

TennCut: Why the state Medicaid program is slashing services to thousands of disabled people

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REBEKAH HEARN | The Daily News

Thyroid disease, congestive heart failure, blood clots, anemia and rheumatoid arthritis are just some of the health problems Memphian Ann B. wakes up to every day. For 11 years, she has been covered under a class of TennCare called Supplemental Social Security, or the “Daniels” class. Ann asked that her last name be kept anonymous.

In 1987, a group of patients – identified by one plaintiff’s name, Daniels – filed a lawsuit claiming TennCare was dropping their services without fairly re-evaluating their eligibility.

So the U.S. Federal District Court in Nashville issued an injunction in November 1987 prohibiting TennCare from re-evaluating the eligibility of Daniels patients until TennCare officials found a way to improve the process.

The case sat on the docket for more than 20 years.

In January, Judge John T. Nixon of the U.S. District Court for the Middle District of Tennessee lifted the injunction against TennCare. Since then, patients in the SSI class have been receiving TennCare re-evaluation forms (often called “peach pages” because of their color) to determine if they are still eligible for the category.

SSI patients are, by TennCare’s definition, low-income people who are elderly, blind or disabled. Ann falls into that category. Her husband is also disabled and receives Veterans’ Administration benefits. They live on Social Security only.

Some call the SSI/Daniels situation “cuts.” Some call it “re-evaluations.” Either way, as of Oct. 2, the most recent numbers TennCare had showed of the approximately 147,000 SSI patients who had been covered for 22 years, about 84,000 have lost their coverage since the peach pages began going out earlier this year.

Currently, 63,000 patients are still receiving benefits; 40,000 of those patients have completed the reverification process and can stay in SSI or be moved to another category, said TennCare spokeswoman Kelly Gunderson. The other 23,000 patients are “still in process,” she said, meaning they are appealing TennCare’s decision, have not yet received their notices or still have time to send in their information.

The media have descended on news of the “Daniels” cuts like it’s the scandal of a lifetime. But TennCare’s changes aren’t affecting only patients in the SSI class. The trimming of services and cutting of other patients in other categories – which also include severely disabled or sick people in need of constant or nearly constant care – are having just as profound of an impact on those who



Linda Fann helps administer a nebulizer treatment for her daughter, Jacquetha Phillips. Phillips, a spinal bifida patient, recently won back some of her health care coverage from the state. -- PHOTOS BY LANCE MURPHEY

could be facing life in a nursing home as soon as next year.

Life and death

Ann didn't know the name of the class she was in. Like many people, she just knew she had TennCare.

At 62, Ann relies on 12 to 15 medications a day plus regular laboratory visits and doctor's appointments to stay not just healthy, but alive.

When The Memphis News called to speak with Ann, she was too sick for an in-person interview. She had been in bed for days with an upper respiratory infection, and after the re-evaluation of her SSI status this year – and her subsequent cut from the class – she couldn't afford to see a doctor.

Ann said losing her TennCare coverage is “like a sentence to die.”

“It'd be different if they were giving us some advice about what to do, instead of just closing the door and saying, ‘That's it.’ I mean, if I don't take my medicine, I'm dead,” Ann said as she coughed.

Ann had been on TennCare until last year. When she received notice in June she was going to be cut from the SSI (“Daniels”) class, she filled out the complicated peach pages by herself and returned them, only to be denied. She appealed – and lost.

“When I was dropped, they did send me a letter that said I had 63 days to apply for health insurance under the HIPAA (Health Insurance Portability and Accountability Act) plan, which means that you're covered with your pre-existing conditions, but every company they sent me was \$1,000, \$2,000 a month,” Ann said. “The cheapest I found was about \$600 a month.”

Ann's Social Security income is less than \$700 a month, and her husband's is just enough to pay their phone, mortgage and other necessary bills. She doesn't qualify for Social Security disability, she said, because she stopped working one fiscal quarter too early.

“And I'd been working all my life,” Ann said. “That's what they said; that's what they gave me. It's just shutting that door in my face, again.”

