

Good afternoon, my name is Jane Atwood from Toledo, Ohio. I am the parent and legal guardian of my 30 year old son, Benjamin DeVorss who is autistic and attends Bittersweet Farms in Whitehouse Ohio for day habilitation.

I believe that the transition plan proposed by DODD does not uphold the true purpose of *Olmstead* and infringes on my son's civil rights. Benjamin suffered throughout his educational career because the system failed. The necessary attention to autism and its needs in the schools were not addressed at that time and now he is suffering again. My son has endured what inclusion in schools and real inclusion in the general community entails, and this is not acceptable. In both settings, I have witnessed my son mocked, provoked, physically assaulted, robbed, treated as someone who does not belong, and targeted as someone who is not wanted. As recently as two months ago, he was unnecessarily yelled at in a local store for simply walking past a spill in an aisle way. I watched as he froze in fear and did not know how to respond. While the contention is that the transition plan offers a positive and rightful choice for some individuals who have a disability, this is not true for others who are IDD or Developmentally Disabled. People with compromised cognition are in the situation where they are unable to make critical life decisions, defend, and personally care for themselves every day, making them uniquely vulnerable to the circumstances and environment around them.

Benjamin has been on the IO waiting list for 13 years. Having continually inquired about the future of his safety and residence if anything were to happen to me as his primary caretaker, I was informed that he will never receive housing or a waiver. I was told that they are only giving IO waivers to emergencies and to move people out of ICFs. To quote: "if you die, I promise we will take care of your son, we will put him somewhere." I cannot express to you how this made me feel. How would you respond as a parent if you were told that your child in need of help would end up "somewhere?" In my own personal efforts to establish housing for my son within the community, I was only able to negotiate a small subsidized apartment in a very rural location where he would remain unsupervised and only receive 4 hours of service each week when not in his day habilitation. This would have put him at great risk, not just for his general well-being and safety but also his life, so I chose not to put him in this position and I do not wanted him forced into a position that could result in emotional distress, injury or death.

Since then, Benjamin has developed several extenuating medical conditions that are potentially fatal when combined with his inability to critically evaluate his own health and his surroundings. In order to take care of these conditions which involve multiple trips to the hospital for blood work, lengthy phone calls to specialists, frequent visits to the pharmacy, and monitoring constant changes in medication, I have had to resign from my place of employment and devote my full time attention to monitor his symptoms, actions, behavior, in order to keep him safe and as healthy as can be.

We have an ever growing population of people with disabilities, instead of displacing individuals from these targeted groups, we should be increasing the amount of Individual Options waivers offered through the counties to support housing and day habilitation programming for the 22,000 disabled people who say they are in need of services immediately. Currently, the waiting list for services in Ohio counties far exceeds what is provided in funding. If the plan does not address how it is going to meet the current and future needs of people with disabilities, how can it possibly propose that “targeted” communities be redesigned and/or eliminated? The transition plan should support outcome oriented criteria in the federal HCBS regulations, however the current proposed transition plan is including restrictive criteria which is limiting people with disabilities’ choices for their freely chosen environment. The plan should be supporting people with disabilities by ensuring fewer barriers are implemented in the process of determining state criteria not creating more.

The transition plan specifically targets intentional communities as not being “home and community based.” If a choice is to be presented, then the whole spectrum of choices should be offered. I contend that Bittersweet Farms is a community which is built on the very premise of what constitutes community; family, friends and home. What is proposed in the transition plan is actually restricting choice by defining what constitutes a person’s “home and community” based on the fact that they are disabled? We certainly do not impose this same ideology upon the non-disabled population’s choices in their communities. Why only the disabled? Isn’t this really what is discriminatory, not the communities they choose to live in? The current proposed transition plan should not force individuals out of their current or future choices that have been deemed appropriate and reasonable by their service care providers and more importantly, where they feel safe, comfortable and at home. This includes all intentional communities such as intermediate care facilities, campus settings, group homes, supported living arrangements, farmsteads and live-work-play pedestrian-oriented programs.

The transition plan does not allow for transparency in the process of developing action steps to address the remediation concerns. To simply indicate convening of “work groups” does not allow for public input into the most vital and important piece of the plan.

Of course I want to advocate for awareness, understanding and acceptance of the positive attributes of these individuals and my son, however it does not change or eliminate the many challenges in their day to day life for which they require and need support.

As a parent of a child who desperately needs the services, care, and necessary housing, I do not understand why we are targeting a model community like Bittersweet Farms that is revered, emulated, and considered to be one of the premier organizations, not just in Ohio, not just in the United States, but internationally, and this is based on the fact that it is a farmstead serving adults with autism?

Public Testimony (full), Jane Atwood

It is time for the State of Ohio, DODD, providers and citizens to push back against this misinterpretation of *Olmstead* and support the rights of those IDD and Developmentally Disabled individuals to have a voice in choosing their own residence and community.