

Lesley Bennett
30 Soundview Drive
Stamford, CT 06902
203-829-7650

Lesley.Bennett@rareaction.org

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My name is Lesley Bennett and I am a Stamford resident. I thank you for this opportunity to comment on the draft of the Department of Developmental Services (DDS) five year plan. While I appreciate all the hard work that DDS employees have put into this plan and the goals that DDS has identified, I feel it is essential that DDS take a more in depth look at the real-life or fundamental needs of the individuals served by the Department and consider updating or modernizing the definition and criteria used to determine eligibility for DDS waivers.

Under the current definition for Intellectual and Developmental Disabilities “The Department of Developmental Services (DDS) is responsible for the planning, development, and administration of complete, comprehensive, and integrated statewide services for persons with intellectual disability and persons medically diagnosed as having *Prader-Willi Syndrome*.”

According to NIH, over 7,000 rare disorders have been identified...and Prader-Willi is only one of many rare genetic disorders that may cause intellectual disability. NIH also estimates that about one-third of all rare disorders are neurodevelopmental and/or metabolic disorders that may cause symptoms such as intellectual and developmental disability (IDD), neuropsychiatric or behavioral health issues, epilepsy, or motor dysfunction. While many DDS employees understand the needs of those with Prader-Willi, often individuals with other rare disorders causing IDD have trouble obtaining needed help or services from your Department.

My family was fortunate. My daughter Kelly (Margaret K Bennett) was born in 1989 with a rare inborn error of metabolism and it was apparent from birth that she had severe global developmental delays and a metabolic, epileptic encephalopathy. The DDS nurse assigned to Kelly’s case realized that Kelly’s condition was severe and helped us qualify for a home based waiver. Kelly was not supposed to survive her third birth day but with a great deal of help from a number of wonderful physicians and your Department, Kelly lived for 31 (almost 32) years. We sincerely appreciate all the help and protections DDS provided our daughter.

For the last 30+ years, I have been advocating for patients, mostly children, with rare disorders. Since many individuals living with a rare disease and their families would benefit greatly from the services and programs provided by DDS, I frequently refer families of those with rare neurodevelopmental, neurodegenerative, or metabolic disorders and rare epilepsies to DDS for help. Often I hear back from discouraged families that their child failed to qualify (meet DDS criteria) for a DDS waiver because DDS personnel did not recognize the disorder as one causing IDD or did not understand that the disorder was neurodegenerative and the child’s IQ and ability to perform daily life functions was declining daily. Several parents of children with rare epilepsies have complained that DDS refuses to test or accept results if the child is seizing—which can be difficult if the child is having multiple seizures per day.

I understand that the definition of IDD and criteria for IDD services varies between agencies or state and federal government...and the exact definition of IDD, including the types and categories of IDD, may vary depending on the source of information used or legislation passed. I also understand that the DSS

definition that includes only one rare disease (Prader-Willi) is based on a law that was passed more than 20 years ago. However, in order to help a number of families in our state caring for individuals with rare diseases, I am asking DDS to please consider updating or modernizing the DDS definition and criteria for qualifying for IDD services or waivers and to be more aware and inclusive of rare diseases that may cause IDD in DDS programs.

Thank you for reading my testimony,
Lesley Bennett