th and again on June 19th. When she called CHIP on June 22, she was told that the missing information was not in the system and that they had not received anything since April. She then appealed again to the local caseworker who contacted senior administrators of the Texas Health and Human Services Commission. On June 26, Margaret was told that she had missing social security numbers and needed to resubmit the entire application. On July 26 she received a letter saying that the children were not eligible for CHIP and that the application would be forwarded to Medicaid. Advocates then appealed to HHSC administrators who restored Medicaid coverage on August 1. The children's identification cards did not arrive until September 9, 2006.

ABIGAIL'S mother is a part-time substitute teacher and her father works in construction. The family earns about \$29,000 a year, within the CHIP range of up to \$40,000 a year for a family of four. The family had been trying since last November to renew Abigail's CHIP coverage. Although Abigail's mother turned in all the required information, every time that she called the state CHIP line, she was told to provide different "missing information" by operators who had no knowledge of her case. First she was told that the state had her pay-check stub, but not her husband's, even though she had submitted both documents on the same page. Then she was told to submit a letter from his employer verifying his place of employment, even though she had already submitted his latest pay-stub as required. Finally, she was asked to submit a letter verifying that the family does not pay child support or alimony out to another home.

Abigail's mother was about to give up, but then Abigail was diagnosed with rapidly advancing scoliosis. Her mother had to cancel an appointment with the specialist because CHIP coverage had not been renewed. She tried to apply for private health insurance, but was denied due to Abigail's pre-existing condition. The Children's Defense Fund met Abigail at an outreach even on June 3rd and worked with the Texas Health and Human Services Commission to restore her coverage, but she represents thousands of other children who never make it through the process or whose coverage is erroneously terminated.

LORNA is a single mother and small business owner who can not afford private health coverage. Lorna's nine-year-old son has asthma, allergies, and serious mental health needs and uses over \$700.00 a month in medications. Lorna's son should also be covered by the Texas CHIP program, but because of repeated processing errors made by the state's new eligibility contractor, he was one of 22,000 children who lost CHIP coverage since December, 2005 when the private firm Accenture began processing applications. Even though Lorna submitted the required documentation, the state continued to ask for "missing

information," including her 9 year old's income. It was only when her State Representative intervened on her behalf that her son's health coverage was reinstated.

RICHARD, a retired AT&T employee, worked for a full year to renew his grandson's CHIP coverage. Richard's son Robert contracted meningitis at six months old and is deaf. As a result, Richard advocates for his grandson. He calls CHIP "the worst fight I've ever been involved in." Over the last year, Richard has received 18 letters requesting different – and often conflicting – missing information on his grandson's case. Names and case numbers have been incorrect, information has been lost, and the family continues to be asked to submit information that has already been provided. Richard went to Austin on July 26th to testify about the problems he has experienced in renewing his grandson's coverage. He showed a panel of lawmakers all the letters that he had been sent and closed with an approval letter that he had received only after the Children's Defense Fund intervened on his behalf. "I'm taking this as gospel that my grandson will now have health coverage." Unbelievably, the same day Richard testified in Austin, he received yet another letter requesting missing information or his grandson would lose his health coverage.

KAREN is a mother of two teenage children, the oldest of whom suffers from severe depression. Karen tried for months to enroll her children in CHIP, without success. Karen first applied for CHIP in late March, and did not receive any communication about her application. Karen called CHIP two months after she mailed the application and was told by the operator that CHIP had just received her application, and that it would take another 45 days to process. When Karen did not hear back, she kept calling. On three separate occasions, during the months of April, May, and June, she was told that no action was needed and that her file was complete. In July, however, she learned that her application had "timed out" and that she did not provide missing information – even though she was never notified about the status of her application or that information was needed.

While Karen waited for the application to be processed, she paid out of pocket for doctor's visits and prescriptions, rationing the doses. Her son was experiencing major depression and she was extremely concerned that his medications would run out. It was only when the Children's Defense Fund intervened with the highest levels of the Texas Health and Human Services Commission that her children were given coverage, after months of worrying about her son's untreated mental health needs.

MILLIE is a mother of six year-old, Edward. Edward has autism, does not speak and requires testing and therapy from the Mental Health and Mental Retardation Authority. Millie contacted the Children's Defense Fund office in tears after numerous attempts to get answers regarding her son's coverage. She was desperate because without health coverage she is unable to get Edward the therapy and services he needs to develop and grow. After being dropped from Medicaid with no explanation she requested assistance. Millie was not concerned about whether her son was covered by Medicaid or CHIP, just as long as he had health coverage. She was hurt and concerned about the letter that she describes as "cold" from TDHS stating "your child(ren)'s Medicaid coverage has ended" with no explanation. The Children's Defense Fund intervened on Millie's behalf and learned that her son's coverage had been denied in error.

Hurricane Katrina Evacuees - Families who Lost Health Coverage When Crossing State Lines

KIM was one of 300,000 New Orleans residents who came to the city of Houston fleeing Hurricane Katrina. Along with her home and belongings, she also lost health coverage for her two sons age 11 and 3. Kim found work at a local school district, but as a single mother cannot afford the costly premiums for her children. The children used to be covered by the Louisiana CHIP program, but the health coverage did not transfer across state lines. Kim tried for months to get the children enrolled in the Texas

Children's Health Insurance Program. She thought the process would be easy because in New Orleans, the whole process, from start to finish, took about 30 days.