Right now, Ann is busy applying for charity wherever she can. Partnership for Prescription Assistance, a national program, is helping her pay for two of her prescriptions. She receives treatment through the Regional Medical Center at Memphis for her rheumatoid arthritis, and while she's applied for the charity program there, she has yet to be approved.

“They have agreed to keep seeing me, but they're going to bill me for it, which I can't pay,” she said. “But I have applied for charity, and Jennifer (Tlumak) at (the Tennessee Justice Center) helped me to get the forms from The MED. It takes forever to get any kind of answers or replies, but finally, after working on it for a long time, they sent me the forms.”

Her primary care doctor also is trying to help her get charity medical care through that office.

While she was on TennCare, she said she was pretty well taken care of.

“I could go to the doctor, and they paid for that, they paid for my labs, they paid for five prescriptions a month. There were several I had to get myself, but most of them are \$4 because

they're generic, so I was able to do all that myself. But since they've taken it away, of course I can't, there's no way I can afford it.

"It's hard for me to say anything bad about them because they did take care of me for 11 years, but ..." Ann trailed off.

Ann knew nothing about the local legal clinics [Memphis Area Legal Services Inc.](#) was offering in conjunction with the Tennessee Health Care Campaign and TJC. She was the only patient The Memphis News talked to who didn't have an attorney helping her with her TennCare issue.

'The same process'

To qualify for SSI, or Daniels, a patient must have a monthly household income of no more than \$674 a person or \$1,011 for two people, with a resource limit of \$2,000 and \$3,000, respectively. Resource limits include savings, trusts and other financial resources not identified as regular income.

SSI is a mandatory Medicaid eligibility category, meaning TennCare is required to offer this category and cover the people who qualify for it.

Gunderson emphasized the SSI re-evaluation is "going through the same process everyone goes through."

"You're either eligible or not eligible for the program," she said. "And this is the same process we do annually for other members. This was just a group of people who, in some cases, never went through the (annual) process to see if they still qualified for the program (after the injunction was implemented)."

Federal mandate requires state Medicaid programs such as TennCare to evaluate their patients on at least an annual basis, if not more frequently. Tennessee evaluates every patient once a year.



Brandon Byrd, left, explains to his son Devon, 11, right, and Chandler Mason, 8, how to check the air filter on a four-wheeler at his Munford home. Byrd is facing the loss of his home health care because of a change in TennCare policies. Byrd, a father of two, became a quadriplegic in 2004 when a fall from a trampoline injured his spine.

Gunderson said the SSI category is still open.

"That SSI category, that's still there for people receiving SSI income," she said. "What happened was that we had these holdover people that stayed in that category who weren't able to be reverified like we do in all of our categories. ... We have to do that for the integrity of our program."

TJC managing attorney [Michele Johnson](#) said one of the problems with the SSI reverification is it wasn't done well enough and many people never received their peach pages.

"(One) reason why this process had never been put into place for 20 years is that TennCare's computer system is not reliable enough to keep the right

addresses for people," she said. "New addresses, current addresses, given to TennCare by the enrollee are overridden by old addresses because the TennCare computer system has to talk to the (Department of Human Services') computer system, which has to talk to the Social Security

computer system. And the result is that they were eating good addresses, so lots of people didn't get proper notice.

"We have lots of calls from people who don't find out until they go to the doctor ... or the pharmacy. That's illegal, and they should be put back on immediately. They should be given an opportunity to prove they are eligible."

Gunderson said TennCare does provide that right. She said TennCare sends out notices to all of a person's known addresses up to four.

"Is it going to happen that we sent out a peach page that somebody didn't get? Yes. But that's why we have the appeals process in place, so if it happened that somebody went to their doctor and said, 'Oh, what do you mean, I don't have TennCare anymore?' they can go through the appeals process. If they can prove we sent it to the wrong address, that's why we have that (appeals) process, and during that process, you will maintain benefits."

