

# **Invest in DDS (1) Innovative Programs, (2) Autism Training, and (3) Appropriate Pay for Staff that Work with Behavior Challenges**

## **by Darlene Borré**

My name is Darlene Borre. I am a Vocational Innovator and an attorney. I am also the mother of an 18 year old son with autism. My son, Ben, is nonverbal- he has severe autism plus an intellectual disability. Very typical for someone with severe autism- he also has seizures, GI issues, sensory processing issues, communication problems, sleep problems and self injurious behaviors and aggressive behaviors at times.

At 21 we know he will transition to adulthood so what is he transitioning to?

As you know, DDS has received many cuts over the years and has not been able to prepare for the deluge in autism. Here is the reality of those cuts.

Several families in the same boat as our family have graduated at 21 and looked for a program for their kids. Agencies have closed or are closing their day and vocational programs that serve people who need 1:1 care and that have behavior challenges.

While the person may have a wonderful behavior plan that has worked to get their needs met and allowed them to be a part of their community prior to turning 21, the reality is at 21 the staff who is **willing** to work at the DDS rates often do not have a college degree, do not have english as a primary language and have difficulty understanding and applying these behavior plans, rendering them worthless.

This leads to an increase in behaviors and also results in staff turnover rates going thru the roof. As consistency in routine is so important to people with autism, a snowball effect occurs until they families are told "you're just not a good fit for our program".

Sheltered workshops which were the safety net for people who needed 1:1 care are closing or closed in CT with nothing to replace them. So now not only is the person sitting at home, but a parent quits their job because their adult child cannot be left alone - so 2 people unemployed.

That's what we are transitioning to? Surely we can do better.

If only CT put money into innovation and vision, we can change that trajectory and save money in the long run. After all, when the unemployed parent dies (we're all getting older), where will people like my son go? With no planning, a hospital stay is inevitable- you better believe that it will be expensive.

There is a trend to develop small businesses for people with severe needs. My son currently has a business and a website. We partner with local businesses who sell his t-shirts, car magnets, cookbooks and grocery bags. So what happens when he turns 21?

I am developing a Makers Space with a great, innovative agency called Futures Inc. but we need CT to invest in new ideas like this. At this Makers Space my son and others like him can go to work on their businesses so they are not isolated at home. We brainstorm together and root for each others' success. Participants have a purpose because we believe The Purpose of Life is to Live a Life of Purpose. Our products are developed with community needs in mind - for example, when plastic bags were outlawed, we created cotton bags with our town's name and worked with local stores to sell them. Our guys are out in the community making free local deliveries, hosting pop up shops, and buying raw materials. We often get product ideas from community partners who are supportive of our mission. College partnerships also come into play with student interns spending a semester reviewing and improving the businesses. For example, School of Business student interns could work on a social media presence while occupational therapy students could help develop workplace improvements (ex. participant needs movement and a walk around the block prior to starting work in order to organize their sensory system resulting in a decrease in behaviors).

We need funds for training. You may be surprised to learn that with the huge increase in autism, there is no autism training provided by DDS to staff. None. Of all the training available for staff, only "restraint holds" is applicable to autism. That is the future for our son. Handing him over to people where the only things they know about autism is "restraint holds".

You have spent many many years making DDS the easy target for spending cuts- with our most vulnerable citizens paying the price. DDS is at rock bottom- we've hit the breaking point.

Investing now in (1) innovative programs, (2) rate increases for staff working with behavioral challenged individuals and (3) autism training will result in cost savings in the future.