

Here's an example of a story (as told by a parent):

My child is 20 years old. He has cerebral palsy, a seizure disorder, and he is autistic, with very limited communication. He lives at home with his sister, father, and me. I am his full time caregiver. Last year, he suffered from a severe illness. He is stable now, but doctors expect that he will relapse.

My son should be in high school, but he has been too fragile for the high school environment. He becomes upset by the noise and commotion there. This means that the responsibility of his care falls on me, and I am worn out. I have considered putting him in institutional care.

My child has had SSI since he was 18, which gives him access to Medicaid, but he has been on the waiting list for a Home and Community-based waiver for 2 years. Since the change from contracted support coordination to Planning List Administration, I have not heard from anyone regarding my son's status on the list.

I understand that many of his peers in his high school class are also on the waiting list for Home and Community-based support. Teachers are very concerned that once students exit school, they will just go home to sit.

The "planning list" a euphemism for the Waiting List, has over 5000 individuals on it. Students like my son are placed on the short term list, in the hopes that they can get adequate services once they exit high school. The reality is that most high school kids who graduate with moderate to significant disabilities end up sitting home for at least several months, if not longer. Employment statistics indicate that there is an 80% chance that if a student with disabilities is not working when they exit high school, they will most likely never work.

The state budget may have shrunk, but the need for funding has only increased. It will continue to do so without the steady, annual infusion of resources, in order to provide some reasonable expectation to families that their member with a disability would have access to community based support.