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Subject: DDS Five-Year Plan 2022-2027 written testimony
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Testimony DDS Five-Year Plan 2022-2027 January 13, 2022

My name is Diana Mennone. My brother, who passed away recently, received services from DDS at a Regional Center; Southbury Training School; and a community private provider from age 4 till age 59. Educational programs and day program options, residential supports and a life filled with wonderful experiences and outstanding staff was what my brother received and what our family looked to and relied on for support. I was able to be a big part of his life as I had a teaching career at STS where my brother lived for 40 years. Although I am a member of a number of organizations with respect to DDS, this testimony contains my own comments on the DDS Five-Year Plan, not those of the organizations of which I am a member.

I have reviewed the proposed Five-Year Plan and want to thank you for the critical work done in recent years. Despite the unprecedented public health emergency, DDS was able to work on a number of areas as well as the unexpected and hopefully the 2022-2027 plan will be able to continue work on implementing the agency's planned and unplanned goals. I appreciate the recognition by the department to work on making information more accessible to stakeholders, the department itself and the broader community. The "Seeds of Change" tour should continue for the purpose of ongoing participation, feedback, review and revision. Just like an IEP or an IP, it is important to update the needs and concerns on an ongoing basis for the department. This is imperative for all stakeholders. Charting the LifeCourse (CtLC) framework and tools sounds exciting and I look forward to hearing about the different ways it will be integrated.

Concerns:

* Page 4 - The "*Number of DDS-Eligible Individuals by Age*" chart shows DDS eligibility of those ages 0-74. I question why no one older was included as eligible in the data. There is no mention of an Aging Plan for individuals in the DDS population although this is a reality NOW and for the future as people are living longer with chronic medical and behavioral issues. As my brother aged and due to his rare degenerative syndrome, he became extremely medically complicated and fragile, finally requiring hospice care in addition to the 24/7 nursing he received at his group home. My biggest fear was the possibility that his needs may not be able to be met and he would be transferred to a nursing home. This option is not a viable one for persons especially with severe intellectual and multi-developmental disabilities like my brother. Perhaps continue to look at the medical models and availability of beds in public settings for late stage of life care / medical oversight / and for others who need advanced nursing care or specialized programs unavailable due to the work force crisis. This applies to others who may not "fit in" due to severe behavioral needs, rare or severe disorders and terminal diagnoses. It may be possible to join with other state agencies to be creative in meeting needs of this group of individuals. The Five-Year Plan stresses a vision for ALL citizens supported by DDS and our "seniors" seem to be a group being forgotten. It was mentioned during the "Seeds of Change" tour but needs to be expanded.

* Page 6 - Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID)
It was stated that the census of public ICF/IID beds was 144 as of June 2021. Could that

number be checked for accuracy? Seems it should be higher.

* An additional topic of interest might be a partnership between DDS with higher education institutions for individuals and / or training opportunities for ancillary staff such as doctors, (especially) dentists, OTs, PTs, etc. Training for future careers may help the work force crisis in the future for many.

* Once COVID restrictions lessen and if additional funding is available, I hope to see out-of-home respite center locations extend an increase in the number of consecutive days per week they offer relief to families. This is especially needed following all the months of the pandemic. I'm sure this is being considered.

Thank you for the opportunity to be a partner in improving DDS resources for the future. I am forever grateful to the DDS community for their expertise and for treating my brother with dignity and respect throughout his life. I support Commissioner Scheff, the DDS leadership team and entire support staff in navigating through the next five years. I applaud your vision and hope the broad range of abilities, ages, and level of need for ALL citizens supported by DDS will be thoughtfully addressed. My brother was lucky to receive the supports during his lifetime and everyone in the entire continuum of care deserves the best quality of life possible.

Diana Mennone Woodbury, CT