

March 4, 2014

In Support of SB-325

Dear Human Services Committee Members,

My name is Sara Wilcox. I live in Storrs and have been a resident of Connecticut for the last 13 years. I am here to support passage of Complex Rehab Technology bill. I cannot stress to you enough how important this legislation is and how important it will be for our citizens now and for our future generations. This is the only way many people with disabilities can get the specialized equipment they need. There are so many reasons this technology is very important not only to me, but for others like me, today I will only focus on a few.

On New Year's Day of 2012, I was involved in a serious accident that would forever change the course of my life. Prior to my accident I was employed full-time and I operated a residential painting business out of Storrs. I am a single parent. I volunteered my free time to the WAIM Community garden in Willimantic and donated the food I grew to a soup kitchen and a nursing home both in Willimantic. I have always maintained employment and was completely independent. My accident changed all of that. I suffered over 207 fractures from this wreck and am still in need of extensive rehabilitation. Even these conditions never made me want to stop working or give up my independence. My diagnosis until recently has been Infected Non-Union of LLE. I underwent 24 surgeries in 24 months; I have had muscle transplants, vascular surgery, skin grafts, irrigation and debridement and revision surgeries all in an effort to save my leg. I have not walked in over two years. My doctors have been trying to get me a wheelchair for the entire two years. I have always been denied.

These denials didn't stop me from trying to move forward with my life. I wasn't able to return to my previous position due to my injuries so I took the opportunity to reinvent myself. I looked at this as an opportunity. Not the end of my life, but the beginning of a new life. One year after my accident, I enrolled full-time at a CT Community College. I found a part time job. I cannot stress to you how difficult it is to find a job on crutches being in a deteriorated state, even with an excellent work history and ethic. Thankfully my potential was seen. My only mobility devise that was approved was crutches. You will find it interesting to know that even though these were my only method of transport when they wore out 6 months after issue and a replacement was requested by my doctor, they too were denied. I have degeneration in both of my wrists, my good knee and two bulging discs in my lumbar spine, none of which were present before my accident or as a result of it.

I use a variety of specialty equipment; my latest devise is an ultra-light weight wheelchair and I have had it for less than one week. Until recently I was fighting to get this wheelchair. It has been repeatedly denied. It was approved because I wrote a letter and sent it to over 90 people in our state and federal government. In my denial letters from Medicaid it states that I have the right

to appeal, which is what I tried to do. My appeals have never come through, I was never given a date, I was never able to speak with anyone. I made copies of everything I sent to Medicaid so there would be no misunderstanding of what I was requesting and the reasons why. However, the letter I wrote did make an impact, my denial for the wheelchair was overturned and I now have a wheelchair that is appropriate for me.

I feel the most important thing about my devises is that they are custom fitted to me and to my particular set of circumstances. The wheelchair I was fitted for takes into account that I have wrist and spine issues and modifications were made to my rims and weight limits to give me the best possible function for the longest period of time. My seating and back components are considerate of my lumbar degeneration and the overall dimensions take into account the specifics of my home, school and work. I cannot go into a store and purchase an off the shelf chair that does this. My specific deficiencies were taken into account by my doctors, my physical therapist and by Jay Hein at Hudson Seating and Mobility, all in an effort to keep my independence. Our bodies are all different and that is why our mobility devises need to be customized by the specific industries who focus in these areas

My devises help me medically because they prevent the rapid deterioration of my physical body, functionally they allow me to continue to live somewhat normally; socially these devises give me the confidence to engage people again. Without these custom devises I would never be able to maintain employment or even continue my education. In my opinion this should be a goal we want for all our citizens, including those with physical disabilities. Many fail to see that people with disabilities are a group that can enlighten and inspire others. We need these custom devises and the qualified personnel these companies employ to do seating evaluations, repair, adjust and modify them to our specific needs.

More than anything these customized devises allow people like me to find things we are good at again. I cannot even imagine having a child with a disability who has been denied this opportunity. Which is what these custom devises are; they are opportunities for people to live up to their full potential. These Complex Rehab Technology devises even the playing field so that someone like me isn't at a disadvantage. Even the most disabled person, given the correct tools, would rather be an asset to themselves and their community than a burden.

This specialized equipment is vital to children and adults with disabilities. It helps reduce healthcare costs and provides independence and safety. The Complex Rehab Technology bill will help improve people's access to specialized equipment and add safeguards to make sure only qualified companies provide these products and services.

Please pass this bill. Thank you for the opportunity to speak to you today.

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