

A Letter To The Editor

Recently I read an article published in the Hartford Current on January 16 titled "Parents Make Plea For More Housing" in advance to a hearing date scheduled for January 21, 2015 which reviewed coverage of the intellectually and developmentally disabled Family Hearing Day. There are dedicated individuals who are helping to coordinate community forums for families to collaborate and share their life challenges with one another. On January 21 the I/DD Family Hearing Day was considered a huge success with more than 300 families gathering in Hartford to call attention to this very real crisis facing families with numerous fears the greatest being their reality that they will need to prepare their loved one with disabilities for the time when they will not be alive to advocate for their needs and hopes and dreams!

On February 11, 2015 from 10 a.m. -2 p.m. at the Legislative Office Building for the launch of "2015 : DDS Funding Can't Wait!" campaign! I work full time and in addition I have a second full time responsible, that of guardian and advocate for my young adult daughter who lives with many types of disabilities. Perhaps the greatest of all are those challenges impacting her life are her emotionally debilitating mental health needs which at the present time are significantly unrepresented areas of needs in our I/DD support system.

In addition to the fact that our families can't wait for Governor Malloy to realize the impact of budgetary cuts on the DDS support system on our loved ones for housing, families can't wait for the State of CT to acknowledge the facts that statistically, children and young adults with Autism Spectrum Disabilities will in their adult life need a much more individualized approach to their future planning. The complexities of this disability, often co-existing with mental health disabilities stemming from severe anxiety and physiological medical challenges, require the DDS to actually honor the very eloquent wording represented in their Autism Website for the Autism Waiver that serves a very minute number of families and is not available for the majority of our loved ones.

My request for Governor Malloy's committees is to provide us with a Commissioner to replace the outgoing commissioner who can create a forum for all individuals with disabilities not limited to those with IQ deficits less than 70th percentile (on paper) and not discriminating to those who do have this IQ deficit (on paper) and live with additional challenges of Autism Spectrum Disabilities and Mental Health disabilities. DSM-V does not support the pre-requisites DDS maintains for the non existent Autism Waiver for the majority of our loved ones.

In closing, I choose to self-direct my daughter's day program, and will be taking on the responsibility to develop a plan for her life long needs including housing because her needs can not be fit into a group model and needs to include long range planning for skill requisition and transition from family to hired staff with mental health qualifications beginning long before her independent adult life.

The web site states all of these are important to DDS. There are beautifully written goals on the DDS site, however, our funding as self directing providers is not the same as group vendors, and our budgets are not the same as what is stated in the website that Autism disabled individuals need to have!

For parents like myself who are willing to do many of the tasks and administrative responsibilities covered by DDS vendors for our individual family members, and for whom we are not asking for compensation, our budgets need to include all that are represented in the Autism Waiver and we should be able to go to our own preferred therapists and day programs as long as we work within the budget we are provided.

Our Families Can't Wait for Governor Malloy to end the dividing lines between Intellectual and Developmental disabilities and Mental Health/ASD disabilities. We need a ***unified system*** that provides for ***all qualified individuals***. To ask us to wait until our loved ones are faced with one parent dying and the other unable to care because of a serious situation is not justified. Our loved ones need us to help build their bridge from our home to their new living situation. Our loved ones need to make this journey with us not without us! We are calling on legislators to address the crisis immediately. The only solution that will give hope to our families is to increase funding for a ***Unified Dept. of Services for People with Disabilities*** inclusive of the research based services represented on the DDS Website for Autism for all who qualify based on DSM-V.

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