

Chris O'Brien

From: Diane Silva <dianemsilva00@gmail.com>
Sent: Tuesday, May 28, 2024 7:10 PM
To: House Finance Committee
Subject: The need for Katie Beckett Waiver

Dear House Finance Committee Members,

I am writing to you today not only on behalf of my 14 year old medically complex daughter, but of all children who receive the Katie Beckett Waiver in Rhode Island. Ella has a multitude of health issues including but not limited to: a history of brain injury due to brain hemorrhage, pediatric stroke survivor, multiple life saving brain surgeries, epilepsy, gtube fed for nutrition, severe scoliosis requiring two full back reconstruction surgeries, hip osteotomy surgery, continuous specialist appointments, hospital stays, procedures and the list goes on. She also requires constant monitoring for her respiratory needs, breathing treatments, cough assist machine, pulse ox machine and suction. She will need rehabilitation services for the rest of her life including occupational, physical, aqua therapy and speech therapy. Our family would not be able to provide Ella all of these services which enhance her quality of life if it was not for the Rhode Island Katie Beckett Waiver.

So many children in our state rely on this waiver to keep them as healthy as possible, to allow them to live in homes and communities that their families live and keep them out of long term care facilities for children which do not exist in our state. As her mother, I am unable to work because Ella requires 24 hour care. In the current health climate, we do not have a full time nurse because we are facing a nationwide nursing shortage. This waiver allows Ella to live not only with her parents, but her best friend...her 17 year old sister, Chloe.

These waivers are saving our children from living in places were their quality of life would be less because they are not living with their families/kin who take the best possible care of them. It is my hope that the Katie Beckett Waiver stays in place for all of our children who need complex medical care while living in their own homes surrounded by those who love them the most and take care of them the best. Without the waiver, we would have to have our daughter live away from us and that is heartbreaking to even think about.

We are grateful this waiver program exists for our daughter, her friends, classmates and all the children in our state that need it to live their best possible lives with their families/caregivers.

I thank you for your time and consideration.

Be well,

Diane M Silva
Chief officer of scheduling and logistics
at the Silva Household/Team Ella