

April 5, 2010

Dear Representative,

I would like to plead our case as to why Illinois' payments to RRAF need to be restored. My daughter Beth currently receives funding for placement in RRAF's developmental training day program. This is a wonderful thing! But now the lack of payments to RRAF is bringing it perilously close to having to close their doors. This would be devastating for us and for the other 28 severely disabled adults (and their families) that attend this program. In general for all concerned, Illinois needs to increase adequate revenue to fund the necessary services for our developmentally disabled citizens.



Our beautiful, sweet, lovable daughter Beth is severely disabled by autism. (Photo is Beth)

She is 24 - going on 2 (24 years old and functions at the level of a 2 year old). She is non-verbal and has very limited language comprehension. She suffers from many challenges; anxiety, tics, obsessive compulsive behaviors, eating and sleeping problems, and absence seizures, to name a few. With Beth's psychiatrist, we have tried to manage her problem behaviors with many different medications. She is very treatment-resistant, and we have not had much luck.

She functions at a very low level. She needs assistance with toileting, bathing, grooming, dressing, food preparation and clean-up--just about every aspect of daily life. The good news is that at the age of 24 she is finally figuring out toilet training. She has no concept of danger and has to be watched constantly.

Because of her autism Beth cannot read, write, speak and understands very little language. The result of this is that she has very few things she can do to occupy her time. When she is bored and has nothing to do (which is often) she resorts to her obsessive compulsive behaviors. She rips up paper, putting the paper in her mouth and spitting it and spit out on the floor, repeating the behavior until she has something else to do. She runs around the house slamming doors, throwing things around, flushing toilets, playing with water and food. When she is outside she does the same ripping and spitting with grass, leaves, dirt and mulch. She of course does these things when I'm in a different room and unable to stop her; she's got that figured out. While in the car she constantly plays with the radio, window, door, and seatbelt. She has a very hard time being still.

When she is anxious she bites her shirt, whines, screams, and cries. She twists, bends and cramps up her fingers constantly. She has uncontrollable tics of coughing, snorting, swallowing air, hitting her chin, and what I call fish-lips.

She did not sleep thru the night consistently until she was 11 years old and always slept less than the normal amount of hours for her age. I've had many sleep deprived years. She sleeps better now most of the time, but she still suffers from occasional insomnia.

She is an extremely picky eater and has a very limited selection of foods that she will eat. When she was much younger she went for a couple of years where she ate very little and became very thin. She then took a medication to increase her appetite and control her behaviors and gained 70 pounds in two years and was very overweight. So, we had to take her off that medication. She lost the extra weight, eats better now, but her behaviors got worse.

Beth requires constant one-on-one attention and care. When she is at home, my time is totally consumed with caring for her, trying to keep her busy, on the move, out in the community, etc. I am her primary care-giver. My husband works many hours, and is unable to provide much assistance with her daily care. Beth's only sibling has graduated from college and has a job, but is not available to help with her care. My mom and sister will watch Beth for a special occasion, so on a rare occasion I get a break. So, other than when Beth is at RRAF, I am her sole care giver, and it's a very difficult job. I've had to sacrifice a lot as have had most caregivers of their disabled loved ones. I was never able to return to my career which ended when Beth was born, and my life became all about caring for a severely autistic child.

We are so fortunate that Beth is able to attend RRAF (Monday thru Friday 9:30 to 2:30). It is a superb program. It is such a great fit for her and her needs. They are a great group of people who do a wonderful job providing a beneficial program for their clients. The thought of having Beth home all day long - every day (if RRAF had to close) is difficult to accept. We want to keep Beth living at home with us as long as we feel I can care for her, since this seems the best place for her, and she is very happy living at home. But for both my mental health and hers, I need the break that her day program at RRAF provides. She needs the caring environment with structured activities to participate in that RRAF provides. Caring for Beth is a relentless, overwhelming, exhausting, stressful job. Programs and services for people like Beth, the neediest of our society, are critically important.

Let's do the right thing and keep funding programs like RRAF for people with developmental disabilities. It's the humane thing to do.

Sincerely,

Diane Carpenter