Testimony to State Legislature

by Sally W Johnston

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February 2, 2022

Good afternoon, my name is Sally Johnston and I am with Disabled in Action of Greater Syracuse, DIA. I’m here today to speak on behalf of DIA, myself and thousands of people with disabilities as well with our senior population.

We are in support of the proposed bill, Fair Pay for Home Care introduced by Senator Rachel May. I along with many thousands of individuals using home care are struggling to remain in our homes. I was born with a disability, was married for 52 years and raised a son. I worked for over 50 years in human services, managing several programs.

My husband died of cancer in 2016 and I began to spend our savings to pay for my home care services. Around 2020 I had spent most of my savings and had to apply for long-term care through Medicaid. I don’t think that I ever interviewed as many people in my working career as I have in the past couple of years trying to hire and maintain good personal assistants to work for me. I am now 79 years old and need personal care more than ever! I need help getting out of bed, going to the bathroom, getting a shower and getting food to eat.

It’s been very difficult for me to keep a personal assistant because the agency can only pay minimum wage which is $13.20 an hour. Most home care workers are women and are financially struggling to care for their families. They often apply for Food Stamps, HEAP and subsidized housing to make ends meet. It’s hard to keep someone when they learn they can go for example to Burger King or McDonald’s and make $17 or $18 an hour.

I’m on a fixed income and so are many thousands of others who receive long-term care through Medicaid. I’m only allowed $800 a month to pay all my bills and buy food. I also use some of my fixed income to supplement my PAs income to ensure that they will continue to work for me. It’s not easy, trust me!
I along with many others are struggling to stay out of nursing homes. We want to remain independent in our own homes. I’d like you to take 5 or 10 minutes out of your day today and just imagine that suddenly you developed a disability or a serious illness. Now you need help getting out of bed, going to the bathroom, help with showering, eating and managing other daily tasks. Just think about how you would feel if you couldn’t get the help that you need because you had trouble keeping a PA. How would you get help getting out of bed getting all your needs met?

During the COVID pandemic, home care has enabled me to stay safe. If you send me and thousands of others to nursing homes, you will be sending us to a place where we will not be safe! COVID thrives in congregant settings. It also costs a lot more to pay for care in a nursing home versus care in your own home.

We know that most of the state legislators are in support of Fair Pay for Home Care and we truly appreciate your support. As many of you know, home care workers did not get any raises in the governor’s proposed budget, only one-time bonuses. Bonuses will not end the home care workforce shortage - Fair Pay for Home Care will. It’s time now for all of you to SPEAK UP and STAND STRONG to ensure that this bill is included in the final budget.

We desperately need your help and support in order to survive! Please make sure that Fair Pay 4 Home Care is included in the budget.

Thank you for the opportunity to speak to you today.