

**Testimony before the Appropriations Committee  
on the Governor's Proposed Biennial Budget**

**March 6, 2015**

**Christine A. Rowan, Newtown, CT**

Good afternoon Senator Bye, Representative Walker and members of the Appropriations Committee.

My name is Christine Rowan, and I am a registered voter in the town of Newtown.

I am here to testify on the Governor's Proposed Biennial Budget.

I am opposed to the proposed cuts to the Department of Developmental Services Voluntary Services Program which provides in-home supports to Connecticut children with dual diagnosis of both a developmental disability AND a behavioral or emotional disorder. The proposed cuts to this particular program are massive, wiping out 2/3rds of the program's current budget and essentially eliminating the program. I strongly urge you to restore these devastating cuts to ensure that vulnerable Connecticut children like mine receive the supports they need to grow up safely at home with their families, costing the State of Connecticut much less financially in the long run.

When I first heard about these proposed cuts, I was in a state of shock and fear, literally terrified about what will become of my family. But my faith has lifted me up to share our story, not only for my family, but for all families who will not be able to keep their precious children at home without this program.

My husband and I are the parents of three beautiful daughters – Amanda, age 14, Katie, age 10 and Jamie, age 8. My eldest daughter, Amanda is autistic, has severe behavioral challenges and is a DDS Voluntary Services Client. Amanda can light up a room with her smile. She loves music, reading, theatre, and dressing up in costumes. She can melt the heart of even the grumpiest passerby as she struts through the community in her latest silly hat, high fiving and asking for hugs from anyone who looks like they could use one. But as quick as the flip of a switch, my sweet girl can transform before your eyes into an aggressive, out-of-control stranger. Amanda needs help with virtually all areas of daily living including bathing, toileting, dressing and eating. She has no awareness of danger and, as a result, we have special locks and alarms on all the outside doors, cabinets throughout the house are locked and knives are hidden within a cabinet securely out of reach.

Three years ago, I was teetering on the brink of a breakdown and running out of options. In addition to the typical stresses of raising three young children, I was dealing with Amanda's extreme tantrums on a daily basis that involved aggression – biting, pulling hair, punching – directed not only at my husband and myself, but also our two younger daughters. Going out in public was a nightmare – dramatic scenes often resulting in calls to security and crowds of stunned onlookers – so we never went out. I relied on other parents to take my younger daughters to all after school activities and sporting

events, even while they voiced their disappointment that Mom could never be there. As Amanda's behaviors were spinning out of control and my emotional exhaustion reached maximum capacity, our entire family received a lifeline – the DDS Voluntary Services Program. This program has literally changed our lives and introduced some realm of “normal” to our family.

Through the Voluntary Services Program, highly qualified personnel come into our home on a daily basis – working with Amanda to become more independent, teaching her more appropriate replacement behaviors, expanding her world and helping our entire family cope with her on-going behaviors and aggression. Amanda, herself, LOVES her DDS Voluntary Service Providers, and her behaviors are definitely improved and more manageable within the structure that these caregivers can provide on a consistent basis. Amanda has been able to venture out in the community much more with the help of these dedicated providers and access some of the activities she loves like going to restaurants and theatre. And I have finally been able to spend some quality time with my two younger daughters, who I neglected for so many years out of sheer necessity. Being able to drive one of my daughters to soccer practice, help them with their homework or simply listening to news about their day are luxuries I now engage in, but will never take for granted. My husband and I have managed to spend some quality time together as well thanks solely to the VSP support which has become a part of our lives, and we are so grateful for.

Within this fabric of “normal”, even with the supports from the VSP Program, are interwoven episodes of extreme aggressive meltdowns. At 14 years old, Amanda is a big, strong girl – weighing almost 150lbs. Although my youngest daughter, 8 year old Jamie, is a tiny little thing, weighing only about 46lbs, she is probably Amanda's biggest and staunchest advocate; Jamie's love for her eldest sister is as fierce as it comes – which is quite astounding because she is also one of Amanda's primary targets in the throes of a difficult outburst. I cannot adequately describe for you as a parent how it feels to literally have to pry your child's hands from your younger child's hair, to hold back her jaw from clamping down on her sibling's skin, to block painful blows from landing on their intended target.

