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My name is Joe Moore and I'm a resident of Tiffin, Ohio in Seneca County. I have a adult son with developmental disabilities.

I am here to urge you to retain and safeguard the language in Section 5123.62 of HB 64 which strengthens the Bill of Rights for Individuals with Developmental Disabilities.

I'm here today on behalf of my son. Along with all the other family members who testify and those who have submitted written testimony to this committee, we are speaking out because the agencies and organizations who purport to represent individuals with developmental disabilities do not speak for our sons, daughters and other family members. I have no doubt that these groups do indeed represent some individuals, but please know that they do not represent everyone. There is a vast silent majority who remain voiceless in this conversation. If we thought our family members and loved ones were truly represented by one of the agencies or organizations, we would not have taken time to come and offer testimony today.

I am, in fact, a bit surprised to see that some of these very agencies have written to this committee to ask that you remove language from the Bill of Right of Individuals with Developmental Disabilities that guarantees families

and guardians have the right to participate in decisions about appropriate services. When the Ohio House added that language, they were securing the right of individuals to have a voice at the table who could represent them in the decision making process. That family member or guardian is a sentinel protecting the rights of individuals who are not able to effectively speak for themselves or in their own best interests. The participation of that family member or guardian in the conversation guards against coercion and makes sure the individual's rights and best interests are protected.

I recently contacted a probate court judge in our county regarding the this topic and he assured me that when he appoints a guardian for an individual, for all practical purposes in the eyes of the court, the guardian and the individual become one. If there is an significant disagreement between the guardian and the ward, that may be a case in which the guardianship should be amended. Otherwise, the participation of the family member or guardian in decision making is essential if the individual so desires.

Just because a person has a right doesn't mean that he/she has to exercise it. Individuals have the right to have a family member or guardian assist them in making decision regarding their care and services, if they wish to exercise that right. If an individual is able to speak for himself/herself and doesn't need/want to have a guardian speak on their behalf, that's fine. Please preserve that language in the Bill of Rights for Individuals with Developmental Disabilities as amended in HB 64.

I would also like to ask you to guarantee the availability of facility-based employment and day services and to allocate appropriate funding to make this possible.

If you've met one person with developmental disabilities, you've only met one. Each person is different. When Employment First proponents state that every person is capable of working in the community if given the appropriate supports, they are out of touch with the reality of daily life. It's simply not true. I whole heartedly agree that individuals who seek and are capable of retaining a job in the community should be provided every opportunity and support necessary to achieve that goal. Restricting such and individual to sheltered employment is just as unfair as forcing others into community employment against their will. But not everyone can, or even wants to work in the community. Some prefer the safety and security they find in a sheltered workshop. That choice should be theirs to make. The fact is that there are persons whose disabilities are so complex that they cannot even work in a sheltered workshop environment, and for those individuals, we also need to ensure that facility-based day services remain available in addition to employment. However, despite the Olmstead decision that says that individuals can choose the setting in which they receive services, it would appear that Employment First initiative is going to usurp their right of choice and will dictate where those individuals receive services.

Allow me to give you a glimpse of how this is likely to play out for John, a student in our school program who just graduated last week. This student, his family and his team don't feel it is in his best interests to pursue community employment. Due to severe anxiety disorder and his other

challenges, he won't be able to find and retain a job in the community despite the array of supports available. If he is able to enter the workshop right away, he may be grandfathered in and allowed continue to work there. Otherwise, he will be evaluated by Vocational Rehabilitation to see if he is considered "employable." If so, he will be forced to go through the unnecessary stress and embarrassment of enduring failed attempts at community employment before the agency realizes that he is not capable of retaining a job in the community and he may become eligible to request admission to the workshop.

While that alone presents challenges, the story doesn't end there. The situation gets even more complex because there are federal issues at play here as well. As parents, family members and caregivers, we are asking for your help in preventing what could become the perfect storm, one that will have catastrophic consequences for individuals in Ohio and across the country.

The perfect storm is being precipitated by an unanticipated convergence of initiatives, rules and laws including the closure of sheltered workshops, Employment First mandates, and the impact of conflict-free case management. Parents and families are left to wonder what the future holds for their children.

Let's go back and see how all this impacts our recent graduate. When John wasn't successful in community employment, the workshop was his safety net. It afforded him a sense of dignity by allowing him to work. It provided a source income. And it offered him a place to go during the day. But if the workshops are forced to close, John will be left without a job, without income, without activities to fill his day and without an opportunities to see friends. Without the workshop, John will likely spend his days at home.

The most obvious solution would be to give John a waiver so that he can receive day services in the four-person cohorts proposed by the Department. That sounds simple enough, but who is going to fund that waiver? If John were a unique case, this wouldn't be such a challenge, but there are thousands of individuals just like John in Ohio, who are not able to get and keep a job in the community. The proposed number of additional waivers will not satisfy the need across the state. And nationwide that number will be staggering. Some would have you believe that the state and the federal government will save money by placing individuals in competitive jobs in the community. The theory is good, but the numbers don't support the claim. The cost to train and place an individual in a competitive community-based job is actually very high, especially for a job that the Department admits may only be for a few hours per week. If an individual is able to retain that job for a period of ninety days, it is considered a successful placement. But you should also be aware that if the individual loses the job or is downsized for some reason, the state will have to pay the additional training and placement expenses associated with finding another job.

And for individuals who won't find full-time employment in the community, where is it that they will spend their non-working hours? The Department talks about a plan to offer day services that will afford individuals a variety of opportunities for community integration. While the concept sounds promising, too many parts of the plan have yet to be clearly defined. The Department talks about 1:4 ratio for supervision, but that number simply doesn't work for a great number of individuals due to health, safety and personal care issues. And perhaps the biggest question of all is transportation.

How are individuals going to be transported to and from all these locations across our county? Even in our smaller community it would require a veritable fleet of handicap-accessible vehicles, not to mention the insurance, maintenance and fuel to keep them running. Transportation is a topic that the Department hasn't even addressed yet.

All of these unanswered questions leave individuals, parents and family members trembling in fear. The future is unclear. It's impossible for us to plan or know what to expect. We cannot allow ourselves to go back to the middle of the last century when individuals were kept at home because services weren't available. We might be more supportive if the Department could show us a successful working model somewhere in the state. It would be easier for us to embrace the plan if it were clearly laid out and explained, if the cost studies had been done and if the Department could offer substantive answers to our questions. However, we are being asked to let go of smoothly functioning employment programs in sheltered workshops and in their place we are being offered a promise. That makes us uneasy.

CMS is trying to fix something that isn't broken and it's pressuring states, including Ohio, to make decisions that will dismantle robust and successful workshops programs across the state. Individuals here in Ohio already have the choice of pursuing community employment or entering a sheltered workshop. That choice is worth fighting for. It should be a choice individuals are invited to make and to reaffirm on a regular basis.

The Ohio House found the formula for a very simple win-win. Choice. Allow individuals a choice in the services they receive and the location in which they

receive them. Work in the community or work in a workshop shop. It's a choice. It's a win for everyone.

The question appears to be whether we, citizens and legislators working together, are willing to push back on CMS and the federal government and defend what we have and prevent this perfect storm. Everything we now have can be lost with a few strokes of a pen, and once it's gone, it will take years to rebuild. Every person who has given testimony on this topic in the recent months represents hundreds of family members and friends who are asking for your help and who will support your efforts. I assure you that you will not stand alone. Wisconsin has already taken that step on behalf of its citizens. Are we, as Ohioans, strong enough to stand up and be counted?

Thank you.