

Fighting to Keep TennCare

By: Jane Doe

My name is Jane Doe. My minor son John was born with physical disability and has severe medical complications. I'm a single mom now; our only income comes from my job at a nonprofit organization. This is a true story, but I'm telling it anonymously.

Years ago my son qualified for TennCare because I had applied for SSI for him during a time of unemployment. I was so thankful because our commercial health insurance carrier reduced the annual cap on durable medical equipment to \$2,500, and that would not have paid for the ventilator John needed to breathe, at that time.

When I didn't get any TennCare letters after the Daniels Case was settled last year, I started breathing easier. My father had said he'd heard on the news that TennCare wasn't kicking any kids off. I'd heard that too, and read it in articles, but that was **Wrong!**

Several weeks before Christmas, I got the 8-page, peach-colored application from my county's Department of Human Services (DHS). I learned it was the same application you fill out when you are trying to get food stamps or other public assistance. I had until January 4 to get it turned in, and I started right away by calling my child's TennCare case manager and trying to get a copy of everything they had spent on my child in recent months. I was told they had never been asked for that before, and referred to the "main" helpline number. Before hanging up on that "main" number, I waited on hold as long as I could -- 15 minutes, 20 minutes and 30 minutes on three call attempts. Finally, determined to talk with someone, I waited on hold 45 minutes, and got a person. She said what TennCare has already paid would not help in this matter, nor be considered as "spend-down," because it had been paid by insurance not by me. Nor could I access the information, she said.

Spend-down refers to money I spent on medical-related bills. Eventually a DHS letter would say I needed several thousand

dollars in "spend-down" and it had to have happened October-January, last year, for my income to be low enough so that John could get coverage.

Still, I started collecting medical bills for that period, intending to document extraordinary need. Regular providers included three durable medical equipment companies for various medical supplies, oxygen, respiratory machines and supplies, orthotics and wheelchair repair; about five doctors; two therapists; a home health nursing agency; and the local pharmacy. It is a jaw-dropping and humbling experience to see what health care costs today. It is even more so for a special needs child who is your own child. If only I could show a judge the expenses from a quarter, he would see that losing TennCare would quickly

throw us very deeply in debt and likely onto the street or into the hospital, and surely then John would qualify.....**Wrong!**

I learned much later that my collection of invoices could still help, by documenting dates of service. I could at least count mileage for medical-related trips as part of spend-down calculations. I missed one of the DHS/TennCare deadlines simply because it took three months to get all those invoices from providers, and I appealed on that basis. I also appealed on the basis of an appointment having to be rescheduled to the next month, because of a snowstorm, which blew my spend-down total. Surely a judge would take that into consideration.....**Wrong!**

By now, I was way beyond getting very nervous. I was losing sleep big-time! My spend-down tally was entirely too close for comfort, especially if the late invoices were thrown out. All the TennCare letters state: "Do you want to see if you can get free legal help?" and contain a county-by-county list of each legal aid organization and their phone number -- English on one side, Spanish on the other. Three times I called and left messages and waited for days, because the recording said I would be called back....**Wrong!**

HELPFUL TIP

You can apply for TennCare online and access all of their rules online
<http://tennessee.gov/tenncare/mem-apply.html>

HELPFUL TIP

Spend-down is a way to reduce your income to qualify for TennCare using bills incurred or paid in the month of, and the three months prior to, application or re-verification.

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THE ARC OF TENNESSEE RECEIVES WALMART FOUNDATION GRANT THROUGH THE ARC OF THE US

By: Loria Richardson

This past spring, The Arc of Tennessee along with 45 other chapters of The Arc (including The Arc of Davidson County) was awarded a grant from Walmart Foundation through The Arc of the US focusing on "school to community transitions," The main goal of the Walmart Foundation and The Arc US was to create "best practice programs" that could be replicated across the country. These projects must demonstrate that participants leave with improved outcomes in self-determination, and at least one of the following areas: employment, post-secondary education and independent living.