In Texas, she never heard anything for a month and a half. When she did, she was requested to provide numerous forms of missing information. One of the proofs she was asked to provide is a copy of a child support order from the court in New Orleans. Unfortunately, the court never reopened since the storm hit, and she could not get the documents. Kim was given retroactive coverage in June, but then was confused when her coverage ran out two months later. With extensive intervention, Kim's children were given coverage by the Texas Health and Human Services Commission on September 26, 2006 - more than a year after the children lost coverage during Hurricane Katrina.

Families Ineligible Because of the Asset Test

"DIANA" is a veteran and mother of three children ages 8, 6 and 4 with a household income of \$1,200.00 a month. She works full-time and is a full-time student attending college through the GI bill. In April 2006, her children lost their Medicaid coverage. Diana was told that they did not qualify because she has two vehicles in her name. Diana owns a 2002 Honda Accord and explained to CHIP that she had co-signed a second vehicle for a friend because she has good credit. She was referred to CHIP and told to wait another 45 days. Although it is evident that this family of four making \$1,200.00 monthly qualifies for Medicaid, the mother attached a copy of the Medicaid referral letter along with the CHIP application and sent it in.

Since then, Diana has been bounced between Medicaid and CHIP. During the waiting process, one of the children was taken to the emergency room twice and then hospitalized with mononucleosis. She has also had to cancel much needed dental appointments and has visited area clinics for vaccinations. Since termination in April, the status of the children's coverage has been in limbo. Diana has made numerous calls to CHIP but has not been able to get any help. She stated that the back and forth between Medicaid and CHIP has been very confusing. She does not care what coverage her children qualify for, she just wants them covered.

One Child Eligible for CHIP and One for Medicaid

"MARY'S" husband is a graduate student getting his Ph.D. in physics. He receives a small stipend to do research for the university and teach a class. The health coverage offered by the university is too costly for the family to afford. Mary is a stay at home mother who takes care of her two young boys, ages three and one. Three year old "Curtis" has asthma and takes a pill and breathing treatment daily for preventive care. When he does have breathing troubles, usually brought on by a common cold, he needs to have respiratory treatments every 4 hours, an oral steroid, and some prescription cold medicine. At one point, his doctor had him on seven different medicines for his asthma, and in the past year he has had major breathing problems every 6 weeks.

Curtis began receiving CHIP in December of 2004, but his younger brother "Johnny" was on Medicaid since birth. Since income guidelines for Medicaid and CHIP are different, in a single family, some children can be eligible for Medicaid while others are eligible for CHIP. Mary submitted Curtis' CHIP renewal in January. For months her application was caught in red tape because it was determined she was Medicaid income eligible, but her assets made her eligible for CHIP. The operator had told the mother that she qualified for CHIP, but the computer did not recognize the family's eligibility. Meanwhile, Curtis went without health coverage for five months while his paperwork was being processed.

Families a Fraction above the CHIP Income Limit and Ineligible for Coverage

TAYLOR is the father of a 7 year old girl with a disorder called hereditary spherocytosis, which means that her red blood cells are not formed correctly. When she gets sick with something as little as a cold, she could become anemic enough to need to be hospitalized and need a blood transfusion. So far, she has been hospitalized twice. She requires shots once a month to manage her condition and also has asthma. She is a chronically sick child, and her mother reports that the chart at her primary doctor's office is over 3 inches thick.

The girl received health coverage through the Children's Health Insurance Program (CHIP) for many years with no problems. Taylor recently started a new job which put the family income above the CHIP limit by \$300. The family received a letter from CHIP stating that the child was dropped two days before the coverage period ended. This is a crisis for the child, who must see the hematologist and endocrinologist once a month. Taylor's new company offers insurance for families, but it costs \$988 a month just for the premiums. No other insurance will cover the child because of her pre-existing condition. Taylor is now borrowing what he can from family members and the bank to cover his daughter's health needs until he can find someone or some way to help his child. In the meantime, his child's chronic condition continues, and the emergency room is her only option.

"JENNIFER" is a single mother and sole provider of 15 year old "Frank," who loves to play football. The small family is settling into their new life in Texas after evacuating from New Orleans during hurricane Katrina. Jennifer has a job, but can not afford the private coverage her employer sponsors which costs \$285.00 for a family. She earns \$8.00 over the income limit for a family of two to get CHIP coverage and can not afford the \$80.00 physical required for him to participate in extracurricular activities. Jennifer also has chronic health problems and is uninsured.

"JAMES" is a 17 year old child with juvenile diabetes. He wears an insulin pump that gives him insulin on a continual basis. James lost CHIP on February 28, 2006, with one day's notice. James was no longer eligible for CHIP because of tightened eligibility rules that no longer included his 19 year old sibling in calculating family size. He had previously been on CHIP since 2001 without problem. As a result of the policy change, the family's monthly income is approximately \$200.00 above the limit. James' mother, "Cheryl", earns about \$2,400 a month as a secretary, and does not have the income to pay the approximately \$600 a month for James' monthly medication and supplies.

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