

Thank you for the opportunity to speak with you today.

My goal is to share how not receiving developmental disabilities support services (DDSS) has impacted my adult children's and our family's life. I am here to speak not only for my family members but for those in our community who are unable to be here today.

History:

I am the mother of six adult children, ages 35 through 41; one who has a traumatic brain injury (TBI) and five who have Down Syndrome, with secondary complexities of early onset dementia, a generalized seizure disorder, deafness, non-verbal communication needs (ASL and augmented communication), OCD, an anxiety disorder, blindness, autism, Hirschsprung's Disease and so much beauty.

We do not qualify our love, expectations or care for our adult children by their diagnosis/labels and are just a family like yours.... The good, the bad and the in between.

I will share our family's situation without making it a sappy story since I am one of the luckiest people in the world. Here goes:

A typical day at our house includes toileting, personal care, and bathing assistance. At meals, three separate meals are prepared: one gluten free meal for our son who has Celiac Disease, one for our son who has a restricted esophagus, and one meal for our son who has an eating disorder/tactile oral challenge.

We must sit next to our son at meals who has a restricted esophagus to monitor food motility, buildup, and blockage, leading to choking. We keep a metal bowl at the dinner table for regurgitation purposes. This same Son has autism and OCD and will compulsively carry out actions and behaviors, even if it is detrimental to his safety, i.e. He has walked into traffic in downtown Burlington. His support staff had to physically pull him back to avoid being hit by a car. The support staff was so upset, she had to seek mental health assistance.

Our Son with early onset dementia requires full care, eyes on assistance to keep him safe from danger, and to process, understand, and comprehend the world surrounding him. A good sense of humor helps, but if all else fails, a box of drake's cakes hidden in a glove compartment does wonders.

We must be the eyes and ears of another son who will impulsively act without a sense of danger and remind him to not use the vacuum around water, to look before he crosses a road, how to stay safe in a parking lot, teaching him how to interact and interpret actions of others, and how to engage in a socially acceptable manner.

Enough with the list, you get the situation. My husband and I are joyfully engaged 24/7 with our adult children and fall in love with them each day. We do need help and support services, though.

Support services allow our adult children to receive training, skill building, education, insight, helpful strategies and perspective from staff to become autonomous, independent adults. We too learn from staff and are grateful for their guidance and suggestions.

Support services enable us to be parents. Without staff and services, we fail our adult children bc I am unable to be a psychologist, case manager, OT, PT, advocate, Teacher, colleague, employment advisor, recreational team, communication provider, technology guru, and advisor.

Service Agencies:

We had been receiving services from a Designated Agency (DA) since 1990 but recently transferred to a Specialized Service Agency (SSA), Champlain Community Services (CCS – VT) after waiting to transfer for 7 years.

The DA deemed our family an intact unit with natural supports since I worked days, and my Husband worked nights and weekends. As support staff and services evaporated down to one individual for my son with early onset dementia, I was forced to resign from my position since I was unable to meet the requirements and travel of the job. Thus began the unraveling of our family.

During this period, we realized our family would never reach the beginning of the DA s ever growing line to receive support services because the staffing shortage was growing, and the DA had no avenue to attract/retain employees due to inadequate and noncompetitive salaries.

We decided to transfer to CCS, a smaller SSA, in the hope that VT policies and actions would change, affording ALL agencies the funding necessary to attract/retain experienced, educated staff. Without adequate funding, DA/SSAs will fail.

Life Without Support Services:

On 3/18/2020, our DA furloughed DDS staff due to COVID. For the next four years our family (except one Son) did not receive support services. If minimal services were provided, it was for employment only.

Most DA support staff did not return to their jobs after furlough and/or found other employment that paid higher wages with much less responsibility.

The staff that remained at the DA were assigned to consumers in crisis or who had critical needs served first. (***as it should be!***) The situation left our family members with no support services, or at best, greatly reduced services. ***It was a long four years without services.***

One Sons employer held his job open for one year, but had to terminate him after support staff could not be reinstated; another son lost a job that he loved, and my other children had their work shifts on multiple days reduced to a two-hour period, 1x a week ***-if at all.***

During the last four years without support services:

My son with early onset dementia has lost cognitive, physical and emotional abilities, skills and independence. I try with every piece of me to save what skills and abilities he has left but I am a poor replacement for the full-time staff he once had. I pray for staff and services every night. It's beyond sad to watch as I lose my son.

My other Son, who experiences panic attacks, OCD and is blind due to Keratoconus, would not leave the house for four years. Yes, four years. No amount of encouragement could coax him out of his fear of leaving the house.

We tried to keep our adult children engaged and active each day, walking 1.5 miles a day, cooking, doing schoolwork, playing basketball, etc. but after the first year, the novelty wore off. Would any of you want to give up your present life to stay home 24/7 with your parents without seeing any friends, colleagues or community members? I'm boring!! Eventually, our adult kids became bored, frustrated and angry that they could not engage in life activities as they did before staff shortages.

That's when our life started breaking apart. One Son became so distraught at losing support services, beloved staff and his job that he began sleeping all day and staying up at night. Most days he would not leave his bedroom until 2 or 3 pm. He told me he had nothing left in his life.