But therein lies another problem: If an SSI patient receives notice of losing their coverage, they have 20 days from the time they receive their initial notice to appeal; if they appeal during that time, their coverage will be continued. After that 20 days is up, the patient has another 10 days to file an appeal, but services will be discontinued during that time. That is the standard timeline for all appeals of changes to TennCare coverage.

Theoretically, if a patient didn't know their TennCare was gone until 20 days down the line, their services would be cut off. If they then discovered that fact in time to file an appeal within 10 days of the 20-day period ending, their services will be closed to them during the appeals process - and could possibly not be reinstated at all, unless the patient could prove without a doubt the pages were sent to the wrong address and the fault lay with TennCare or the patient still qualifies under the same or a different category.

Gunderson emphasized the enrollee does have the responsibility of notifying any state agency of a change in address.

But that's not all

People in the SSI class are not the only ones facing the cuts TennCare began this year. TennCare offers a category known as the Medically Needy Spend Down category. To qualify, an individual "must either have income no more than the figures provided ... OR he must have sufficient unreimbursed medical bills to 'spend down' to these income limits," according to TennCare.

After paying those unreimbursed medical bills, a single person can't earn more than \$241 a month. A family of four cannot make more than \$325 a month. There's also a resource limit of \$2,000 for one person and \$3,000 for two people.

Medically Needy Spend Down is an optional Medicaid category, meaning TennCare does not have to offer it. The "spend down" level is set by the state.

[Brandon Byrd](#) is an Atoka resident who has been fighting not one, but two, cases involving his TennCare coverage. Byrd is a quadriplegic who was injured in 2004 when he fell off a trampoline while playing with his two sons.

As a result of the injury, Byrd also damaged his trachea, leading to the need for a tracheostomy.

The initial operation, called a tracheotomy, is an incision into the trachea, or windpipe, forming a temporary or permanent opening called a tracheostomy.

The insertion of a tube into the opening allows air passage and removal of secretions. For this to be done regularly (especially for a quadriplegic), someone with medical training must be on hand to perform these duties, or the patient could suffocate and die.

Byrd was injured when he was 24 years old. He turns 30 in November.

Formerly a full-time industrial worker, Byrd was covered by private insurance when he was hurt. After a couple of months in the hospital, his private insurance dropped him. Not long after, he had to get TennCare, a process his wife, who has since separated from him, took care of.

“I’ve been on TennCare since then,” Byrd said. “I was just trying to live; I was not really worried about TennCare. But my wife went through a lot of different things to get TennCare started ... she had to deal with paperwork, and loopholes, and back doors. ... Everything’s so complicated. It makes it very hard for someone to get what they deserve.”

Byrd, who had been working since he was 13, began receiving 24/7 private duty home nursing as a member of the Medically Needy Spend Down category. Because of the assistance TennCare provided him, he was able to continue to see his children – two boys, ages 5 and 11 – at least every other day and even studied full time.

But in June 2008, when Byrd began receiving paperwork that his home nursing services could be cut from 24 hours a day, seven days a week, to four hours a day, five days a week, he got angry.

“I began writing letters,” he said. “I actually was desperate. So I started sending letters and I guess someone passed it on to the Tennessee Justice Center, and they got me in touch with (Linda) Casals.”

Casals is Byrd’s attorney through Memphis Area Legal Services. Neither she nor Byrd is clear on why TennCare is trying to cut his services.

To add insult to injury, TennCare is saying not only will Byrd’s services be cut, but the state is also arguing Byrd is not eligible for the Medically Needy Spend Down category anyway, Byrd and Casals said.

Casals said it was “weird” that Byrd was in that category to begin with, because after his six-month stay in the hospital following his fall, “TennCare put him in that category, but he didn’t have to submit invoices to get into the category as it was set up at that time.”

“I’m still confused about this,” Casals said.

Casals and Byrd had a hearing in early October to argue Byrd needed to keep his private-duty nursing. Both still are waiting to hear from the state on when the hearing will be about keeping any TennCare eligibility.

