



Support: testimony in Support of SB-0441 and HB-0318

House Health and Government Operations Committee

Mary Grelli, Kenneth Garove for Francis

January 20, 2021

Hello, I am Mary Grelli and my husband is Kenneth Garove. I am writing to express my concern that DDA, in most recent waiver language, intends to force participants in the self-directed Community Pathways Waiver, to appoint a designated representative. My son, Francis Garove has been in the Community Pathways waiver for the past 5 years. Francis has multiple severe disabilities including Cerebral Palsy and Intellectual Disabilities.

My husband and I have been advocating and caring for our disabled son in our home since he was born 29 years ago. Recently I had the unfortunate experience with a DDA regional office representative challenging my legal standing to ask for current information regarding my son. He asked me who I was. When I reiterated that I was his mother, he explained that he meant who I was regarding guardianship, designated representative or other title. He explained that he did not want to speak with me regarding the issues at hand because of HIPPA restrictions. He also said that he preferred to speak to my son's CCS. This line of questioning was a surprise and left me incredulous. I then explained that I had never heard of this restriction and I subsequently scoured the DDA website for guidance on designated Representative.

After much research and consultation with SDAN I found other elements of the current proposal regarding designated representative (DR) that increased my concern-mainly that no family members of the DR could be employed as staff for Francis. Eliminating all immediate family members of the Parental DR as potential employees is profoundly disruptive for this reason: the unfortunate reality of staffing is that there are few people outside of family willing to do this work. As a rule, family is more reliable, committed and achieve the best possible outcome for the individual.

If the appointment of a DR will remove the ability for a parent to communicate with the DDA regional office or any other agency that the individual receives services from, then that person will potentially lose what is most likely their best caregivers and strongest advocates. The goal or mission statement of DDA for a happy and healthy team based on "...providing support for individuals **and their families** to determine what is important to and for them to achieve that goal" is nullified with this restriction. Let us continue to support the "DDA vision of the good life partnering with people with disabilities and their families to provide support and resources to live fulfilling lives" by specifically suspending consideration of the current DR proposal and supporting house Bill 0318.

Sincerely,

Kenneth Garove *Mary R. Grelli*

Mary Grelli, Kenneth Garove
Parents of Francis