If anyone is thinking that we could have imposed natural consequences/ punishment, or positive reinforcements, to change sleeping patterns and behaviors, it's not doable with someone who has reinforced patterned behaviors of OCD and autism. The trick of his life is to establish patterns of success and rely upon established schedule of events/activities. Loss of support services has devastated my son's life.

My daughter became sullen during the four years and wanted to know why she couldn't have her old life back.... why she couldn't go to work like she used to, why she couldn't go out anymore and why we were doing this to her. She became very depressed and angry.

During the third year of not having support services, a case manager responded to my question of when we'd have support services re-instated by telling me: you adopted them, you take care of them.

I do not fault the case manager for their response; they were as stressed as we were trying to fill ever increasing critical needs with staffing shortages and trying to find solutions in an untenable reality.

The kids were angry, were losing abilities and skills, and I started feeling overwhelmed and paralyzed with the thought that there would never be staff or services again. I was failing the kids, became despondent and clinically depressed.

I made it through this dark period by the unwavering love and support of my husband, kids, and great care from doctors.

Around the end of the fourth year of no support services, we received a call from CCS-VT asking if we were still interested in transferring to their agency. We jumped at the opportunity but still worry about the consumers we left behind at the DA who are not receiving support services. I am here to speak up for them.

I'm happy to report that upon transferring to CCS-VT, my daughter, who was angry with me and the world now enjoys two days of employment, peer activities, joined CCS advocacy group, and most importantly, has a friend and a sense of belonging and community. My Son who was homebound has worked with amazing staff at CCS and is venturing out of the house, enjoying life again. WOW, the IMPACTFUL POWER of SUPORT SERVICES.

We're still working on my Son with early onset dementia and my Son who sleeps all day and stays up all night, but CCS staff is THERE for HIM and US, providing insight, strategies, encouragement

and most of all, a sense of CARING. The sense of caring gives us hopeful encouragement as we continue our journey.

Transferring to CCS-VT and receiving support services has provided our family with the pieces to put our family back together one Stamati at a time. We still need staff and services. We aren't whole yet, but my hope is this Committee will effect changes.

Staffing Shortage:

Staffing shortages are a national problem and are not specific to VT. To address staffing shortage and possible solutions, I contacted DAIL and suggested the following:

- Policies and wage increase that would attract and retain employees who are educated, qualified, committed and interested in a long-term career in human services.
- ***Affording agencies the resources and ability to do their job and hire staff.***
- Internships that provide loan forgiveness for a two-year commitment of employment. These internships could be like the program offered to address the SRS staffing shortage in which participants were forgiven tuition, book, and peripheral costs for a two-year employment commitment. VT already has tuition assistance funding in place, so the internship would only cost the State book and peripheral costs.
- Incentivizing/retaining employees to join/stay in human resource field if they were able to become VT State employees, just as aides are in each school district. School Aides essentially perform the same/similar duties as DDS support staff. This action would attract and retain MANY employees to commit to a long-term career.
- I requested DAIL to define what constitutes support services, to include whether they would allow agencies to creatively support consumers in different ways than is currently allowed.
- Whether DAIL would agencies to provide services via a scheduled group activity with transportation provided to/from activities.....whether DAIL would allow agencies to purchase vehicles to carry out such services, whether DAIL would allow agencies to cover entrance fees to activities.
- I also suggested DAIL consider allowing individual agencies to partner with each other, sharing resources, activities and employing staff at a ***consistent rate and benefit package.***
- Agency compensation and benefit packages are not consistent throughout VT resulting in staff inability to move from/to another agency without losing salary increases, benefits and time off. (Please see above. If agency employees in VT were govt. employees, there would be consistency in pay, carryover of benefits, time off and career advancement opportunities. Plus, DAIL could provide fiscal oversight and quality control of VT employees).
- Partnering with other non-profit agencies, such as good news garage, to receive donated vehicles for agency and support staff use? Vehicles are expensive and it has been estimated that support staff depletes a vehicle every three years.
- If cars were received from a nonprofit, such as good news garage, opportunities would abound. Chittenden Co. has multiple college/universities in the area and most students do not bring vehicles to school. Having the use of an agency car would enable students to become employed in our community and may extend hours of support services to include weekends, nights, overnight and after agency closing times.

DAIL Interview Panelist

Recently, DAIL chose me to be an Interview Panelist for Conflict Free Case Management bidders. I was beyond excited thinking I would be able to positively impact actions to address DDS staffing challenges.

I now have grave concerns for the future of VT DDS services, (IMHO) the dismantling of existing agencies/services and the slippery slope leading to institutionalization under the guise of efficiency.

If this Committee, or the Governor, can release me from the NDA, I will GLADLY avail myself to this Committee to share my experience and concerns.

I also ask this Committee to consider Governor Scott's message which asked legislators to fix problems instead of continuing to fund them, to look for solutions that will benefit VT in the long run and economically trickle down to VERMONTERS within our community, building a stronger State.

Now is the time to work together to strengthen Vermont's DDDS service model with actions of fiscal responsibility and a sense of caring for each other. Let's do it!

Respectfully Submitted,

Lisa A. Stamatis