

5/12/15

Hello. My name is Jane Hash and I have a connective tissue disorder called Osteogenesis Imperfecta. I'm also the East Central Co-Chair for the Ohio Consumer Voice for Integrated Care and a lifelong resident of Ohio. The homecare services I receive through MyCare Ohio, CareSource, and the Area on Aging, allow me to live independently in the least restrictive environment, which is my house.

This open letter to the Senators, State Representatives, Governor, and legislators of Ohio serves as my personal testimony regarding:

- the importance of Consumer choice regarding homecare services
- the proposed wage reduction for Independent Providers
- MyCare Ohio

Many of us have been receiving these homecare services for a number of years and jeopardizing them would be a huge step backward for civil rights and the state of Ohio.

Any reduction of our necessary services and our Provider's wages is not acceptable. You are our elected officials. Your decisions on these matters are not reflecting what disabled Ohioans need to continue living safely and independently in our community.

All of us who depend on our Independent Providers breathed a sigh of relief when the Kasich administration removed the language from their previous proposal, regarding the elimination of IP's. However, immediately after the offending language was changed, the administration proposed a reduction of wages for our IP's.

This indicates to me that we have failed in communicating to you what personal care means to us, why it is important that we get to choose who provides this care to us, and why these Independent Providers deserve a raise instead of a reduction of wages – without sacrificing other services we depend on. Therefore, I feel it is my responsibility to share a piece of my story with you, to help you understand the impact your decisions have on my life and those who provide care for me.

Until I was about 20 years old, my Mother was my only Caregiver. She was a single mother of five and I am the youngest. As she aged and became increasingly more disabled, I knew I had to find alternate care options for myself to avoid being placed in a facility.

I did this research completely independently, before Google, and against the wishes of my family whom I lived with. It wasn't easy spending days at a time on the phone calling every government agency in the phone book for help especially with all the resistance I was getting from my family. I often had to argue just for someone in our household to hand me the phone book.

Finally, through my Medicaid Case Worker, I learned about the Ohio Homecare Waiver Program. For the next five years, I received Homecare services from multiple home health agencies. Most of these agency caregivers were recipients of some kind of government assistance because they were not paid enough to support their families. The majority of the care I received from these agency workers was very poor. Often times they would bring people with them who were strangers to me or they would not even show up. They were inconsistent and undependable.

Simultaneously, as I did my best to manage my own care with the substandard support the agency home health aides provided me, my Mother's health began declining rapidly. She became completely unable to provide any hands-on, personal care for me. She also lost her ability to manage my mentally ill, alcoholic older brother. Gradually, he took control of our household and my environment became so dangerous that I often had to call the police for help. The Lake County Court and Madison Police Station likely still has records of these events, should you doubt my sincerity.

When these agency home health aides would come to work at my family's home, they would see freshly punched holes in walls, broken furniture laying in disarray, and mistreatment of my Mother and I at the hands of my brother. Instead of advocating for me and making an effort to help me, they just wouldn't come back. Some even conspired with my brother in stealing my mother's medication.

Eventually, my physical and emotional health began to spiral out of control. I gained a substantial amount of weight. My face was so covered in acne that I no longer looked like myself. I was on several medications to control my asthma, which were having undesirable side effects. To cope with my out of control reality, I began drowning my sorrows in alcohol. I felt like I was dying and I almost didn't care.

Before I gave up completely, I called my Medicaid Case Worker again and explained that I was not getting proper care from the agencies that were servicing me and my health was suffering. That is when and how I learned about Independent Providers.

I received a list of active IP's in the mail a few days after I made that phone call. By the next week, I had interviewed and hired my first IP and my life began to turn around immediately.

That IP showed up every time she was scheduled to work. That was a new experience for me. She recognized my family's shortcomings instantly and discretely asked me if I felt safe and was happy. For the first time since the decline of my Mother's health, I felt like I had an advocate again. I had hope that life could be better.

Within two months of hiring my first IP, I moved out of my Mother's home and into a regular house with several roommates. That was fifteen years ago. I never moved back home with my family and now have a home of my own.

Over the next couple of years after moving out of my Mother's home, I transitioned myself away from agencies all together and assembled a reliable team of Independent Providers. With their support, I quit drinking, lost a third of my body weight, reduced my stress level significantly, and improved my overall well being so much that I have been free of all medications for over ten years.

The support I get from my IP's allows me to make my own healthy choices and maintain a safe and healthy lifestyle. Some of the services they provide to ensure my health and safety are things that nobody else will do, exactly when it needs to be done.

When I called 911 at 3am because I was woken up by a bat flying around in my bedroom I was told, 'good luck but the police and fire department don't deal with bats.' When the bat hit the ceiling so hard that it briefly knocked itself unconscious and landed next to me in my bed, I panicked and called one of my IP's. She dashed over to my apartment in her pajamas and handled the situation.

Awkward and uncomfortable are both accurate descriptions of some of the other necessary services my IP's provide for me. I practice a very aggressive oral hygiene regimen because of dental issues I have that are symptoms of my disability. Since I have a limited range of motion though, so I am required to use an electric toothbrush. On one occasion when the batteries died in my toothbrush, I did not have any money to buy new ones. The only other batteries in my apartment that would work in my toothbrush were in my vibrator. My boyfriend wasn't coming over until the weekend, I couldn't get the batteries out myself, and I needed to brush my teeth. Without judgment, a lecture, or unsolicited advice, my IP handled the situation and put the batteries where I needed them so I could brush my teeth.

I could go on and explain the challenges of assisting me with changing my tampon while using a public toilet but I think I have made my point. I hope that now you truly understand how valuable IP's are. I know there isn't enough money in the budget to pay them what they are worth because they all deserve a million dollars for what they do every day. They deserve a fair wage though and anything less than what they are making right now is not fair. Furthermore, they do not deserve disrespectful, bullying treatment they get from the watchdogs at PCG.

Last but not least, I have a few thoughts to share about MyCare Ohio. For the past twenty years I have been receiving homecare services and some things have changed. The name of the waiver programs has changed. The company overseeing the implementation of these programs has changed. All of these changes thus far have been relatively smooth...except for the MITS nightmare but that's old news. However, MyCare Ohio has been nothing but a huge source of stress and confusion in my life and many others. I get about three fullcolor, high gloss, expensive brochures from CareSource each month, informing me how easy MyCare is making my life now that I only have one point of contact whenever I need something. That little slogan is a lie. I have never in twenty years had so many points of contact before. I'm on the MyCare program, which is being managed by CareSource who is outsourcing to the Area on Aging for Case Management. When I have questions about things like wheelchair repairs, each one of these contacts gives me a different answer. These situations do not facilitate trust between Consumers and their Care Team. These situations lead Consumers to believe that either everyone is lying to us or we are relying on a team of ignorant people to keep us safe and healthy.

In closing, please understand that personal care is deeply personal. Imagine your mother, wife, sister, or daughter being the care recipient in the scenarios I described in this testimony. Would you prefer that caregiver be someone who you know and trust, or a stranger with questionable motives?

Thank you for allowing me to share my testimony. I am ready, willing, and able to consult with the administration on any future policy changes that will directly impact my life and those I advocate for. Improvement of the Self-Directed options for receiving homecare services would be an excellent starting point. There should be no decisions about us, made without us.

Respectfully,

Jane Hash