ANNUAL REPORT 2020

Empowering and supporting all Vermont families of children with special needs



Giving a Strong Start Lifting Family Voices Advancing Inclusive Communities

CHIEF ADMINISTRATIVE PERSONNEL

Pam McCarthy President/CEO

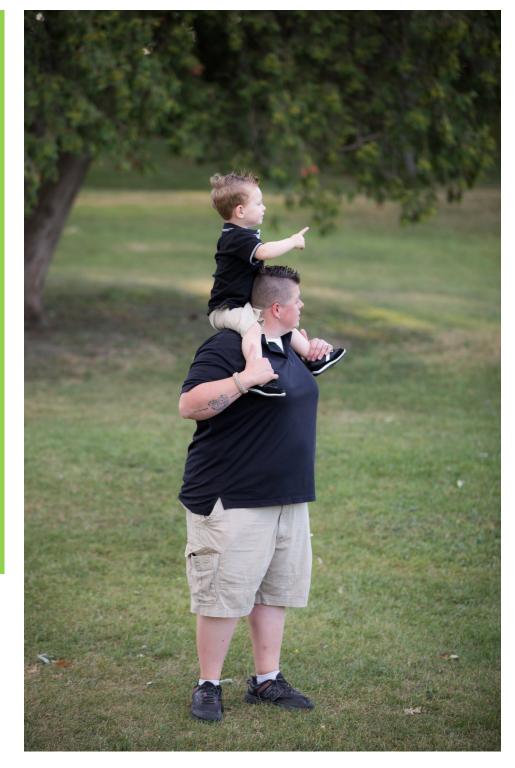
Sarah Wallace - Brodeur Director of Operations

Rachel Boyers Director of Children's Integrated Services- Early Intervention

Jamie Rainville Co-Director of Family Support Karen Price Co-Director of Family Support

Charles Teske Finance Manager

Sarah Vogelsang - Card Program Manager, Puppets in Education



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* DENOTES PARENT OF CHILD WITH SPECIAL NEEDS.



Dear friends and families of VFN,

We are so happy to share the work of Vermont Family Network over the last fiscal year, July 1, 2019-June 30, 2020. It has been a most unusual year. In March, as a result of the COVID-19 pandemic, we, like many organizations, had to shift all that we do to virtual platforms. All of us are still working from home at the time of this writing. Our staff and volunteers, with excellent support from our Board, came up with creative solutions to continue serving families and provide a whole new level of impactful support across Vermont during this crisis. Our signature family-to-family support, information, and trainings reached 922 families and 150 professionals, lifting family voices for positive change and advancing inclusive communities throughout the state. Our Children's Integrated Services Early Intervention (CIS-EI) program gave a strong start to 584 Chittenden County infants and toddlers and their families, making an immediate shift from face to face home visits and childcare supports with amazing agility when that became necessary this spring. Puppets in Education (PiE), has continued to increase VFN's reach within and beyond Vermont, engaging 6816 people throughout our State, New York, Massachusetts, and New Jersey, helping all children address difficult issues like bullying and abuse. To meet the needs of children and families isolated by COVID-19, PiE created a video on dealing with anxiety, as well as one to help children at risk of abuse reach out for help. As Vermont's Family Voices and Parent Training and Information Center, we have continued to be involved in advocacy efforts around prevention and early intervention programs, special education, payment reform, and budget decisions that impact families of children and youth with disabilities and special health needs. We continue to build our partnerships with other organizations and businesses, and are so grateful to have weathered the pandemic challenges to date.

Our organization is in its third year of an exciting sustainable funding strategy that we call "VFN Thrives." Our Board and staff are building a culture of philanthropy that is inspiring on many levels. Through our "Meet the Family" tours--- now on Zoom --- we are able to share VFN's unique mission, vision, and impact through engaging, and compelling family stories. Participants are invited to attend our wonderful Strong Families, Strong Futures fundraiser this fall, our first ever virtual event! The proceeds of this annual fundraiser are allowing us to diversify our resources and build a future that is not so heavily reliant on grants that are most often level-funded and/or time limited. We are striving to build capacity to meet families' needs as they define them, and to ensure that VFN is here for families well into the post pandemic future!

Enjoy our Annual Report—we believe you will be impressed by the impact Vermont Family Network has had over the last year! We invite your thoughts on our work, including new ideas for programs, collaborations, advocacy, and more! Please feel free to contact us: CEO Pam McCarthy can be found at (802) 238-1106, or pam.mccarthy@vtfn.org, and Board Co-Chairs Ellen Zeman and Craig Giles may be contacted at (802) 651-5912 and (802) 249-3456, respectively.

Be well, and know that we are here for you and your family!

