

Testimony
Senate Bill 2276
Senate Human Services Committee
January 24th, 2023

Senator Lee and Members of the Senate Human Services Committee, my name is Brittany Armstrong Hanson, and I am here before you today, in Favor of SB 2276.

I am a single mother of three children with developmental disabilities. My daughter is 12 years old, and my sons are 10- and 14-years-old. My boys are both Intellectual Disability/Developmental Disabilities (ID/DD) Waiver recipients, Early Intervention (EI), and Early Childhood Special Education Program (BECEP) graduates. All three have an education plan, Individualized Education Plan, Individualized Learning Plan (ILP) or 504, each with an, at least, annual meeting to update and review the plan. All three children, until recently attended outpatient habilitative therapy service appointments with Speech (ST), Occupational (OT), and Physical Therapy (PT), multiple times a week, with 9, 6, and 4 appointments for by 10-, 12-, and 14-year-old, respectively. With each habilitative therapy specialty comes twice annual reevaluations, that is 3 OT, 3 ST, and 2 PT re-evaluations, which include, at a minimum, 3-4 assessments that are several pages long that I have to fill out, updates to clinic paperwork, and coordination with school staff to have school/teacher versions of my forms filled out by the school/teacher and returned to the clinic. Each of my children also have co-occurring medical conditions as well and see multiple medical specialists throughout the year, in and out of town, with each requiring completing detailed health histories and in-depth medical exams. We have had out of state referrals, but I simply have not been able to manage traveling out of state for intensive diagnostic and/or evaluation clinics.

In addition to the habilitative therapy and medical care appointments, exchanging of information, and coordination of care, there is ongoing, most often daily, communication with, and school staff, from front office staff, dietary and kitchen staff, school nurses, special education teachers, paraprofessionals, general education teachers, and other support staff. This high level of communication not only ensures my children's the health and safety but also provides for a warm handoff between myself and others who interact with and support my children on a daily basis so that varying plans of care can be carried out.

I am Mom, and in my case, working double time to desperately try to make up for there not being another parent in the home, case manager, care coordinator, and Mom Uber extraordinaire, and still somehow have to figure out how to provide the ordinary (non-extraordinary) care to my children; feed and bathe them, wash endless loads of laundry, grocery shop, and still make time to be able to hold and hug them, help them fall asleep, listen to them when they are happy, sad, or need a shoulder to cry on, plan and celebrate birthdays and holidays, and just be with them. I am constantly reminded to incorporate self-care, not just for myself, as their caregiver, but for all of us, as we are the entire family unit. I am told to remember that I need time to breathe, bathe, and maybe even socialize, so that I can better care for my partner, all of my children, and my aging parents. Thank goodness for other parents who get it and still care for and love me despite my inability to consistently communicate or are there to pick me back up after periods of falling off the face of the earth because all that I had left in me was enough energy to retreat, for sanity's sake.

But wait, there's more! I am also an employer.

We have been utilizing ID/DD Waiver services, particularly, self-directed support services (SDS) with In-Home Supports (IHS) and Equipment and Supplies for over 12 years. That means that I have recruited, hired, trained, coordinated schedules, ensured reporting and receipt of quarterly authorization of service

hours by fiscal agent, computed authorized hours with consideration of employer taxes to determine actual employee compensation rate and resulting hours, completed twice monthly payroll consisting of review and verification and submission of logged hours/timesheets, and have had the pleasure of doing so with two fiscal agents, their paper processes, online platforms, integration with the DD Division's internal processes, implantation of Electronic Visit Verification (EVV), COVID medical leave, end of year tax statements, annual employer tax rate issues, and fielding all the Q&A from employees. I have worked with numerous families who have shared in my experiences and were trying to figure out how to walk the same path without assistance from the DD Division. I say this because, with self-directed supports, we receive very little support from the DD Division.

The DD Program Managers (DDPMs) try to assist families and individuals who elect (choose) to utilize the limited-service options available in a self-directed model, to the very best of their ability, in completing the enrollment packet (a lovely stack of paperwork!) which creates an account with the State's designated fiscal agent, submits an application for an Employer Identification Number (EIN) with the Internal Revenue Service (IRS) establishing the individual or designated individual, often times, the parent or guardian of service recipients, as the employer of record. The service recipient(s) and employee(s) enroll and each separate accounts. The DDPMs are not trained to, nor do they have the ability to, assist with anything fiscal agent related. There is not a liaison or other connecting person or entity between employer of record and the recipient(s), the fiscal agent, and the DD Division to assist with this service option.

DDPMs meet with individuals and families quarterly and complete annual assessments to determine ongoing eligibility/qualification for services (PAR or SIS Assessment), annual review of the Individual Service Plan, Overall Service Plan,

or Individual Family Service Plan; assessments and names of service plans vary depending on the age of the wavier recipient. Individuals and Families also work with the DDPMs to complete the annual application for in-home supports, which determines the quarterly authorization of service hours, based on classification of the type of service hours needed (respite, 2nd pair of hands, and supervision) and the need for such hours, overall. Application and determination of eligibility for the ID/DD waiver is most often a long, stressful, and complicated process. Despite the initial eligibility criteria defining "Developmental disability" as "a severe, chronic disability ... which: ... Is likely to continue indefinitely", eligibility and level of care and an application for in-home supports services must be completed annually.

We have been lucky to have had only had three different DDPMs for my boys over the years and the same DDPM for both boys for the last 8 years. Just recently, the boys were assigned a newbie, who is a temporary employee, so the possibility of losing her with the current workforce situation, but I'm holding out hope that she will stick around. She has big shoes to fill, is still learning the ways of my busy little circus and is doing unbelievably well keeping up with my need for detail, 20 bajillion questions, in depth discussions, and has already nearly mastered the art of keeping me focused and on task despite the ever-growing list of things pulling me in other directions. Needless to say, I have been more than happy with the support we've received from our DDPMs.

And lastly, employment. Yes, I've juggled trying to maintain employment in addition to all of this.

Time off and the need for flexibility in scheduling or alternative work schedules for all the medical, therapy, and school appointments makes it all too easy to burn through any accrued paid time off/annual leave and sick leave which has left me

having to choose between proving income or providing care for my family far too many times.

I have been a nurse for a decade and a half, worked rotating day/night shifts at local hospitals, did contract nursing across the state to have more flexibility in my workdays, worked in the schools as a school nurse, and was only one of three nursing working with intensive outpatient dual diagnosis treatment teams in the state. I've worked as a nurse consultant in infection control and dabbled in some legal nurse consulting and got to worked in my dream job, as a disability advocate, for a short time. Ultimately, the choice to provide income or provide care always roars its ugly head. Providing care will ALWAYS win and I will continue to pick up the pieces, figure something out, and keep going, one way or another.

But, I want to be very clear, under no circumstance, did I or will I ever choose to "forgo employment outside of the home", as the Department has phrased it. I have had to make the choice between parenting, providing all the care I've described previously, and employment, which in turn supports parenting and providing the various other care roles, and funds basic survival. A choice that no family should have to face.

You will hear lots of other testimony about more specific extraordinary cares provided to individuals by primary caretakers or legally responsible individuals, today. I encourage you to take a moment to really consider what you consider ordinary cares or typical caregiver/family member interactions and just how much each of these families here today have sacrificed, have been unable to be attain, what they have lost in the complexities of providing all the above and beyond cares, or everything that they have "forgone", in the Department's words, while trying to not only meet needs but to provide the level and quality of care that each of their families deserve.

Thank you. I will stand for any questions.