Research has shown that though an IEP (Individualized Education Program) team meeting is supposed to be "about the student and for the student," students actually participate the least of all the team members. When the student is empowered to lead his/her own meeting and other team members (parents and educators) learn to support that action, research indicates student goals are more connected to future plans of work and/or education and independent living, and that the goals are more likely to be met. Students who lead their IEP team meetings have a better chance of continuing their education, becoming employed and living more independently in the community.

The Arc of Tennessee's project will pilot self-directed IEP training with three Tennessee school systems – one each in West, Middle, and East. The project will focus on teaching students, families, and educators about self-determination and self-advocacy. In the Spring, the participating students will facilitate their own IEP Team Meeting.

In addition to demonstrating improved outcomes in the areas mentioned above, additional goals of the project include increasing:

- Student Self-Determination (knowing oneself and making choices)
- Student Self-Advocacy (speaking up for oneself in a productive way)
- Student Supports (making friends outside the classroom)
- Inclusion in general education and school activities
- Social Skills

Each year the project will focus on one school system:

- 2010 - 2011 Benton County Schools
- 2011 – 2012 Warren County Schools
- 2012 – 2013 TBA

After a series of "pre-project" student assessments of the students are completed, training will begin for Benton County students, families, and educator groups around a core curriculum focused on:

- Disability Sensitivity, Student Empowerment, and People First Language
- Basic IDEA (Individuals with Disabilities Education Act)
- Secondary Transition Process
- Using Assistive Technology in Transition Planning
- Introduction to Self-Directed IEPs

These, and nine other training sessions provided to the students in the classroom, are designed to help students aged 14-22, receiving special education services, to lead their own IEP team meetings. Our goal is to provide the training to up to 30 students each year.

For more information about this project and Secondary Transition, Self-Determination, or Self-Advocacy, contact Treva Maitland at 731/559-4187 or tmaitland@thearctn.org or Loria Richardson at 615/215-2065 or lrichardson@thearctn.org.



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Letters from the county DHS also have a phone number and state that you can talk to your worker and identify them by name. I don't know how many messages I left for that DHS case worker. No one ever called me back. Indeed, I was incredulous that it took me eight calls to find out the county DHS fax number so I could fax in the peach form, which they suggest. I am a time-challenged, working mom, and this was frustrating!

On school days my son's needs take seven hours of direct, hands-on care and assistance at home. When he is sick, in the hospital, or on weekends and school vacations, his care takes more time. Most of his authorized nursing hours are used at school. When we are not staffed, I assist him at school. We are frequently not staffed.

Because of pneumonia, John's doctor sent him to the hospital via the emergency room/department, about a week before Christmas. He needed IV antibiotics. After four days, we went home and began the exhaustive home regime which involves respiratory therapies, monitoring and meds every few hours around the clock, for days. The home health nurse was mostly off because of the holidays. John got better but then suffered additional problems a few weeks later with some lung collapse. I also suffered under the burden of the additional work and anxiety spurred by the peach paperwork!

Every time I called TennCare, even at opening time, I was put on hold 40 minutes or longer. I

HELPFUL TIP

Tennessee Health Care Campaign (THCC)
 615-227-7500 or
 877-431-7083 (toll free)
www.tenncare.org

needed help. Finally another mom responded to an email that my friend had broadcast. Perfect. She suggested I call Dan Ramey, LCSW at Tennessee Healthcare Campaign. She also mentioned the Tennessee Justice Center. I called both right away. And they called back!

HELPFUL TIP

Read closely each letter from TennCare, and seek help understanding the consequences or implications of each letter, especially if not readily apparent.

Dan, who is a social worker with a nonprofit consumer health care advocacy group, helped me understand how TennCare was getting my son off their roles. First they had taken my son off of TennCare Select, which had been for

the sickest/neediest kids, and put him on TennCare Standard with a managed care organization. I remembered that letter which I had tossed in to the to-be-shredded pile. It did not seem unusual or significant, and TennCare recipients receive a ton of mail. Once the appeal deadline passed on that change, John was on TennCare Standard, and I had to prove that we still met the requirements for that program. Because I had access to health insurance through my employer, he did not.

