

Appropriations Committee Hearing - February 18, 2016
Statement from Debra Zboray
House Bill No. 5044 AN ACT MAKING ADJUSTMENTS TO STATE EXPENDITURES
FOR THE FISCAL YEAR ENDING JUNE 30, 2017
Privatization of Group Homes due to Budget Cuts

Good Evening. Senator Bye, Representative Walker, and Members of the Appropriations Committee. Thank you for the opportunity to speak before your Committee. My name is Debra Zboray and my brother-in-law, Richard Zboray, lives in a group home apartment at Waterford Commons Apts. located at 200 John Olds Drive in Manchester.

Rick is 63 years old and was born with Down Syndrome and developmental disabilities. He is hearing impaired and was diagnosed with Alzheimer's Disease this past year. Rick's doctor and a behavioral specialist, both, indicated that more than ever before, he needs a calm, stable environment with consistency and familiarity.

Research on early stages of Alzheimer's disease also shows that changes in routine, environment and caregivers should be minimal, as it causes a great deal of anxiety and confusion.

Rick has lived with some of the same roommates since he first moved to a group home in 1978 and some of the same staff for over 25 years. They are receiving consistent care from people who are familiar, well trained and have grown to love them. It has taken them all these years to totally bond as a family. They interact like any family does. They laugh, tease, argue, and have their roles in the family unit, but most of all they have learned to count on one another. Over the years, they have learned to effectively communicate with one another in a way that they are understood and have developed a loving, trusting bond, which allows them to feel safe.

I was panic-stricken when we received a letter from Commissioner Murray and Deputy Commissioner Scheff informing us that Rick's group home, as well as others, have been selected to immediately become privatized -- in order to help balance the budget! The letter stated that DDS will handle the transition carefully with the best interests of the residents in mind. However, the best interest of the residents would most certainly be to let it remain a State-run group home keeping the staff that has been part of their day-to-day family for years.

I don't believe that the general public understands how difficult change is for Rick, his roommates and others living in these group homes. Most people don't embrace change, but usually after a short period of anxiety, they adapt. This is not the case for these individuals. Many of them don't have the coping skills that most people have and they don't understand what or why a change is happening. It takes a long time for the fear and anxiety to go away and a long period of consistent coaching to learn a new routine. It takes even longer and lots of patience all around to get to know a new staff member or roommate well enough simply to communicate and be understood enough to feel somewhat comfortable. Some of these individuals have worked for years with familiar staff just to feel safe and gain some self-esteem. To come in and undo all of this progress, as well as put these individuals in emotional turmoil is terribly wrong and will devastate them.

Rick worked in a job that he loved at a restaurant for more than 15 years, where he vacuumed the carpet, emptied the trash and completed other basic tasks, under the supervision of a job coach. Ten years ago the restaurant closed and Rick lost his job. Rick has never been able to recover from this loss, because this was the last time he had a job that was doing the same duties over and over and was able to "own it". They loved him there, it was a great fit for him and you could see how proud he was. Since that time, he has struggled tremendously in day programs that were not well suited for him and his need for order, structure, and consistency. Rick is not able to manage and communicate his feelings of confusion, anxiety and fear. This proposed transition can only make this more difficult for him.

Rick and his roommates have also been through considerable loss over the years with staff members retiring and a few roommates needing more skilled care. Very recently, George, one of their long time roommates went to a different home for more care, Billy, a long-time roommate who had moved to a nursing home, passed away and a staff member retired. It is hard enough for Rick and his roommates to deal with one loss at a time. You can imagine how devastating all these changes have been over such a short period. Rick, and some of his roommates are unable to get over these losses, because they are not able to voice their feelings. The losses just keep piling up and adding to their anxiety. How will they ever adapt to the loss of half of their day-to-day family and the addition of all new staff? As we understand it, the private agencies have a high turnover rate, so they will deal with such loss over and over again. This is not an acceptable way for any human being to be treated, let alone our most vulnerable citizens.

I know there are compassionate human beings who work for private agencies, however, I wouldn't want my family members being substituted with strangers, no matter how nice they are. Would you? It seems to be a misconception that privatizing these homes would help the people on the waiting list. Funding is also limited in the private provider's funding stream. Since these individuals are already in a home, perhaps the private funding should first go to those on the waiting list.