All our best,



Ellen 1. 2





Family Story - The Owens Family



"As I think back to the worries and fears we had when our son was a baby, our circumstances have significantly changed. The change in those 9 years is amazing, and we believe a lot of that is because of VFN." My name is Gretchen, and my husband Ed and I have two children, Izzy, 12, and Teddy, 9. When our youngest had complications during birth, VFN provided invaluable support to our family in the first months and years of Teddy's life.

When I was pregnant with my son, I did not experience any complications. As this was my second child, we expected the experience to be a little easier. After all, we had done this once before! That all changed when I went into labor.

We rushed to the hospital and Teddy was born within minutes of our arrival. He was born without a pulse and without breathing. Teddy went without oxygen for eight minutes and experienced significant brain trauma. Unbeknownst to me, I had developed a blood clot that was cutting off my baby's oxygen in the womb.

After he was resuscitated, Teddy was sent to the NICU right away. He was put on a cooling blanket, which at the time wasn't the standard of care. We are grateful for all the doctors and nurses who cared for Teddy and are especially lucky that they started Teddy on cooling therapy within 30 minutes of his birth.

It was a scary time. Teddy was given a 10% chance of survival in those first few days. He also failed his newborn hearing screening, but at the time we were not very focused on that as we had other pressing concerns. We began the pregnancy with one set of expectations and moved quickly to a completely different set of expectations. We were unsure of what the future looked like for him and our family and it felt like life as we knew it had been shattered into a million pieces.

During our time in the NICU with Teddy we got to know VFN Family Services Coordinator, Theresa Soares. She listened to our story, shared her personal experience, and reassured us that VFN would help us in the weeks ahead. We did not know about Early Intervention services or the many supports available to families like ours. It was so helpful to have a knowledgeable, caring person thinking about a plan for the months ahead because we were 100% focused on our son's immediate needs. With Early Intervention Services on board, as soon as we got home with Teddy, we had a team of people surrounding and supporting us as we went through one of the most difficult times of our lives. All of the providers were fantastic. They helped us get organized and schedule follow up appointments with specialists. They also helped us to set up services through the Vermont Center for the Deaf and Hard of Hearing.

The amount of parent education during those first few months was integral to our ability to care for our child. Teddy had physical therapy that VFN helped to coordinate and he was eventually able to move away from needing therapy. He had weekly visits from a deaf/hard of hearing consultant, which taught us how to help Teddy listen and pay attention to the sounds around him.

A situation that was so scary and unfamiliar was made so much better with VFN support. We could always reach out to them with questions. VFN also helped us fill out the mountains and mountains of paperwork that most families of children with disabilities will know well. VFN was there when we needed them the most and when we were at our most fragile. They helped us access all the incredible resources that Vermont has to offer.

In addition, with the organization's help we were able to get Teddy hearing aids by the age of 6 months old. For my son, having his hearing aids has been a key to his success. All of these early interventions have led to a happy, successful little boy today.

As I think back to the worries and fears we had when our son was a baby, our circumstances have significantly changed. While Teddy has moderate to profound hearing loss, he is also an active, caring, and independent child. We no longer worry about seizures or wonder if he will meet his developmental milestones. The change in those 9 years is amazing, and we believe a lot of that is because of VFN.

Family Support Program

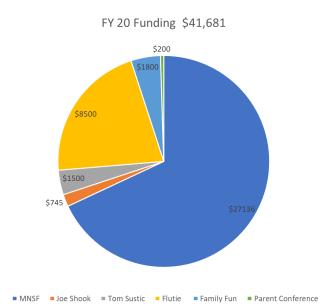


VFN's Family Support Program is founded on the work of its highly experienced and dedicated employees who are all parents of children with disabilities or special health care needs who have "walked the walk." Several staff members have been committed to this work for over 10 years and continue daily to support families who are navigating the complex health and special education systems. The complexity of these systems often leaves families in need of assistance with understanding laws, parental rights, and how to collaborate with a wide variety of professionals who are part of their child's team. Supported by federal grants as Vermont's Family-to-Family Health Information Center/Family Voices state affiliate and the Parent Training and Information Center, our staff is skilled and ready to support Vermont families in this process. Our federal and state grant funding provides families opportunities for leadership, conference, and training experiences, and we collaborate with Children with Special Health Needs at the Vermont Department of Health to help families pay for medically necessary services and products that are not otherwise covered by insurance. As the Vermont Parent to Parent chapter we have connected hundreds of parents who want to share with another parent who has similar experience with a child with a disability or special health need. During the past few months of the pandemic, there has been an increase in the number of families requesting a connection with other parents. We are developing a new and improved Support Parent training to respond to this need. Through this updated training, and our new and more efficient database, we are confident we will help facilitate a record number of parent matches in the coming years.