Perhaps he could get TennCare Medicaid, but without spend-down, he would not be eligible for that. And then my January dental appointment got bumped to February because of the snowstorm that closed Nashville, thus bumping a thousand dollar dental bill into February and off of the spend-down tally. Our goose was cooked!

I gave written notice of my appeals. Appealing was confusing, because we got letters denying each type of TennCare, and some came from DHS and some had TennCare letterhead. I would get a letter from DHS stating John had no coverage one day, and the next day I would get another letter from TennCare stating he had coverage. I appealed every denial. Each appeal got a different 9 to 11-digit docket number, and I was careful to use those in my correspondence, along with a 9-digit case number. Then I started sending my letters to both DHS and TennCare. When I finally got all the medical invoices for spend-down, I put together my own packet and hand delivered it to DHS, and mailed it to TennCare. In one reply I learned that I would not get a hearing in front of a judge unless I could show facts that their Rules had not been followed.

It cost \$436 to add my son to my health coverage at work. With that plan there would be no home health nurse. How would I work? Their annual cap on durable medical equipment was \$2,500. Even without a ventilator, equipment, supplies and orthotics easily cost many times that amount. When John got his first power wheelchair seven years ago, we were floored that it cost \$30,000. That is \$27,500 over this annual cap with

no supplies included! The in-network, annual deductible is \$3,000, and out of pocket is \$6,000, before the insurer pays 80 percent. That is \$9,000 I knew I would have to pay every year. Couple that with \$5,200 in premiums and you have half my salary. Continue to deduct the expenses not covered, and simple math proves it didn't make sense for me to work. I hated that. To me, that is **Wrong**.

What could I do? Declan Gould, a client advocate for the Tennessee Justice Center suggested I reapply for TennCare online, even while I awaited action or response to my appeals for denial of coverage. That saved us I think, and it made a lot of sense, because it reset the date period for spend-down so my dental bill could count. Dan suggested I call Social Security and reapply for SSI. I also bought (charged) a used overhead lift because I could no longer pick up my child who cannot walk or stand. I think these three action steps kept us from losing or lapsing John's TennCare medical coverage.

In this deadly serious fight, I did everything I had ever heard of to do. John and I talked with our legislators in person, and I wrote letters. I talked with my supervisors. I talked with providers and persons in disability-related professions, and persons they suggested. I spent tons of time researching, asking questions, and looking things up in the TennCare rule book. I could not help but think

that a person without a college education, internet access, and bulldog determination and "stick-to-it-tiveness" would have lost coverage.

I took my son out of school to attend the long interview and paperwork exchange at the Social Security office. Our numbers were tight. It was hard to predict the outcome of the odd math formula they use. It was not the SSI money we sought, but the associated Medicaid coverage essential to our survival. The next week we were called for an appointment at DHS, resulting from the online TennCare application. I had the bill for the lift with me of course, and the DHS worker told me right then it would qualify my son for the spend-down. On my way home that worker called and said my son's SSI was active, so she did not need to continue with the DHS application.

Sure enough, within days my son got an SSI check. We kept his TennCare coverage. This five month battle to retain medical coverage for my child with a disability was extremely complicated, difficult, frustrating, nerve-wracking, stressful, and time-consuming. Still I fought. I persevered. I prayed. What else could I do? Having to quit my job to have medical coverage for my son is **Wrong**, and you know that's **Right!**

HELPFUL TIP

Appeals must be based on things that are not done according to TennCare rules
<http://tennessee.gov/sos/rules/tenncare.htm>

HELPFUL TIP

Tennessee Justice Center
615-255-0331 or
877-608-1009 (toll-free)
info@tnjustice.org