My name is Doug Beilke. I have been a PDSP for my nine year old son, Desmond, since July 2022. Desmond has cerebral palsy. He is non verbal, non ambulatory. He can crawl around the house but otherwise relies on a wheelchair. He is unable to toilet himself. He has a seizure disorder and must be monitored for petiit mal seizures which happen often and also for tonic-Ionic seizures that require rescue medication when they happen. He has dysphagia, which is difficulty swallowing. He requires thickened liquids and must be monitored closely when eating due to risk of choking. He is allergic to peanuts and must have an epi pen with him at all times. He requires constant supervision as he cannot keep himself safe. Prior to becoming Desmond's PDSP I worked full time. His mother is disabled and although she is not completely unable to care for him it is difficult for her to do alone, especially as he gets bigger. We relied heavily on DSPs to help care for Desmond while I was at work. Our experiences have been mixed. We must train new DSPs on how to care for our son, handle emergencies due to medical or behavioral issues as well as using the many pieces of adaptive equipment such as his wheelchair, assisted stander, gait trainer, and adaptive tricycle. Some of this equipment is provided by the school and DSPs must be trained by a physical therapist from the school before they can use these devices at home. We must schedule a time to take Desmond and the DSP to the school to have the training done there. We take new DSPs to Desmond's private physical therapist for additional training on therapies such as walking with hands on assistance and any therapies he is working on to encourage him to use his right hand and arm as he does not like to use it due to lack of dexterity and sensation. All of this training takes a considerable amount of time and effort. The high turn over rate creates some issues. We have only had one DSP last longer than six months. Desmond's high level of needs cause people to get burned out. We caught one DSP smoking pot in our backyard while he was in charge of Desmond alone as we had just gotten home when we caught him. We fired him on the spot. Attendance has always been a huge issue but we have not fired anyone for that because it is difficult to even get applicants at times and having a DSP sometimes was better than not at all. We gave every applicant a shot if they still wanted the job knowing his level of needs. With every new hire it takes a long time to build trust with someone. We always have remained dubious because you never really know what someone may do when we are not around. Our son cannot tell us. Our son is very high needs and it is hard to trust anyone with his care.This causes us a lot of anxiety as parents. It is all very stressful for our family. When I was working outside the home I frequently had to leave work to help care for my son. He is frequently sent home from school and I would have to leave work to pick him up because I am the only one in our household who is physically capable of loading him and his wheelchair into the car. Being the

parent of a special needs child causes job insecurity. No employer is happy with an employee who has to leave work to take care of their child once a week on average. I received reprimands from my employer due to my frequent need to leave work. I worked in a field where you must be on site to do the job so working from home was never an option. The physical and mental and physical toll it took to maintain my full time job and come home to take care of my son was hard on me and my family. After going nine months with one part time DSP and several failed hires for the full time position, I found out that I could be Desmond's PDSP. It was the best decision for my family. We no longer have the worry that the DSP will call out and leave us without adequate care for Desmond. We will always need additional help of DSPs, but now we don't rely on it to the degre