

Testimony for the Appropriations Committee February 21, 2020

My name is Adrienne Benjamin, I live in New Britain with my husband and our 23 year old daughter who has both autism and intellectual disability.

Thank you Senator Osten and Representative Walker for this opportunity.

The quickest way to describe Zoe is to think of a toddler, because that is her level of development. She brings the joy of a toddler, she needs help with almost every aspect of her life, and worse, has temper tantrums.

I am grateful for the funding which enables Zoe to attend HARC's wonderful Day Program, and the fabulous DDS Respite services.

Ironically, yesterday's Atlantic Monthly's cover story is entitled:

**The Coming Care Crisis as Kids with Autism Grow Up.  
That's exactly what I want to talk about.**

To amplify this point, The American Academy of Pediatrics' December 2019 study reports that of those with Autism, 40% also have an intellectual disability and 30% are non-verbal. We are going to have an influx of people with extremely severe and complex needs.

Unfortunately, in Connecticut, our non-profit agencies, like HARC have been underfunded for more than a decade and some have closed both group homes and day programs. I strongly support the 5 year proposal of The Alliance of Non-Profits to increase funding by 460 million dollars.

Plus, we need to expand residential options. Let me explain why:

Life with severe autism is often very loud, disruptive, unpredictable, and, I hate to say it, violent. The National Council on Severe Autism has stories every week of families in tremendous chaos & crisis. Their kids and young adults have behaviors very similar to my daughter. Yesterday, Zoe's tantrum was triggered by her favorite earbuds not working. I had 4 extra ones, but they were the wrong color. So, things went sideways very quickly, and it took another 20 minutes and extra medication to calm her down.

I'm hoping we can rethink how we utilize DDS resources. Especially the existing Regional Centers around the state. Many have been closed due to the movement to close all congregate settings. I think that pendulum has swung way too far. There are 3 open now. In Newington, Lower Fairfield and Torrington. But, they're generally not open to new admissions.

Regional centers are campus-like, fairly secluded centers where there's smallish homes, cottages or apartments. Not in traditional neighborhoods. I feel that would be an advantage for my daughter and others like her. Much less traffic, almost no strangers, no neighbors to stare or call the cops when there's lots of noise and a bit of mayhem.

It would be it's own little neighborhood, full of people with similar issues and, of course lots of staff. Perhaps each center could build a sensory room to address the intensely complex needs of those with Severe Autism. Plus, lots of space to safely walk and blow off steam when things are overwhelming.

Of course I'm not proposing this for everybody. But, we need to address these crucial and challenging needs with some innovation. The best part being these Regional Centers already exist...we don't have to start from scratch.

I'm not talking about a return to the very bad old days of institutional abuse and neglect. I'm talking about offering a person centered choice for those families who feel it's best. Currently this option has been eliminated.

There are several national organizations are asking for similar options. The Voice of Reason, and Together for Choice, along with the National Council for Severe Autism. I was happy to see that the Centers for Medicaid Services issued new guidelines last March to add more flexibility to the rules governing residential settings.

I'm sincerely hoping we can develop more choices to help meet these extreme needs in Connecticut.

Thank you,

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