

**Human Services Public Hearing**  
**CommCare Waiver**  
**Testimony of Anna Marie Childress**  
**April 16, 2015**

Honored to be here before you so you can listen and hear me.

Suffered multiple TBI's (Traumatic Brain Injuries). Suffer from short/long term memory problems, extreme fatigue, focus, concentration, balance issues, loud noises, gait issues, etc. Also have an auto immune disease.

Grateful for the assistance CommCare Waiver affords me- personal emergency response system, community integration, in-home care (light cleaning), cognitive therapist.

When placed on CommCare Waiver, I was put on Medicare/Medicaid for my healthcare.

Grateful to have prescriptions paid for (had been in deep debt when on Medicare only because of the doughnut hole)

- Before Medicare/Medicaid was able to see any doctor I chose
- With Medicare/Medicaid there are very few physicians who take both
  - Will take Medicare, will take Medicaid but not 'both because of low reimbursement and an immense amount of paperwork. Access is a nightmare.'
  - I cannot go to the hospital I want because almost none of their doctors will treat me once I'm out of the hospital
  - Not getting the best treatment I can b/c I would have to pay "out of pocket" and cannot afford that
  - Are many alternative treatments that work for those with brain injury, we know they work, but medical insurance won't pay for them
  - Thankfully medical supplies paid for

## Speaking of...

- CPAP (Continuous Positive Air Pressure) Machine
- Have Obstructive Sleep Apnea
  - Machine broke in early February- spoke with the provider for that particular model
  - Medicare will not pay for new machine for 5 years
    - This manufacturer's machine cannot be fixed (Fisher/Paykel)
    - Machine is only about 3 years, so I'd have to purchase a new one (over \$1,000- unaffordable) or purchase a refurbished one that has no guarantee for about \$438.00 (again, unaffordable) I went back and forth between the provider and doctor's office.
    - Since we could not work this out I remembered that my Waiver might cover it because it covers Medical Equipment
      - Wrote to my Supports Coordinator who wrote that it's not an item they deal with.
      - Was told she'd meet with her supervisor to discuss the CPAP machine and whether they might be able to help me.
      - Was told they'd need to get 'special permission' to maybe accommodate me
      - Over the next few weeks I wrote often to see where we stood as far as the purchase of even a refurbished machine
      - My health was going down hill. I already had fatigue and when not being able to sleep at night was exacerbating my ill health. I was shocked that my health was and continues to get worse. I explained my problems.
      - Again she had to meet with her supervisor. Near the end of March, I received yet another e-mail from my Supports

Coordinator saying they should be able to get me another machine in a while.

- I wrote back asking 'are you talking months?' I'm afraid so, I was told. I wrote back telling her to forget it. Waiting months would worsen my health.
- When I wrote back I told her I was coming to this hearing and would let them know that these waiting times are ridiculous. We need more money from the legislature especially when our health is at risk. Please appropriate more funds to the CommCare Waiver.
- I was not asking for anything frivolous. We need support for those things that are necessary for as good a life as we can.
- Interestingly, a few days after I let her know I was coming here I received a phone call from my Supports Coordinator saying they could get me a CPAP machine the following week. What is going on???
- Yesterday, April 8, 2015, I received an e-mail saying we were back to square one. What am I to do?
- Now I'm in contact with the Disability Rights Network. More paperwork before proceeding.

## **Procedures**

- Please make sure the procedures and the Department of Human Services make sure I get what I need under the CommCare Waiver.

## **Funding**

- We need more money from the legislature especially when our health is at risk. Please appropriate more funds to the CommCare Waiver.

## **My Future**

- We all have uncertain futures and I try not to think too much about mine. I wonder where I'll go should my husband pass or become incapacitated.
- There has been so much transition in my life since my first TBI, much of which I have had no control over. My life is little more than a shadow of what it was in my former life...life before TBI. I have worked very hard to become who I am today.
- The next transition I look at is that of being a person with TBI who is aging. What might happen to me? My greatest fear is landing in a nursing home. With my insurance, lack of money it is apparent I will end up in a dump. Will there be money for me when I need it? Will someone make the calls to make sure my needs are met? This will, again, be out of my hands.
- Who will stand up for me? Who will advocate for me? No one can possibly understand how I feel and the fervor with which I approach advocacy for myself. It is quite difficult to know I will be at the mercy of others. Everyone gets to go home and leave me and leave me with my issues...alone.
- I pray I will die in my home where my children were raised and where Barry and I have wonderful memories rather in a nursing home. I hope you are hearing me. Please be sure there will be money left so I can die with dignity and for now meet my needs.

Anna Marie Childress  
155 Game Farm Road  
Schwenksville, PA 19473

