

My husband and I have a 26 year old son, David, who has Down Syndrome and cerebral palsy. He is profoundly developmentally delayed. He lives at home with us. When David was born it was discovered he had a heart defect, a hole between the chambers of his heart. At first we were told that it would close on its own and David would be fine. He became very ill when he was 4 months old and had to be hospitalized. We discovered that the hole in his heart was much more serious than we previously were told. He needed surgery to repair the hole. He sailed through the surgery, but during his recovery his pulmonary artery ruptured and we very nearly lost him. He needed further surgery to repair the rupture. By the grace of God and the many prayers of friends and family he survived but had to remain in the hospital for many months on a ventilator heavily sedated. He struggled with his health for his first few years and was left with cerebral palsy and severe delays. He is unable to walk independently. He has no balance and needs to be supported in order to walk. He is mostly transported by wheelchair. Because he was sedated the first few months of his life he never learned to chew or to drink from a bottle. He now requires a pureed diet and thickened fluids. He has a gastrostomy tube for hydration and medications. He cannot verbally communicate but makes his needs known by his behavior and body language. He has self-abusive behaviors as well. He will slap his face and bang his head on a wall especially if he is not feeling well, having pain or is just plain frustrated or bored which is frequently the case. He wears a protective helmet for these reasons. Needless to say this behavior is very distressing to us and to him. We've tried several medications for this but most of them he could not tolerate. David requires total care for all his needs, feeding, bathing, toileting. He can never be left alone as he has no safety awareness. He can scoot around on the floor and will throw anything and everything he can get his hands on. He is also strong enough that he can move furniture around. He needs constant supervision to keep him safe. He attends an adult Day Program during the week which allows me to work a few hours each week. We have Home Health Aide services for a few hours on the weekend and occasional respite weekends which used to be once a quarter this has recently been cut. All these are helpful but are not enough. I'm finding as I age my body is showing signs of wear and tear. David's care is extremely physical. I wonder all the time how long will I be able to do this? Time is running out for us. David is on the list for residential services, but I know that the list is very long and not being addressed as it should. My desire for him is that he would be able to live in a home with his peers and live a fulfilling life. I believe he wants that as well. I fear reaching my "golden years" not knowing what will happen to him and if there will be the appropriate care for him. I ask you to support HB 5534 which would make sure that David and others like him and our families receive the services they so desperately need. They are our most vulnerable population.

Thank-you,

Marc and Brenda Brennan