Don't take away the only means of stability and day-to-day support these individuals have. Don't take away their ability to feel safe and secure with people who are familiar and they've grown to love. Put yourself in their shoes. How would you feel? How about if it were your child? Would you want them treated this way? Would you want to be treated this way? Think about how frightening this must be! Please make sure these individuals are not forgotten! There has to be other places where there is true spending waste – this is NOT one of them.

(NOTE: I urge you all to peruse the attached copy of a letter that I sent to Commissioner Murray recently. I sent versions to Governor Malloy, Senator Cassano, Representative Currey and others at an earlier time, as well.)

Thank you.

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February 12, 2016

Morna A. Murray, J.D.
Commissioner
State of Connecticut, DDS
460 Capitol Avenue
Hartford, CT 06106

Dear Commissioner Murray:

I am writing to you to implore you to intervene in an urgent situation that will devastate my developmentally disabled brother-in-law and his roommates.

My 63 year old brother-in-law, Richard J. Zboray, has Down Syndrome, mental retardation, is hearing impaired and this past year has been diagnosed with Alzheimer's disease. Rick does not have the ability to communicate and understand his feelings, such as when he is frightened or confused or overwhelmed or extremely anxious. The only way he can show these feelings is by crying or acting out.

Rick resides in a group home in Manchester, Connecticut at Waterford Commons Apartments (apartments, now called The Place at Catherine's Way) located at 200 John Olds Drive, Apts. 111 and 112 with his roommates.

This situation needs your urgent attention! Rick's group home has been selected, in order to balance the State budget, to become immediately privatized. This will devastate him! There has to be other ways to balance the budget. There must be places cuts can be made that will not adversely compromise the safety and well being of our most vulnerable family members!

Rick and his roommates, some of whom have been together since 1978, have an extremely difficult time adjusting to change. They have been with some of the same staff for 25+ years and have bonded with them. As you can imagine, having the same staff for a long time, they all become family. It takes a long time and a lot of patience to get to know one another well enough, not only to effectively communicate, but to develop a loving, trusting bond, which gives them the feeling of security they desperately need.

Although the individuals in this group home have varying intellectual abilities, Rick is one who in most ways has the mind of a child. Imagine your child having a good part of their family taken away and replaced with strangers and not being able to do anything about it. Like Rick, your child doesn't understand what is happening or why and he can't voice how scared, confused, anxious, and unsafe he feels.

Despite their unique developmental disabilities, Rick and his roommates have been through a varying degree of emotionally challenging times. They are already currently dealing with the loss of a long-time roommate, George, who needed different care and another long-time staff member who just retired. These losses, as well as a new roommate to replace George

coming into the home, are already overwhelming enough for them to deal with. Rick has cried uncontrollably over this and gets emotional each time he talks about it.

In addition, Rick has been going through a very difficult time in his day programs in which the work and environment has been the opposite of what he has always required to function: consistency, structure, and order. All he could voice is that he wanted to go home, as he is unable to voice the reasons why or what he was feeling. As a result of being forced to go to a job and then a senior program, day after day that was not what his developmental assessment recommends for Rick, he acted out to the point where he was a danger to himself and others. He got so agitated, confused and terrified that this was all he could do! I am further extremely worried that as Rick continues to try to voice his fear, confusion and loss in the only way he is able, he will be permanently labeled as “difficult” and will be “pushed out” of a private group home and then what? This is not his nature. He loves people and loves helping people and is a pretty easy-going and fun guy. All the loss and change he has experienced in the last several years, along with the onset of Alzheimer’s disease, is more than he can deal with. Now, more than ever, Rick needs a consistent, familiar, calm, safe environment to live in.

I am terribly frightened to think about what this change to a private company, the loss of their whole staff (family to them) and replacement with all new staff and change in their day to day routines would do to Rick, Mike, Brian, Gene and Paul. This change will “turn their worlds upside down”! With the extremely high turnover in staff of these private agencies, this will happen over and over again. This could be the change that puts some of them, including Rick, “over the edge”! This seems, to me, like inhumane treatment of the most vulnerable members of our families! All Rick and his roommates want is to live with their day-to-day family in harmony. Is that really too much for any human being to ask?

Please, I beg of you, picture your own family members being treated this way and intervene on their behalf! Please stop this process before it is too late! In your position as Commissioner of DDS, I’d appreciate anything you can do to prevent the emotional destruction of these fragile individuals.

Thank you for your prompt attention to this urgent matter!

Respectfully,

Debra L. Zboray
Sister-in-Law to Richard J. Zboray