

A Consumer Workforce Council for Pennsylvania

Testimony Provided for the Aging and Youth and Labor and Industry
Committees of the Pennsylvania Senate

Submitted by Kelly Valdez, Executive Director of LIFT (Life and
Independence for Today, a Center for Independent Living)

Good morning.

My name is Kelly Valdez and I am the executive Director of LIFT. I support the CWC today in my role as a leader in the disability rights movement, and I'm really proud to join other centers for independent living in endorsing this initiative. Endorsing CILS right now include Liberty Resources for Independence, Tri-County Patriots for Independent Living, Voices for Independence, Disability Options Network, the Center for Independent Living of Central PA, Freedom Valley Disability Enablement, Inc., Life and Independence for Today, the Center for Independent Living of North Central PA, Disabled in Action or PA and the Disability Empowerment Center. We're from counties like Washington and Fayette and Lawrence, and also Philadelphia and Montgomery and York and Cameron and all across the state. And the list gets longer every day. I am also really proud to be joining senior organizations like AARP and PARA. At my CIL we often say that anybody who needs supports is a person with a disability, and some of us are older, and some of us are younger, and all of us want the same thing: the ability to choose the services and level of independence that is right for us. Finally, I am happy to be standing with community organizations like AM Vets and the Pennsylvania Council of Churches.

Today, however, I am here to talk about my life *before* LIFT. Because I am an example of what is all too common in our homecare system, and that's an attendant who quit her job. But let me begin at the beginning.

It was about 10 years ago when I first met Dave, a guy in a wheelchair who I met in the coffee shop and around Emporium PA. Dave and I hit it off, and after a while he started bugging me to think about becoming his attendant. For a long time I said no, because I didn't think it was work I would want to do and I was making OK money at the job I had. But finally he wore me down and I decided to give it a try. I became Dave's attendant.

It didn't take me long to realize I had found my calling. And I want to spend a few minutes talking about what made the job so great. Most importantly, of course, was the fact that the work was extremely rewarding. I think just about everybody in this room knows the joy of having meaningful work, and working to serve people. And people who want meaningful important work know that it's OK not to make top dollar or to have to struggle a little – that's all part of having a purposeful life. Recently someone in Dave's family told me that my working with Dave undoubtedly added years to his life over what would have happened if he went into a nursing home. It's incredible to be able to make that kind of difference.

And there were other things I liked a lot as well. Dave and I were in the consumer-employer program, so we had a lot of flexibility about how to arrange our days. Dave's particular disability meant that afternoons were down time for him – mornings and evenings were when he could live life most fully. So he wanted to schedule me to come in the morning, leave him alone in the afternoon, and then come back later on. This worked out really well for me, because it let me put my kids on the bus and then

meet them in the afternoon, and then go back when Dave needed me again. As we got to know each other better, we really fine-tuned our lives to mesh perfectly. Dave was OK if I had a family emergency and needed to schedule differently, and a lot of times he would join in my family's activities when he wanted to get out and about. Being an attendant was a win win for me and Dave, and I cannot stress enough how much I loved being an attendant.

If we had a way to locate all the thousands of former attendants and talk to them, I think you'd hear stories very similar to mine. Attendants are special people who do very important work. And working in the consumer directed model with a wonderful person like Dave can really be a good career choice for younger women and men who have children and complicated schedules. Yet fewer than half of attendants have a year on the job, because as you know, we leave.

Turnover rates for attendants are alarmingly high – as a CIL director I often hear from people who have 10 different attendants in 10 years and whose attendants leave before even starting because they find work that lets them do better by their families. In my own case, there were really two major issues: health insurance, and also dignity.

Let me say a few words about health insurance. I know everybody in this room has a meaningful life serving people, but I bet most of the Senators have little idea what it is to have no health insurance. And I don't begrudge them that! No one should be in that position. When I finally gave up working for Dave, I was 38 and was working enough to

be ineligible for Medical Assistance. I literally could not afford to get sick – I was afraid of making my employer ill and I could not afford to go to the doctor or prescriptions. I know that my experience is not uncommon. Many dedicated hard-working direct care workers leave their positions for better jobs that offer health benefits. As a woman with children, I needed access to health insurance, though I hated to leave a job that offered so much for all of us. I want Pennsylvania to be a state where people who love being an attendant don't have to make the choice that I made.

I also want to say something about dignity. If you work full time supporting a person so that they can have a good life, you deserve a good life yourself. If you spend your days helping people enjoy participating in the community, you should be able to participate in the community. I have already said that being an attendant provided one very important component of a good life, and that's making a difference. But you are not having a good life when you live in constant fear of illness, when your phone is always being shut off, when you can't afford to put gas in the car, if you have a running car, when you can't, in other words, participate very easily in the community.

We want a way to address these things that doesn't involve hand-outs. We want to begin to work together and work with our consumers to get our long term care system where it needs to be, so that we don't get told by the Department of Aging and by provider organizations that we should apply for welfare and Adult Basic. I understand that that advice is given with the best of intentions, but attendants want to work together with their consumers to do a little better than that. States that have Consumer Workforce

Councils have been able to get wage increases and a little vacation time and real health insurance to attendants. I think we should aim for that too.

I have one more thing to say, and that is about government. I know that some people are saying that the CWC is bad because it creates a government run agency and bureaucracy. I don't really understand that, since the Council is just a board of consumers who meet with attendants to try to do what is best and fairest in the consumer-employer system. It's run by seniors and people with disabilities, not bureaucrats. We have plenty of Councils in Pennsylvania, and I don't think anyone sees them as government run agencies.

But I do think there is a role for government in the CWC, and that is to help us to create it. I'm sure most of the Senators know that the proposal for the CWC was put together last summer by a committee that included attendants, advocates, and consumers, and we worked hard to make it a good proposal. It seems to me that when the people who are affected by something come to government and say, hey, we have an idea for how to run this system that makes it better, and that furthers many of the state's aims, and will save taxpayers money to boot, that government would want to respond, not by tearing holes in our proposal, but by figuring out how to make it happen. I hope that's not completely naïve.

Thank you very much for allowing me to testify today.