“I didn’t hear anything in October, so I’m guessing it will be November,” Casals said. “I don’t know. They haven’t told either of us yet.”

The Medically Needy Adult Spend Down category is closed to adults, according to the TennCare Web site. Gov. Phil Bredesen froze that category in 2005, just after Byrd qualified for it.

The state cites budgetary concerns as the reason for cutting TennCare services and closing categories. In September 2008, Bredesen in an address cited budget-tightening as the reason for private home duty nursing categories being reduced. He also said the category is “clearly being used in an abusive way” as he used the example of a couple, both on TennCare, receiving private duty nursing.

“They live in the same home together and each of them has a 24/7 private-duty nurse sitting in their living room. At \$325,000 a year for each of those nurses,” Bredesen said.

But Byrd said he isn’t abusing the category. His only income is Social Security disability.

**"It'd be different if they were giving us some advice about what to do, instead of just closing the door and saying, 'That's it.' I mean, if I don't take my medicine, I'm dead."
– Ann B.
Former Daniels class patient**

“It’s not like I get a lot,” said Byrd, who added he would “gladly give up” his SSI income, except “my kids enjoy having food and clothes, and I enjoy eating, too.”

Citing the “stack of paperwork that all says the same thing,” Byrd said, “I don’t know what TennCare is trying to say – other than, ‘Since you have this Social Security income, you don’t qualify.’ But I don’t have enough to pay for this kind of care.”

He’s even offered an alternative to keep down TennCare’s costs for his care.

“The nurses being here 24/7, it is expensive,” Byrd said. “But I could do with maybe not a licensed nurse the whole time – I could probably do with a (personal nursing assistant) half the day and the other half, have a nurse – I just need someone here who can do the medical stuff I need. It doesn’t have to be a (licensed practical nurse).”

But if Byrd loses his coverage, or if TennCare cuts it to four hours a day Monday through Friday, he won’t be able to stay at home.

“There’s no way private insurance would cover this,” he said.

So his only option would be a nursing home. In terms of cost, that is actually cheaper for TennCare. Gunderson confirmed it costs around \$300,000 a year to provide 24/7 private home duty nursing for a patient, whereas it costs around \$60,000 a year to put that same patient in a nursing home.

But those numbers don’t add up to receiving the same quality of care.

One health care worker who briefly talked to The Memphis News on condition of anonymity said, “\$60,000 a year is close to one nurse’s salary. If someone is paying \$60,000 a year for care for someone who previously was not only operating on, but improving on, a plan that cost \$300,000 a year, well, you can see how their quality of care will go down in that home.”

And Byrd is improving. Thanks to his physical therapy, he has started to regain some movement in his left arm.

“When I first got hurt, I had no movement at all,” he said. “Now I’m starting to move; my shoulders are really strong, and I’m getting some movement in my bicep and my elbow of my left arm. If it keeps going at the rate it’s going, by next year, I might be able to move my left arm around.”

Although he said that’s literally one-sided, he also said he doesn’t care.

“All I need’s one arm. If I could just reach out and touch my kids and hug them – or even point in a direction,” he said.

If he’s left with minimal or no coverage, with no Level II nursing homes in Tipton County or within 60 miles of his home, Byrd said he’ll probably remain home and try to stay alive as long as he can.

“They can’t make me go,” he said. “I would stay at home as long as I could. I probably wouldn’t make it any longer than a week and a half. But I don’t want to go live in a place that could be even worse than prison, where I can’t even see my kids.”

In the meantime, though, Byrd said he hopes for a positive outcome at his coming hearing, and plans to continue going to business school full-time if TennCare continues his coverage.

“I try to do as much as I can,” he said. “I try to be as much of a part of my kids’ lives as I can; they still think of me as Dad, I still do everything that a dad does, but it’s kind of hard to do that in a nursing home somewhere.”

Byrd’s commitment to parenthood has not gone unnoticed. This past spring, the TJC honored Byrd with its Father of the Year award. Byrd said that was “so meaningful” to him, as he suffered a bad childhood himself.

