

Laurette & William Shrage

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March 18, 2014

Re: Jaclyn Shrage and her Special Needs

Dear Legislators and Committee Members:

Firstly, we wish to start off by thanking you for this opportunity to tell the story of Jaclyn Shrage and for listening to why we as a family are reaching out to our legislators in order to seek assistance in improving the provision of services in a more humane fashion that is provided by DDS. To this we ask that you support HB5534. Our family's wish is for a much needed group home for our daughter as well as many others like her. She has been on a waiting list that never moves for seven years with little hope given for any placement. I can only say that when one is entered into the world of having to care for a severely handicapped child one discovers how lonely and big the world can feel. We believe that Connecticut has abandoned its most vulnerable constituents and their families and has made it clear that they are unimportant, last to be considered and first to be looked at and cut when funding resources become an issue. This was further confirmed after listening to Governor Malloy's budget presentation. We also believe that the State of Connecticut has created a system that does not allow the families a voice in how the needs of their adult handicapped children can be met.

Jaclyn is a 28 year old severely cognitively impaired young woman. She is diagnosed with Turners syndrome, seizure disorder, sleep apnea, developmental disability (previously known as mental retardation) and Autism. She functions at about a 2.5 year old level with limited expressive language and better receptive language. Jaclyn requires 24/7 care and supervision. She needs assistance with grooming, bathing, making her meals, managing her health and all adaptive daily living skills that the average person can do independently. She is a sweet, loving and easily loveable individual. As her parents we have done everything in our power to make her life as parallel to that of a typical daughter as is feasible considering her disabilities. Currently she attends a day program at STAR in which she participates in a sheltered workshop environment. On the weekends we seek out opportunities for her to participate in community activities. However, due to her limitations this becomes very difficult. As she is a very vulnerable adult, we are extremely protective of her in order to ensure her safety. In order for us to do this we have had to sacrifice much of our lives to care for our daughter. This includes missing weddings, graduations, routine family events that most people take for granted.

As our daughter ages her needs continue to be significant. In addition as she ages so do we. With age our own personal needs have increased. Jaclyn's father has just within the last year needed open heart surgery, and now spinal surgery and is suffering significantly with extreme back pain. Jaclyn's mother although in better health at this time has had some minor health issues and finds herself being the sole caregiver of both a disabled adult daughter and a semi disabled spouse (hopefully temporarily). Jaclyn's mother's family does not have an extended family to turn to for assistance. Jaclyn's father's family is spread out over the country and not available to assist with Jaclyn's care nor would we expect them to.

Jaclyn's paternal grandmother is 82 years old and is entering the years where she will require care herself.

Currently, Jaclyn is on the State of Connecticut's waiting list for a group home and has been since she aged out of the school system. Although, every year we ask her case worker for assistance in getting her placed, we are told that there is no possibility for her to be placed in a group home as there is no space. We have been informed that we have to either be in our 80's, deceased or incapacitated to the point that we can no longer care for her before they will consider placing her in a group home. The one option offered by DDS to speed up the process is to tell us that we can abandon her in an Emergency Room Hospital and give up guardianship at which point she would enter into a "homeless" situation and be on an emergency list and her care would be totally out of our control. Clearly this is not an option that we can as her parents even contemplate. What parent would want to put their most vulnerable child in this type of situation? Frankly, this idea presented by the people who are supposed to be providing us support leaves us with a feeling of helplessness and is truly inhumane.

Based upon this we are parents who will continue to have to sacrifice our lives and will not be able to age gracefully. We will be forever tormented by the needs of our child and the concern of who will take care of her when we die. We will not be able to have peace of mind as we enter our senior years because we will not have any idea of how our daughter will survive after we are gone. Additionally, we do not know how we will be able to care for her as our needs become more and more significant and we become less financially and physically capable of meeting her special needs.

We will be forever grateful to our legislators if they provide us the help needed to create a safe and caring place for Jaclyn with the proper lifelong environment necessary to meet her needs and provide her with a meaningful life surrounded with love and quality of life by supporting HB5534 . It will allow us to age with dignity and confidence in knowing that our daughter will be well-cared for now and when we are no longer here to care for her.

Sincerely,

Laurette & William Shrage

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