



Families Speaking
UP



Bringing all voices to the intellectual/developmental disabilities debate.

December 18, 2014

Dear Governor Markell,

Families Speaking UP is a group of individuals with intellectual disabilities, family members, caregivers and other vested parties who are very involved in the process of how and where state and federal funds are allocated, dispersed and used according to the CMS Regulations on HCBS Settings issued earlier this year.

We wholeheartedly applaud the fact that the CMS HCBS Settings Regulations, which were issued to implement the Olmstead decision in Medicaid Waiver programs, recognizes the importance of person-centered planning. As such, it is important that the full range of options for serving people with disabilities be considered. CMS has said that States have a great deal of flexibility in deciding how to respond to the HCBS Settings Regulations. In guidance on non-residential settings, which was issued on December 15, 2014, CMS reaffirmed that the definition of HCBS settings is based on "individual experience and outcomes, rather than one based on a setting's location, geography, or physical characteristics."

In creating a transition plan for Medicaid Waiver services, the state of Delaware must create a proper and comprehensible plan that takes into account each individual's needs within the broad spectrum of differences that exist. Our state must provide flexibility and expand the opportunities available to people with disabilities, not restrict and eradicate options that could facilitate a fuller functioning capability. We must retain useful choices that work for such individuals, not contract the availability of viable and innovative projects.

In an ideal world, it might be possible to impose a rigid ideological structure without harm. In the real world, the consequences of denying funding for a full range of choices would have the unfortunate result of taking away opportunities and creating a vacuum. This puts the affected individual with disabilities in a position that is similar to the total segregation people experienced in the past and thus would nullify the intent of liberating them from the restricted life the federal regulation was meant to deliver them from. If the true intent of the regulation is to enhance the lives of such individuals, then the purpose served should be a major consideration when making the decision to qualify or disqualify settings. A serious effort should be made to factor in the practical logistics of a situation and recognize the objectives and aims achieved.

People with intellectual disabilities, their caregivers and those who care deeply about the future hope that you will keep all options open as recognized by the Supreme Court that "one size does not fit all."

Respectfully,

Our mission: Families Speaking UP is a non-partisan grassroots group of people with intellectual and developmental disabilities (IDD), their families, friends and caregivers. We work to ensure that all voices are heard in the IDD debate. We share our knowledge and experiences, advocate for and include our loved ones with IDD in decision making, serve as a unifying voice, and educate ourselves and policymakers. There is strength in numbers and our many strong voices must be heard.

Our vision: Through family support, networking, social media, word of mouth, and with the power of our numbers, we will seek to advocate for and influence Federal and State policy for all persons with IDD.