

## Theresa Utton

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**Subject:** FW: feedback on impact of proposed cuts for services

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Sent: Tuesday, August 12, 2014 4:28 PM

Subject: re: feedback on impact of proposed cuts for services

Attention Theresa:

I am the 60-year-old parent of a severely disabled 24-year-old daughter (requires 24-7 help meeting all needs), and we have been receiving assistance in caring for her since she was six years old. She is part of the pediatric/adult high tech program and receives care from both nurses and personal care attendants.

The impact made by these caregivers on the health and well-being of both my daughter and the rest of my family is truly incalculable. The help we have received has enabled my husband to work full time and me to continue teaching on a part-time basis. It has enabled my husband and I to address the needs of owning and maintaining a home that must be addressed while not leaving my daughter "on her own" -- where she would be unable to meet any of her needs. It has taken some of the burden off of us for her physical care -- including twenty-four years of constantly interrupted sleep. It has enabled us to get our daughter, who is extremely social, out into the community.

And it has given us the hours and hours and hours of time each week to trouble shoot difficulties with insurance providers (we are currently out of our daughter's formula and the provider has a "hold" on her shipment due to an improperly completed form submitted by her primary doctor).

During some years, the available help has been dependable and exceptional. Other years, the help has been sparse and mediocre. Truly, it wouldn't take an outside observer long to make the connection between the years our family has been relatively stable with all members (we raised two other children as well) encouraged and relatively rested with the years of consistent service, and the more unstable and overwhelming years with the years of lean or undependable service.

So far, I have been talking in general terms. Allow me to be more specific. What is the impact when a caregiver must cancel a shift and there is no replacement (there is rarely a replacement)? Sometimes it has meant missed work. Often it has meant cancelled appointments -- and we all know how far in advance appointments have to be scheduled these days. Sometimes it has meant my daughter did not get to scheduled programs in the community (Flynn Theater productions, for example). Always it means that important things which were going to be accomplished are not going to be accomplished as the burden of care for my daughter is unexpectedly thrust on a family member -- usually me. If this happens frequently enough, the entire family is easily overwhelmed.

Are you aware that per diem nurses can leave without notice? That has happened twice to us this year. Although training for new nurses is provided by other nurses in the home, the money is not available for many of these training sessions. The burden of training new caregivers falls primarily on me. It takes about six months to train a new caregiver in my home, due to the learning curve involved in using my daughter's equipment and in reading her body language. It is not due to the nit-pickiness of her parents:!) I have gotten to the point that I dread caregivers leaving not only because I have grown to appreciate them and because my daughter has grown to look forward to them coming, but because I know how much time I will need to spend bringing a replacement up to speed. Turnover of caregivers is one

of my biggest nightmares in this life! Yet it is testimony to my need of them that I continue to welcome them to my home.

I hope my feedback has been helpful. Caregivers are my family's lifeline. I KNOW that my husband and I could in no way care for our daughter without this help, and I know that my family is infinitely better off for their being in our home.

I would also put in a plug for the programs which allow parents to find their own caregivers and administer the funds set aside for this. Because of this program, I have been able to pay my personal care attendants a competitive wage, which in turn has enabled me to find and keep a few exceptional ones for more than a few months.

Sincerely,  
Beth Masters

PS I would be thrilled to answer any questions or talk further with anyone about this topic. I apologize for my tardiness in getting this to you. I was informed about this hearing today -- my daughter's case manager just learned of it late yesterday afternoon. If you are truly looking for the input of the families impacted by any changes, I think it would be a good idea to give the families fair warning of such opportunities. Honestly, my husband and I do not have the time to watch government sites for such opportunities. Our lives are crazy enough trying to meet our daughter's needs.