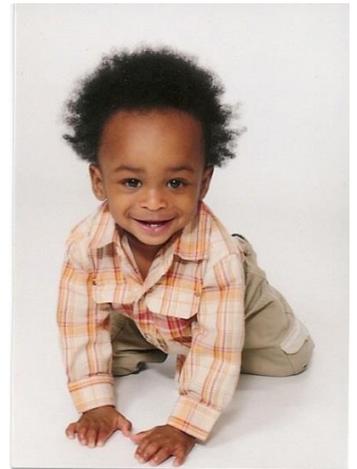


Example of a family story that was delivered to Governor Walker and to the media.

## Our Family Story:

### How the CLTS wait list affected my family

Brigit Frank,  
Madison, WI



We adopted our infant son, JD, from Wisconsin. We're so fortunate to have him in our lives! He's a sweet, funny child who loves music, animals, sports and building things with his dad. We were informed that he may have some health issues due to his premature birth, however, there wasn't a specific diagnosis when we brought him home.

As JD moved from baby to toddler he began getting diagnoses, and we began working with more and more specialists and therapists. Our family was chaotic, and I had to forget my plans to returning to work when JD turned three.

Despite our best efforts, by the first grade JD had significant behaviors and his health wasn't stable. A mom suggested that we apply for Children's Long-Term Supports (CLTS) to get a service coordinator who could help advocate for us and help us find the services that we knew existed, but couldn't seem to locate on our own.

JD was found eligible to the CLTS program and put on the wait list.

While we were on the wait list, JD's health continued to decline. He began losing skills, he dropped further off of the growth curve, he had a hard time speaking, and he developed tremors and ticks. All of his doctors and therapists agreed that the best course of action would be a short term hospitalization at a facility that could safely ween him off of all of his medications and then develop a comprehensive treatment plan. But, the hospital in our area that specialized in this type of care could not initiate an intake because we were still on the wait list. They required a CLTS case manager to cosign the plan both to cover cost not covered by our insurance and help implement the plan for future care.

Our family continued on this way for about three years. JD had more therapists, labs and medicine changes, but nothing helped him regain his health. He also missed countless days of school, which put him even farther behind his classmates. Finally, when he was in the fourth grade, his condition was so bad that our pediatrician placed JD in our community's children's hospital, instead of the facility that was originally requested, for weight loss and failure to thrive.

JD was in the children's hospital for 16 days. He had two surgeries, including a G-tube placement. And, after his release, he required intensive speech, occupational and physical therapies in order to gain back the skills that he he lost. JD's decline and all these additional cost associated with it could have been prevented with timely access to the care he needed. We were forced to watch helplessly while our son's health failed because our name wasn't at the top of the wait list.