

A Consumer Workforce Council for Pennsylvania

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

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Independent Living of Central Pennsylvania and
Living Well with a Disability

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Thank you Senators for giving me this opportunity! I am especially pleased to see Senator Vance, who represents many of the people I work with at the CIL of Central PA. My name is Theo Braddy, and I am the Executive Director of the Center for Independent Living of Central Pennsylvania.

About 2 years ago, I started a new program called Living Well with a Disability. The main purpose behind Living Well is that everyone regardless of their situation wants to live well. If you are a person with a disability, you want to live well. If you are a senior, you want to live well. And for the purposes we are here for today, if you are one of the extraordinary attendants or caregivers who assist persons with disabilities every day, you want to live well.

The CIL of Central PA offers both the agency and the consumer model and we're excited to give every consumer that choice. The Consumer Workforce Council addresses only the consumer employer model, and I'm here to talk about these today.

People with disabilities fought very hard to make Pennsylvania introduce the consumer-employer model. We are very thrilled with it. This model – which allows individual seniors and people with disabilities to choose hire, fire, manage, direct and schedule their own attendant – is not for everybody. But many people – most people under 60 and increasingly our seniors – like the control and independence that the consumer-employer model offers. The consumer-employer model is very precious to us and we get very touchy when somebody tries to infringe on the rights of the consumer-employer model.

But if we are honest with ourselves, we admit that the precious rights of the consumer employer model are eroded and undermined every day because seniors and people with disabilities cannot find or retain attendants. Our precious rights become somewhat empty when we can't get out of bed or get to work because our attendant's car has broken down and we have no back-up. Even our good days are filled with anxiety about when our good attendant, who has finally learned to do things just right, will have to quit to take a job

that pays better or offers benefits. We created a model that offers us real independence, but our unstable workforce every day accentuates our inability to truly control our lives. And since we are determined to live well, we are determined to address the workforce instability that undermines us.

Now the people in this room are all serious-mined people, so we are able to acknowledge that turnover and instability are driven by poverty wages and no benefits. No health insurance, no sick days, no vacation, and no retirement. Turnover and instability are also driven by the absence of hope -- for attendants can have very little hope that there is a way, even a way that might take time, to improve their situation. And because we are serious-mined people, we are also able to acknowledge that although many of us have tried over many years to address turnover and wages and benefits, we have failed. \$9.10 an hour may be better than folks have it in Alabama, but it only amounts to \$18,000 a year in Pennsylvania, and when we are honest, we admit that attendants' real wages have actually DECLINED over recent years. And so we must choose: we can commit ourselves to addressing our workforce problem in a serious way, or we can oppose change while cynically claiming to be for it.

For now, I would like the Senators to understand that consumer-employers do have a proposal for reducing turnover, improving wages, and benefits, and restoring hope for ourselves and our attendants. It's called the Consumer Workforce Council.

What is the CWC and what does it do? First of all – and this is very very important – the CWC corrects a glaring moral flaw in our consumer-directed model. Our model, precious as it is to us, has for years deprived our attendants of the right to advocate on their own behalf in their own interest. In our movement, we have the slogan “nothing about us without us,” and we take that slogan to heart, since it is a fundamental tenet of human dignity and justice and indeed of human hope. We aim to live by that motto, but our consumer model was built in a way that leaves our attendants with no legal avenue to come together to speak in one voice about their lives and their needs. That is wrong and it's hypocritical. If CILs, and the homecare association and nursing homes are

empowered to form organizations and pay dues and speak up for themselves in our system, then attendants must have that right as well. So we designed our Consumer Workforce Council to restore the right of self-advocacy to the attendants who support us, and we feel very good about that.

But seniors and people with disabilities who enjoy the consumer-employer model want to be very sure that attendant self-advocacy doesn't interfere with OUR rights. Attendants must never interfere with the consumers' right to hire who they want, fire who they want, to schedule or manage or train their attendant. Our proposal for the CWC makes that very very clear. Attendants must never threaten consumers with strikes or sick-outs, and our proposal makes that very very clear. Finally, attendants' better wages and benefits cannot come at the expense of consumer services. The Consumer Workforce Council is the way we ensure that attendant needs AND consumers' needs are addressed in a fair and balanced way.

And that is because the Consumer Workforce Council ensures that attendants talk TO us, not around us, as they seek improved funding. When attendants join together to improve their wages and benefits, we consumers want them to bargain directly with us, through the representatives that we elect to the CWC. This empowers consumers to look at available funding and work with our attendants to strike a balance that makes the system work better for everyone. We might say no, we can't afford health insurance without cutting into consumer services, or, in a better year, say, yes, there's funding now to make raises happen. We will always want to protect consumer services, but we will want to make improvements for attendants in years that we can, because as consumers we know the pain of losing attendants and we know why improvements are absolutely necessary. The Consumer Workforce Council does not alter individual consumers' ability to choose, hire, fire and direct their own attendants. It adds to those powers the ability to talk directly with our attendants about the best way to allocate funding so that we serve the most consumers in the best way possible way. The Consumer Workforce Council does not alter individual attendants relationship to their consumer, but it does give attendants as a group an avenue for seeking the improvements they deserve, and in doing that, gives

them the dignity, and the hope, that comes of with being able to speak on one's own behalf.

At bottom, the Consumer Workforce Council is a negotiation between consumers and attendants about the funding and services that affect their lives. This negotiation is not a state run agency. This negotiation is not a giant bureaucracy. This negotiation is dialogue between people whose lives and needs are intertwined – people who have chosen to have a fair and honest discussion about how they will conduct their business and augment their human dignity.

We are very proud of the fact that Pennsylvania's consumers and attendants came together to create the Consumer Workforce Council. We admire our attendants for their vision and determination and we look forward to working with them in a wonderful new way when our Council is established. We are proud in the disabled community for having the courage to acknowledge reality and to put aside our fear, in favor of healthy and necessary change. We would ask those who are not stakeholders in our consumer-employer system to treat our proposal with the respect it deserves and to think – to really think – about why they stand opposed to the people who are affected. Together we can build on what is beautiful and strong in our entwined lives and in our common effort to live well.