“That was one of my big things even before I got hurt,” he said. “I wanted to make sure I was a good daddy. So getting that (award) made me feel good, because I do try hard.”

Crunching the numbers

With the governor and TennCare citing budgetary concerns, a brief look at the numbers is in order.

TennCare’s operating budget for fiscal year 2009 was \$7 billion, with \$576 million in reserves. The state’s “rainy day” fund sat at about \$700 million.

A continued decline in sales tax growth in July meant Tennessee experienced a full fiscal year of negative growth, according to press reports. Sales taxes account for about 60 percent of the state’s money. State economists have estimated it will be 2011 before Tennessee sees any growth in sales tax revenue.

July, August and September all saw revenue decreases as well. The latest numbers show September revenues at just more than \$920 million, 5.7 percent below September 2008. Not only were sales tax collections coming in at around \$37.8 million less than what the state had budgeted for, but gasoline/motor fuel collections and inheritance and estate taxes also came in under expected amounts.

But the American Recovery and Reinvestment Act of 2009 brought \$1.1 billion to Tennessee. Overall, the federal stimulus provided \$87 billion in additional federal Medicaid funding for states.

The stimulus law says the increased Medicaid funding will be available for Medicaid expenditures between Oct. 1, 2008, and Dec. 31, 2010.

Gunderson emphasized none of the stimulus funding was put into reserves - neither TennCare's reserves nor the state's rainy day fund.

But Johnson, the attorney at the TJC, said all stimulus funds were to be used actively for health care and she said the governor's office put the money into reserves.

“Among other things, the federal law said that states cannot put the stimulus money into reserves, either directly or indirectly,” she said. “They have to spend the stimulus money, and they have to spend it on health care.”

No non-verbal documentation of where this money went was available to The Memphis News by press time.



Nurse Carolyn Offer comforts patient Brandon Byrd after he learns about the death of his grandmother, who raised him from age 10.

Another important aspect of ARRA is that for states to qualify for the Medicaid fiscal relief, they must maintain the income eligibility levels that were in place as of July 1, 2008, and “they cannot make it more difficult for individuals to apply for or keep Medicaid,” according to a summary of the law by FamiliesUSA.org.

States had until July 1 to undo any changes that would disqualify them from receiving the temporary additional Medicaid funding.

The stimulus bill also increased the federal matching dollars for Medicaid programs. Prior to the passage of ARRA, Tennessee used to receive \$2 from the federal government for every \$1 the state spent on TennCare. The stimulus bill increased that matching fund to \$3 for every \$1 spent.

“That’s what we are going to get, about 75 percent matching funds from the United States government,” Gunderson said. “That used to be about 65 percent. So (the increase was) due to stimulus money.”

With the extra matching funds, temporary stimulus help and Medicaid reserves that are among the highest in the nation, how can TennCare cut services or purge people from its rolls – especially since to receive the funding, which Tennessee did, the state has to keep Medicaid levels where they were as of July 2008?

“I think the best way to say that is, the way it was written in the bill is that eligibility categories could not be more restrictive than they were on July 1, 2008,” Gunderson said. “And that basically means we could not take away an eligibility category. And the eligibility category is still the same (in SSI). There is not a change in who is eligible. What changed is we were now able to check to see if people actually qualified in that category.”

With regard to the Medically Needy Spend Down category, Gunderson said “the important thing to note is that with the stimulus funding, if we were to make an expansion in Medicaid, we would not get that increased amount for the expansion.”

But what about a patient like Byrd, whose services are being cut and his eligibility contested?

Gunderson could not address specific patients’ situations. But even the oft-cited “Myth vs. Fact” page on the TennCare Web site doesn’t explain this phenomenon.

“You know, the whole purpose of the stimulus money and saying you couldn’t change eligibility is that we are in an economic crisis,” Johnson said. “We want to make sure states don’t use the economic crisis by cutting people’s health care, because if they do, it’s going to spiral and hurt the whole community.”

