February 16, 2022, Human Services Committee Testimony By Kristofer Medina
Issues Impacting the Lives of People with Developmental Disabilities Living in Vermont

Hello everyone! My name is Kristofor Medina, and I am Autistic. I am 39 years old and the only home I have ever had is with my mother and older sister. My family moved to Vermont in 1984 when I was eighteen months old. My mother told me that my early development was quite typical of others my age until all of a sudden I lost most of my ability to speak. In 1985, I was diagnosed as having a Pervasive Developmental Disorder which was later confirmed as Autism.

I was fortunate to live in Vermont where inclusion was the norm and not the exception. I attended Barre Town Elementary and Middle School where I was educated alongside my peers. When I was in second grade, I was introduced to a new method of supported typing or facilitated communication. It was through this method and the belief of presuming my competence that I found my voice. Presuming competence is a vastly growing term in the disability world. One of my favorite quotes by Rosemary Crossley is “Not being able to speak is not the same as having nothing to say.” A lot of people believe that verbal speech is a showcase of the intelligence that people possess, holding onto the theory that if a person cannot speak using his or her own verbal speech, then he or she can’t possibly receive information to process and understand. This way of thinking can be deadly to people’s growth personally and intellectually, It limits opportunity and decreases one’s overall quality of life. We must always believe in one’s intelligence and the amazing things that people can accomplish, just by believing.

All of my thoughts, needs, wants, and feelings that had been trapped inside my head came pouring out. Having this newly found sense of myself, my life changed. I now had the ability to truly communicate, to share what I knew, how I felt and excel in academia through typing. My verbal ability remained the same and still consisted mostly of echolalic or delayed echolalic speech.

Over the years, I have had MANY different people who supported me come and go, mostly due to poor wages and increased responsibilities. Every time, a new support person was hired, they had to be trained to work with me. After graduating from eighth grade, I moved on to Spaulding High School, leaving all the people behind, who not only knew me but celebrated my accomplishments. Transitioning to high school brought on even more challenges but with the ongoing support that I received at home and at school, I graduated with honors.

I applied to the University of Vermont without disclosing my disability and was accepted and granted a scholarship. Working at UVM to earn my degree in English and Special Education took eight long years but was the most challenging yet rewarding time of my life. My trained support staff were not provided by UVM but were funded through my home and community based waiver.

After graduation, I joined Green Mountain Self Advocates and was later offered a job. It was there that I found my true purpose in life, to not only advocate for myself but for other people who could not. I wrote articles, testified, and was asked to present at conferences throughout New England, Massachusetts, New York, Iowa, and California. I became an active member of The Communication Alliance, The Vermont Communication Task Force, and The Center on Disability and Inclusion at the University of Vermont. In 2019, I was selected to represent Vermont and attend the annual CDCI conference in Washington D.C. While attending the conference, I was asked to join a small group of people from Vermont to meet with Bernie Sanders staff at the Capitol to inform them of what was happening in Vermont and what needed to be done to protect and support the rights of people with disabilities

Almost a year later, I was about to start a new job at Washington County Mental Health as the Director of a Peer Mentoring Program when COVID hit. My last full day of receiving services was on March 4, 2020. I lost my Case Manager and my trained 1:1 communication, community, and employment support person and became homebound. Fortunately for me I have always lived with my mom. She had already retired from 38 years of teaching but had to quit her part time job. My Home and Community Based Service waiver was for 30 hours of direct service, and I was left with no support. It has been almost two years and the only direct service I have received is 3-5 hours a week and the only respite service I received was from my older sister during her vacation breaks from her job in New York.

What happened to the $$$ that would have been used to pay for my support staff through my 30 hours per week Home and Community Based waiver???

Washington County Mental Health has been vigilant in their efforts to hire support staff but due to poor wages, no one has applied that has the skills and commitment that my support person needs. Without 1:1 direct communication support for my typing, I am left with only my limited verbal speech. I love my home but the added stresses during COVID have increased my level of anxiety and struggle to control my autistic compulsive behaviors. I miss working, socializing, and collaborating with my peers in the community. My mom has been a champion in facilitating my participation in ZOOM meetings and daily support at home and in the community with my typing. COVID still looms and it is the nagging feelings of uncertainty and the lack of control in knowing the outcome that makes it impossible to focus on anything else.

What is Vermont doing to increase the pay for our trained, skilled, and committed support workers???

I have voiced many times during my yearly ISA meetings that I want to explore other living opportunities. However, the Shared Living Provider model appears to be the only option in Vermont. Why would I want to live with another family? We need to have CHOICES! My mom isn't going to live forever, and I feel her struggling with what my future will be. She joined a group of parents who are also concerned about their son's or daughter's future called the Developmental Disabilities Housing Initiative. My mom told me that many of these parents' adult children cannot or have difficulty advocating for themselves, so their parents are advocating for them.

I know what I need, and I know what I want! I want a FOREVER home!
I want a home that will provide me with the 24/7 stability, safety, and consistency that I need. I want to live in a home with several of my peers within my community and be supported by caring people who will help us to lead healthy, productive, and fulfilling lives. I want the same home for my peers and am determined to make it happen in Vermont!

Thank you for listening !