

Submitted September 24, 2014, at the Legislative Office Building, Hartford CT

To: Legislative Program Review and Investigations Committee

Re: Written Testimony Concerning Adults with Autism: Urgent Need for Services

My name is Elizabeth Zownir. I am the mother of a 22-year old son with autism. His name is Andy. Andy aged out of the Manchester public school system in June of 2013. He has a very serious language disorder--his language ability is in the bottom 2%, and he has social deficits that are obvious to all who encounter him. He only reads on a third grade level, so higher education is out of the question. Andy can learn (mostly visually), but does not have the ability to be a self-directed learner. He isn't able to plan for his future, handle his own finances, or make his own medical decisions. He will most likely never drive, because in addition to the complications caused by his autism, he also lacks acute vision in his right eye. My husband and I are conservators of both his person and estate. In spite of this, Andy's full scale I.Q. measures in the low seventies, so he does not meet Connecticut's statutory definition of "intellectual disability" and does not qualify for DDS services.

Andy is on the Autism Division waiting list, and our understanding is that the current waiting time for services is five to six years. When he graduated from school, we were hopeful that Bureau of Rehabilitation Services would be able to help him get at least a part time job, so that he would have something productive to keep him busy since he does not qualify for any of the day programs that intellectually disabled people are able to attend. BRS hired Transitional Employment Unlimited to evaluate Andy's employability. This started well enough; Andy was done with school in June, and in August of 2013 TEU did a 40-hour job evaluation with Andy at Chili's Restaurant. He was taught portioning, and he picked it up very well, according to the report. However, Chili's did not actually have a job opening. (This is often the case with BRS evaluation sites--it is just meant to be a test of one's ability to learn a job.) Since it went so well, I expected BRS to move on to the next step of getting Andy a working interview somewhere, but that did not happen. The BRS representative said "Well, portioning jobs are hard to find", leading me to wonder why they had considered this to be an appropriate test site in the first place, but she went on to say that they wanted TEU to do a second 40-hour evaluation at a different site, to test a different set of skills.

It took five months for TEU to find another evaluation site. For all that time, Andy was mostly home with me, and I struggled to find activities to keep him busy and productive. The second evaluation site was a daycare center for elderly adults, and Andy was to help with the preparation of snacks and the noontime meal. TEU had not used this site before, and it turned out there were a number of problems with it: the workload was uneven depending on how many people came to the center each day, and the routine varied from day to day. Some days they didn't have enough work to keep Andy busy, and he would wander around and sing. The job coach said this was inappropriate. She also indicated that he was not social enough with his co-workers, even though in another section of her report she stated that Andy greeted everyone, answered their questions to the best of his ability and responded nicely to their requests--I thought that for someone with autism and a serious language deficit who was in new and unfamiliar surroundings he did pretty well. On the basis of this evaluation, BRS tried to terminate

services to Andy, saying he was not ready to work at this time. I didn't accept this, and pointed out to them that I had their previous report stating that Andy was competitively employable under certain circumstances, and it seemed to me that they needed to find a job for him that was more similar to the first one they tried him at. I also pointed out a number of things about the second evaluation site that indicated to me that it was a poor choice for a client with autism in the first place. I also pointed out the unfair burden placed on someone with a serious disability who not only has to learn the job, but apparently also has to pretend they don't have a disability in order to fit in.

The worst part of the second evaluation was my son's reaction: He thought that it went pretty well, and was visibly shaken when he heard the BRS worker say he was not ready to work. He hung his head, covered his eyes, and said "I am so stupid!" It was heartbreaking.

BRS compromised with me and agreed to do a third evaluation, but would only agree to 20 hours. They are in the process of arranging for this; it will probably be bagging groceries, and if he's not perfect, they will most likely terminate services.

As it turns out, (this is how it was explained to me) if someone has an autism diagnosis and will need more than just short term job coaching (and most of them will), BRS doesn't feel they can continue to work with them because of their budget constraints---they say that people with autism are "eligible for a comparable benefit from another state agency", and that the Autism Division should be paying for their job coaching---they quickly add that they are aware that the waiting list for the Autism Division is said to be 5-6 years long, but it's not really BRS' problem.