When the VSP supports are there, side by side with Amanda, these involuntary acts of aggression are rare. This is the primary reason we need this program and the support it offers – to keep Amanda safe in our home for as long as possible and to keep the rest of the family and members of our community safe as well.

Trying to save money by cutting funding to the DDS VSP program is a bad financial decision; it will backfire. It costs the state much less money to support my daughter in our home, than it will to support her out of the home. Without the VSP program supports, it is doubtful that we will be able to care for Amanda at home much longer.

Another reason cutting funding to the VSP program is a poor financial decision is that 50% of all state funding into this particular program is reimbursed by the federal government. Thus, if the State of Connecticut puts 20 million dollars of funding in the

DDS Voluntary Services Program for children – 10 million dollars of that funding is reimbursed back to the state through federal funds. It just doesn't make sense to make such drastic cuts to a program supporting children and families so desperately in need of that funding when the State of Connecticut would have received half of that funding back anyway.

Also, the DDS Voluntary Services Program is **not** a free program. Families are assessed based on their income each year in accordance with a formula deemed fair by the State of Connecticut, and families that have the means to do so actually contribute financially to the services their children receive through VSP.

In addition to conducting a financial cost benefit analysis when considering these cuts, there is a moral and humanitarian cost you must consider which cannot be quantified. I am from Newtown, Connecticut where, in addition to 25 other precious lives, Josephine Gay, the autistic daughter of my dear friend Michele was murdered. The State of Connecticut knows all too well the tragic implications of leaving children with emotional and behavioral disorders and their families without the vital supports and interventions they need.

In their latest draft sent to Governor Malloy, the Sandy Hook Advisory Commissions' Mental and Behavioral Health Recommendations state the following: "To promote healthy child development and foster robust communities, our system of care must attend to the factors affecting family welfare. Current funding structures must be revamped. The Commission recommends **support** for models of integrated care driven by family needs in which all providers focus on family strength, address their risk factors, and accept the family as a partner in treatment." The DDS VSP Program specifically serves at risk children with emotional and behavioral health challenges and supports their families as partners in treatment as recommended by the Commission.

The VSP program empowers families by allowing parents and caregivers to play an active part in tailoring and managing the program set up for the unique needs of their child and family. For example, one unique aspect of the VSP program is the self-hire option utilized by more than 50% of all VSP clients. Self-hire allows families to procure highly qualified providers of their choosing by tapping into autism and behavioral experts within our own communities that have worked with our children in other arenas and care about our families. Currently, I have both a highly experienced special education teacher and a functional skills teacher providing expert instruction and interventions to Amanda and our family in our home and community through her VSP funding – for a fraction of the cost of the actual value of their services. Through the flexibility the VSP program offers, caregivers and parents like me learn how to effectively and resourcefully manage and participate in our children's treatment and care in a way that best suits our family.

Services accessible through insurance alone will **not** provide an adequate substitute for the supports provided by the VSP program. If families are only able to access services through insurance with rigid rules, limited providers, tons of red tape and endless

paperwork for meager supports that they have to wait ages for in a system that is difficult for anyone to navigate, exhausted caregivers are much more likely to forego interventions their children so desperately need at great potential cost not only to that child and family, but to the larger community as well.

The proposed cuts to the DDS Voluntary Services Program would be absolutely devastating to my family. I truly don't know how our family will survive, intact, any longer without these supports.

Please hear my voice as the **collective voice** of VSP clients and their families. My situation is **not** unique. My daughter/my family **is** the population this program serves. Even with supports, most of our families are still isolated and in constant survival mode – either completely unaware of these proposed cuts or unable to muster the energy for any type of fight outside of their own homes.

I implore you, do not steal away our families' lifeline and with it, our last shred of "normal"...our hope for our children's futures...our hope for some joy in the present. Choose to protect Connecticut's most vulnerable at risk children and their families by restoring the funding to the Department of Developmental Services Voluntary Services Program.

Thank you.