“The whole intent of that provision of the stimulus bill was to freeze everything – and that would include the Daniels folks. The bottom line is that everybody would stay the same.”

However, Johnson said the law did not say Tennessee could not do what it was doing with the SSI category, or "Daniels," injunction case.

“I think (TennCare) would argue that they’re not changing eligibility, because (some of) these people were never eligible, or aren’t anymore,” Johnson said. “I think that’s more of a technical argument, because it was never intended that they would send all this money to the states, and then what is happening with these Daniels cuts is one of the largest cuts to the Medicaid program in the history of Medicaid.”

The largest cuts to TennCare were made in 2005, when Bredesen purged more than 200,000 people from the rolls. In March 2005, the Centers for Medicare and Medicaid Services approved Bredesen’s overhaul plan, but just days later, U.S. District Judge William Haynes Jr. halted all TennCare cuts until the completion of a hearing in his court to determine if the state has that right.

In April 2005, a three-judge panel of the Sixth Circuit U.S. Court of Appeals in Cincinnati said Haynes overstepped his bounds in stopping the state from making the cuts, and subsequently, TennCare announced its plans to cut enrollment by 323,000 people beginning in summer 2005. Some services were also reduced or cut completely, such as mental health care and addiction treatment.

What's next?

Gunderson said TennCare is excited to implement the Long-Term Care Community Choices Act of 2008. TennCare announced in July that federal officials approved changes to Tennessee’s long-term care program.

The Long-Term Care Community Choices program does away with the “slot” mentality, so there’s no set maximum number of people TennCare can cover under it, but also no set minimum.

Gunderson said the start date for the Choices act is March 1 for Middle Tennessee, and TennCare will implement East and West Tennessee enrollment later in 2010, “within the first quarter of the fiscal year.”

“And once the Choices program is up and running, it will change how we run the program, but it will still have people being able to be at home with those home- and community-based services,” she said.

Formerly, “... we had this waiver from the federal government, and we had ... 6,000 slots in that waiver throughout the state to serve people who stay home on the Home and Community Based [Services] waiver,” Gunderson said.

The slots under the Home and Community Based Services waiver, which Gunderson said opened in October, came after CMS approved an amendment to a federal waiver for TennCare that will let

managed care organizations (MCOs) coordinate all of a TennCare member's needs. The new waiver allowed for 6,000 slots.

HCBS has allowed "a record number of people – approximately 6,000 Tennesseans – who would otherwise need nursing home care are instead receiving Home and Community Based Services (HCBS), getting the quality health care services they need in their own homes instead of being cared for in a nursing facility," according to a TennCare press release.

Gunderson said of the 6,000 "slots" the federal waiver provides for HCBS, currently there still are openings in that category. The TennCare eligibility category Web site does not give a description or the requirements of this category.

If slots are available in the HCBS category, people like Byrd could be left to wonder why they may be left in the cold.

Home services are a big budget problem for TennCare. Bredesen said last September TennCare's budget for in-home nursing has grown by 53 percent since 2000, totaling \$243 million this year.

Gunderson got more specific.

"In 2000, we spent \$18 million (on private-duty nursing)," she said. "In '07, we were spending \$243 million in home health private duty nursing, and if the trend had stayed on target like it was, that would have escalated to about \$496 million in 2009.

"So we are going from \$18 million (in 2000) to a possible \$500 million (in 2009) in that benefit alone, and again, we are talking about a very small group of people. That's a lot of money to spend on a very small pool of people."

In TennCare's fiscal year 2010 budget proposal, long-term care would take up 12.4 percent, or about \$950 million, of the program's proposed \$7.6 billion budget.

No one is clear on how the federal health care reform could affect state-provided Medicaid services, and everyone from patients to TennCare representatives themselves are sometimes confused about the specifics.

But with the recent announcement that CoverKids, a program of Cover Tennessee, will stop accepting new enrollees Nov. 30 despite increased federal matching funds, people all over are wondering: What's next for TennCare?

"You almost just can't believe you're in America," Johnson said.