



2024 SUPPORT SERVICES SURVEY RESULTS

The *Support Services Survey*, an informal survey developed by the Developmental Disabilities Housing Initiative (DDHI) to understand the impact the staffing crisis has had on our adult sons/daughters with I/DD and their families, revealed:

- 18% of the families are receiving ZERO of their budgeted support hours
- Clients with less than 24/7 supports currently receive only 53% of their eligible direct support service hours, which equates to a loss of 13 direct service hours/week. They are further negatively impacted by staff vacations, unplanned call outs and lack of subs.
- Families are paying \$23/hour on average for Respite. Paying higher hourly rates with existing respite budgets means families receive fewer hours of support.
- At least 26% of the responding families have had to leave jobs or reduce the number of hours they are working to provide the necessary care and oversight for their adult children due to the staffing shortages. This is a conservative number as the survey did not directly ask this question.

Due to lack of support, I have gone to a 2-day a week job and took a substantial cut in hourly rate on top of it. I take our son everywhere I go as we don't have anyone to help us - comes to all my appointments, etc. ~ DDHI Parent

Families relying on HCBS waiver services are facing a dual crisis that profoundly impacts the daily lives of both parents and their adult sons and daughters.

FOR PARENTS, chronic staffing shortages often force them to step into unpaid caregiving roles, leading to disrupted careers, financial strain, and severe physical and emotional exhaustion.

FOR INDIVIDUALS RECEIVING CARE, the consequences are equally dire. Many are isolated, unable to consistently access social and community activities.

It's very challenging for our daughter to have her schedule in flux or not being able to access her regular activities. Choice is completely obliterated for her. ~ DDHI Parent

The unpredictability and insufficiency of services disrupt short- and long-term stability, leaving families in a constant state of adjustment. These staffing shortages threaten to erode the progress these individuals have made in achieving greater independence and community integration.

To address these challenges, legislators must prioritize investment in the direct support workforce by:

1. **Increasing Compensation.**
2. **Providing Ongoing Training and Career Pathways.**
3. **Implementing an Annualized Medicaid Rate Review.**

Notes:

1. As of 12/6/24 57 families with adult sons/daughters with I/DD being served by the HCBS Waiver responded.
2. Please see the attached sampling of quotes from survey respondents about the challenges faced due to lack of services.
3. Contact info: Karen Price, karen.price@vtfn.org



Here is a sampling of quotes about the impact the staffing crisis has had on their families:

I cannot find respite workers. I cannot work, we struggle financially. As a full-time caregiver doing it as a single parent the burnout and physical and mental toll is immense. They insist she needs 2 people with her because of her needs, yet I am expected to do it on my own. She is not getting what she deserves and needs. The system isn't working!! Everything is a fight.

My son is spending more time watching TV, gaining weight & becoming less comfortable with conversation.

I am unable to work a full work week most weeks because neither our family nor our designated agency is able to hire and keep DSP staff. Because of the low pay and the huge challenges of direct service work, talented and compassionate DSPs leave for other opportunities. The result is lots of disruption for our young adults which can result in regression, depression, and poor quality of life for them.

The chronic staffing and substitute shortage isolates our son from potential enriching community opportunities and small peer group experiences. Less critical is the fact that we need to be available each day that staffing is not possible.

No one wants to work with our kids for that little amount of money an hour... I work with them in a school setting and make \$30+ an hour plus benefits, so let's pay these people that are willing to put in the effort to help our kids.

I have 2 Respite people who care for my daughter while I work. I cannot compete with all the employers out there that can pay \$20+. If I give them more pay, then I have less in my Respite Budget.

Inhibited my son's development and path to being more independent. Negative impact on mental health of other family members.

My daughter has NO direct support staffing, even though she is approved and funded for it. At this point, I take her to and from her two jobs each week as well as coordinating her other activities and getting her there. I had to stop working so that I can get her where she needs to be and involved in activities that improve her quality of life.

Lack of direct support for our autistic son has led me and my husband to cut back on our paid work. My husband is currently on unpaid family leave. As a result, our household income has been cut by 50%. In addition, my and my husband's mental health has seriously suffered.

My daughter is regressing & missing activities & peers. She is beginning to not want to leave the house and is sad she is only gets to work 1 morning a week now. It's also putting a lot of stress on my job and financial situation as I've had to miss work because of no coverage.

My son spends too much time alone as it is, and when his support people can't make it for one reason or another he can't go to work, and this happens pretty frequently.

While my hours are being met, I have had 7 different DSPs assigned to my son in 5 years! Retention is horrible. Supporting an individual with I/DD is a very demanding job and individuals entrusted with the care are not compensated enough to retain good help.

We had to give up our jobs to do the work the agency is NOT doing.

My hours at work are dependent on care for my son. I work PT because we can't get permanent or dependable folks who want to do this job. It isn't the easiest or "fun", but we need a change. My husband works a different shift due to constant care for my son. Hiring qualified and dependable people has been a challenge.

I can't find enough support people who can deal with my daughter's significant needs for me to continue to work full time. I honestly don't know what to do.

We are becoming increasingly home bound. Our adult son requires highly skilled support staff due to challenging behaviors and medical issues.

My son no longer gets out of bed, has regressed to the point of being housebound, and I had to quit my job to care for him. This is a critical crisis. We haven't had care since March 2020.