I asked the BRS representative how BRS defines "long-term job coaching", and she said that anything over 15-20 hours is considered long-term, and they can't pay for it because the Autism Division should be doing that. Now, think about what that means for my son, who can learn but has a serious language deficiency and learns best by having a job directly demonstrated to him and then practicing what he has learned: If Andy managed to get a part-time job with a 4-hour shift, he would only have job coaching for the first 5 days, and then he would be on his own, and have to do the job competitively as if he didn't have a disability. I'm not saying he would need job coaching forever, but probably longer than 20 hours to thoroughly know the job.

So, in other words, BRS says "long-term job coaching for people with autism is the responsibility of the Autism Division", but the Autism Division says "we don't have the funding to help any more people".

If someone is actually receiving services from the Autism Division, I can understand how some of that money might be expected to pay for job coaching if the client needs it. However, I don't understand how having a place on the waiting list could possibly be construed as the same as actually receiving services. Surely Andy isn't costing the

state any money by just being on the waiting list, is he? So why is BRS so limited in what they can do for him?

We were told that BRS could continue working with Andy if he could pay for continuing services. Andy is an unemployed, disabled citizen of the State of Connecticut--why should he have to pay for any of the services of a state agency that exists to help disabled people find work?

Just out of curiosity, since Andy's place on the Autism Division waiting list seemed to be such a stumbling block to him receiving continuing help from BRS, I asked hypothetically what would happen if I requested that he be taken off the list, since he would most likely not get benefits from the Autism Division for five to six more years and it would be nice if he could get a job and have something productive to do before then. BRS told me it wouldn't make any difference at all if he were taken off the list; in fact, anyone with autism who is not on the list and in need of more than 10-20 hours of job coaching would be instructed to apply to get on the waiting list. (And as a consequence, wait five to six years for any further help finding employment? That's what it means, right?)

I was told that even if BRS funding for long-term job coaching was increased, none of that money could be used to help my son, because the Autism Division should pay for whatever job coaching he needs.

Parents and school system transition programs work very hard together to teach young adults with autism that they will have to work someday--we deliberately put this expectation into their heads. When Andy finished school, he had great enthusiasm and optimism for the idea that he might get a job. Despite a very serious language deficit, he had made a lot of progress on work-related social skills. Now, a year later, he is discouraged and confused, and is starting to noticeably regress. For people like my son, the delay in services for them is disastrous, and undoes some of the hard won progress they made while in their school transition programs. A long period of unemployment following the end of school is very isolating, and I'm sure that the longer it goes on, the more difficult it will be for them to acclimate to an employment setting and lead productive lives.

This situation is especially disillusioning because, two years ago at an informational meeting at the legislative office building when a roomful of parents was informed of how limited the capabilities of the Autism Division were going to be for years to come, we were all encouraged to think of BRS as our first and best source of help when our kids aged out of school. This is not turning out to be the case for people like my son. They are falling in the cracks and being left with nothing to do--no job, no day programs, nothing to do but what their parents can find and afford.

Meanwhile, I can't even find out my son's position on the Autism Division waiting list. I know it won't change his situation, and maybe it's just morbid curiosity on my part, but I'd like to know what number he is on the list. I have called and emailed, and have been told they would get back to me, and then they never do. One time they told me "it doesn't matter--nothing is opening up." I am starting to wonder if this "waiting list" is really just a myth--could it be there really isn't a list? It seems like I'm asking a simple enough question. I received a notice with a decision date of 8/16/12 signed by H. Steven Zuckerman, Ph.D. stating that Andy appears to be eligible and would be put on the waiting list, so why can't I find out where he is on the list?

I am doing whatever I can to help my son adjust to life after school, but Andy is a 22-year old man. He doesn't need a mommy---he needs a job, and age-appropriate friends and social activities. I see his chances of ever living a fulfilling, productive life crumbling as time goes by with no help available for him. I know the government can't do everything for everyone, but people like Andy are innocent victims of a devastating disability and, through no fault of their own, they need help just as much as the intellectually disabled, the mentally ill, and all the other vulnerable people for whom the state sees fit to provide services.

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A handwritten signature in black ink, appearing to read "Elizabeth S. Zownir". The signature is written in a cursive style with a large, looped initial "E".

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