

My name is Dan Jones and I am from Fairview Park, a Westside suburb of Cleveland. I am Kelly Marie Jones' dad and I speak for Kelly and the rest of her family this afternoon.

Kelly is 29 and was diagnosed at an early age as having a rare genetic disorder called Cornelia de Lange Syndrome (CdLS). It causes a range of physical, cognitive and medical challenges and does not discriminate—it's seen in all races and ethnic backgrounds. Kelly is approximately 4' tall, her weight typically is around 85 lbs., she can walk, she cannot talk. Intellectually, she functions at about an 18-24 month level.

Kelly has lived at Flat Rock Care Center – an Intermediate Care Facility home that is surrounded by 500 acres of woods and open farm land near the north central Ohio community of Bellevue, OH for 17 years. I am happy to say that despite her mental and physical challenges, Kelly is thriving and has outlived the initial prognosis the doctors and specialists offered when she was born.

Why is Kelly thriving? Choice. When our family looked at the options available for placing Kelly in the care of someone else, we looked at group homes, farmsteads, and intermediate care facilities throughout north central and northeast Ohio. We selected Flat Rock because it was the right choice to make when considering the full scope of Kelly's needs and requirements.

The state's Plan for HCBS in response to the CMS Transition Plan clouds the fundamental right of choice (as clearly defined in Olmstead) for I/DD individuals. Instead, the Plan introduces sweeping changes without choice. We have been told that the ICF home system is not within the scope of the CMS Transition Plan, but yet we have also been told by DODD officials at public meetings that ICF homes do not meet home and community based setting criteria; clearly a target has been placed on ICF homes. Further, the state's plan will not permit group homes or workshops to be located adjacent to ICF homes. This marginalization of ICF homes speaks loudly of the state's intentions to downsize and close these facilities.

When it comes to changing where I/DD individuals live, work and play, change for the sake of change is ill-conceived and poses a threat to their safety and well-being. There are documented reports of the negative results that other states have experienced in making the type of changes our state is planning.

Kelly is doing so well now after years of attention to help her find balance – in her diet, her medications, her living environment, her various therapy requirements, and the community she lives and plays in.

I want to finish my testimony this afternoon by sharing a story with you.

Kelly loves to swing. She would do it 24 hours a day if she could.

It is summer before last. Kelly and I are on the playground at the Flat Rock campus. She is on her favorite swing. A warm summer evening, a beautiful sunset in the making, it is so quiet on the campus that you can hear the breeze in the pine trees near the playground. Kelly started to let out one of her infectious belly laughs and began what I call her Stevie Wonder imitation – rolling her head side to side with an ear to ear smile and laughing big time. And then Kelly let out a burst of gibberish noises, like she was singing from her soul. I had never heard her make those sounds before. At that moment, I felt as though I was hearing Kelly find her voice for the first time in her life. Oh the simple joys and life lessons our children can teach us when we take the time to listen.

Governor Kasich, Lt. Governor Taylor, Ohio Health Transformation Director Moody, DODD Director Martin, state legislators, please listen to the voices that matter. You are making decisions that will impact the lives of the most vulnerable citizens of our state. You do not simply have to bow to the CMS Plan or kowtow to veiled threats of litigation from Disability Rights Ohio. They do not speak for anyone except the Federal Agencies that fund them or the Department of Justice who has their back.

There are thousands of I/DD individuals throughout the state that can speak for themselves just fine. Those DODD representatives and others that are here today and presented at the Public Forum in Cleveland on January 8 can attest to the passionate and desperate pleas delivered by numerous I/DD individuals when they heard the changes that you have in store for them. Their responses were genuine and their questions asked sincerely. Why should they be forced to change where they live, work and play simply to satisfy your biased definition of what constitutes a community? Many of the +300 people in the room found your responses to these individuals unsettling, offensive and riddled with half truths. People with disabilities who cannot speak for themselves, do speak in other ways, and we as parents are biologically and emotionally tuned into that speech in a way that DRO and DODD can never be.

Don't acquiesce from what you know is the right thing to do. The path that the Olmstead ruling has laid out is clear. You have a responsibility to protect the lives of I/DD individuals by ensuring they can live, work and play in a community of their choosing not yours.

Thank you for your time this afternoon.