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## Lead for Ohio Advocacy Taskforce

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## **Proponent Testimony for House Bill 33**

Thank you Chairwoman Carruthers, Ranking Member Liston, and members of the House Health and Human Services Subcommittee, for the opportunity to testify on the importance of investing in the inhome care workforce. I also want stress the importance of the budget language that would require at least one person with a Developmental Disability (DD) be appointed as voting members to their local county boards of DD.

My name is Renee Wood. I am a member of multiple organizations in Ohio and currently Chair 2 of these organizations. Specifically I am here today to speak on behalf of the Ohio Advocacy Taskforce. The Taskforce was initiated by an Ohio Developmental Disabilities Council grant in 2018, to increase the voices of People with Developmental Disabilities so "that {their voice} is recognized and respected by elected officials, stakeholders, and policy makers". The voting members of this taskforce are people with DD, however the Taskforce includes non-disabled community allies as non-voting members. This Council grant ended in October, but the Taskforce is still meeting and is looking for funds to become self-sustaining to carry on our work.

In deciding how the taskforce would increase the voices and respect for people with DD, we realized, and it was confirmed by a survey the taskforce sent to 88 County boards of DD in 2019, that only a few individuals receiving services (people living with DD) were being appointed to the County Boards of DD. Of the 58 County Boards who responded, 47% of those 408 seats were filled by parents. That same year we found that of the 616 board seats throughout the 88 counties, only 11 (.07%) were occupied by a person living with DD. Taskforce members saw this as a barrier to having our voices recognized and respected by others in the community at large, if our own county boards weren't asking appointing authorities to search and appoint qualified people with DD. It would have been appropriate for the county boards to explain to appointing authorities that the voices of those who actually utilize the services are missing as voting members. Since this effort was not made, it appears that county boards who know us, don't miss our voice at the table, so why would the community at large see our voices as valuable. Through the efforts of the taskforce we have increased the numbers of people with DD on county boards, but it is still not where it should be. The proposed language only solidifies the original intent of the law which was to have the county commissioner appoint at one person eligible for services, whenever possible, to the county board, or a family member. "Whenever possible" was the way out. We are honored that the Ohio Department of Developmental Disabilities included language in the budget that clarifies the original intent of the law.

I would also like to speak about my support of the budget to increase pay for direct care workers to lessen the effects of the direct workforce crisis on people with all types of disabilities, no matter what system they receive their Community Based services through. Parity in pay is paramount to ensuring all people with disabilities benefit from a pool of direct care workers, and these workers don't choose a particular service system because it pays more for the same work. Please know that whether it's the DD

system, Ohio Home Care through ODM, or aging, they all serve people who have varying levels of disability. In other words, there is no one system that serves "the people with the most significant disabilities". The only difference in these service systems is the age of onset of the disabilities. That is why parity is crucial throughout the service systems.

My colleagues and I recommend an average pay of \$20 per hour for direct care workers, and they explained the details of why that needs to happen, so I won't go into that again. However, I will not benefit from these increases for the direct care workers, I am solely here as a disability rights advocate. I want to make the committee aware that my situation in much different than many of my peers with DD as well as other disabilities, in that I am not on Medicaid and therefore do receive any kind of waiver services from any of the services system such as DODD or Ohio Medicaid – I guess I am even old enough for aging services, but we won't talk about my age. Since I chose to live a life like anyone else; a career, college and marriage to a non-disabled man, this disqualifies me from any of these services due to our combined income. However, I do get services from my local county board of DD through what is called an Individual Budget. This affords me the luxury of hiring, training, paying and terminating workers for which I am reimbursed by the County Board by submission of receipts. Although my workers know I get reimbursed, to them I am a private hire.

The status as a private hire allows me to hear things from these workers that they think are wrong with the system. Some of them vow never to work in the system again. I watched testimony from last week where many of you asked questions that I felt went unanswered. From what I remember you asked what could be done legislatively that would improve the workforce situation. My following answers in no way diminish the primary needs for an increase in wages of direct care workers to at least \$20 an hours on average. Without that any benefit from legislative changes will be minimum.

Some of my workers are STNAs, Nurses (not that I require nursing care, she is just interested in helping people), and other qualified people who used to work in the system through agencies as well as independent providers. What I am hearing from them is that the system is overly burdened with regulations that get in the way of truly caring for the individual's needs. I will bullet point some of these regulations, although I can't site them in the Rule for you, I just know that they exist.

- Independent providers have said it takes too much time and effort just to be certified to work as an independent provider. Sometimes it can take three to six months of unpaid time. Some of them have worked without pay until they were certified, just because they cared about the person. This does not encourage people to become workers.
- Also even when they are certified some of them don't receive a check for a while. Also any
  obviously minor errors are treated as if they were intended as fraudulent, rather than just asking
  them to correct the minor error, such as a date, so they can be paid. Treating everyone as a
  potential scammer does not bode well for retention.
- As far as agencies, of course, they say they pay too little, with no benefits such as health insurance, paid vacation, or paid medical leave.
- Many said because they were very good workers the agencies take advantage of them (understandably so because there are few good workers in agencies).
- Many agencies discourage healthy relationships between client and worker. Many think this is because agencies don't want workers to get know their client, for fear they will start advocating for the needs of the client.

• Another issue that they talk about is that they don't know who the boss is. Is it Medicaid, is it the agency, is tit the count board, or is the person receiving the services? The person receiving services wants one thing, but the gamut of the system may say something else. It could be a simple as a trip to Walmart – these workers just don't know who to listen to.

These are only a few examples of people who really want to assist people with disabilities but no longer want to do it within the heavy bureaucracy of the Medicaid system.

Thank you for listening. And I will take questions if you have any.