Family Support is a vital part of Vermont Family Network's mission. We listen to families and offer resources, support, and growth opportunities. We disseminate information to families through workshops, webinars, social media, our website, and printed materials. Families of children with special health needs and disabilities return to us several times throughout their children's lives. From the receipt of a new diagnosis to transition to adulthood, we are ready to assist however we can. Our goal is always to empower families with knowledge and experiences that will help them to move forward with confidence. As experienced parents of children with disabilities, our staff are uniquely qualified to achieve this goal.

Top 5 Family Concerns:

- 1. IEPs/IFSPs
- 2. Funding
- 3. Parent/professional communication
- 4. Mental Health
- 5. Transition to Adulthood



<u>MNSF</u>-Medically Necessary Supplemental Fund helps income-eligible families with unmet medical needs such as equipment, medications, travel, and therapies.

Joe Shook Fund-In memory of Joe Shook, this funding helps families with a distinct financial need that might not be otherwise met.

<u>Tom Sustic Fund</u>-In memory of Tom Sustic, this funding is for families with children and teenagers with cancer who are involved with hospice care, long term hospitalization, and/or transplantation. Funds are available for families who are referred from the Pediatric Oncology Social Workers at VT Children's Hospital at UVMMC and Children's Hospital at Dartmouth Hitchcock Medical Center.

Flutie Fund-from the generosity of the Doug Flutie Foundation, families who have children birth to age 22 with an autism diagnosis may request this funding for needed equipment, respite, camp, therapies, emergency childcare, or to attend a conference related to their child's diagnosis.

<u>Family Fun-</u>during a particularly difficult summer with COVID-19 restrictions we offered a one-time grant to families that went a long way towards reducing the stress of COVID-19 isolation.

<u>Parent Conference</u> -Funding to help parents with the cost of a conference related to their child's diagnosis. Covered expenses include registration, lodging, and travel costs.

13 Support Group events including Sibshops and Parent Chats 37 Trainings and Workshops, both live and virtual



"Parents become the experts on their child's care. Doctors learning from parents can be empowering to the parent, just as parents learn from doctors." - Parent

Children's Integrated Services-Early Intervention Program



VFN's Chittenden County Children's Integrated Services - Early Intervention program (CIS-EI) is part of Vermont's statewide system of coordinated services for pregnant women and young children. CIS-EI serves children ages birth through 3 years old with developmental delays or health conditions which may lead to developmental delays and provides coordinated services in natural environments, such as homes and early care and education programs where children without disabilities also participate. CIS -EI coaches parents/caregivers on ways to integrate play-based developmental interventions that are interesting and functional into the daily routines of their children.

For over 30 years, Vermont Family Network has held the contract for Vermont's largest CIS-EI program, providing these important supports and services for hundreds of families each year in a unique model that emphasized family expertise and family-centered practice. Our Family Resource Coordinators (FRCs), skilled and caring individuals with personal experience navigating the system of care for their own children with special health needs/disabilities, have been a gold standard of parent-to-parent service coordination. Our Developmental Educators, whose expertise is early childhood special education, have been successfully paired with the FRCs as "dynamic duos" serving families in close partnership with other CIS providers throughout Chittenden County. In FY 20, we served 584 infants and toddlers and their families, many of them in their childcare settings.

Over the last year or so, Vermont's Agency of Human Services has been going through the process of payment reform which includes the funding for Children's Integrated Services (CIS) throughout Vermont. Through this process, we were informed that Chittenden County would receive a decrease in funding. To ensure that all CIS services could continue with the funding cuts, the Chittenden County CIS contractor, the Howard Center, put all the CIS subcontracts (for Early Intervention, Specialized Child Care, and Strong Families Vermont Nursing and Family Support Home Visiting) out to bid in the spring of 2020, amidst the COVID-19 pandemic. VFN submitted a proposal for the Early Intervention subcontract, one that VFN has held since the days of Vermont's Family, Infant, and Toddler Project. We are sad to say that our bid to continue this work was not successful. The new CIS Early Intervention contract was awarded to our sister CIS provider in Franklin & Grand Isle counties, Northwestern Counseling and Support Services (NCSS). As of September 1st, 2020, NCSS is providing the Early Intervention services for the Chittenden region, collaborating with the other CIS subcontractors in Chittenden County. We hope that NCSS will build on the successful CIS EI services they already provide in the communities of northwestern Vermont, and their strong relationships with the state as a Designated Mental Health Agency.

Since the Governor declared the Coronavirus pandemic state of emergency in March, VFN's dedicated CIS-EI providers worked diligently to provide virtual supports and services to hundreds of families as we all worked from home. Throughout the summer, we also worked closely with NCSS and the Howard Center to provide a smooth transition for all children and families in this unprecedented change of providers. Needless to say, our CIS-EI staff are children's champions! It is some consolation to know that many of these amazing individuals have successfully moved into other roles within the early care, health, and education system; some even taking positions in NCSS's new CIS-EI program, providing some continuity for Chittenden County.

We celebrate the legacy of service our CIS-EI program leaves behind, and the strong starts our FRC's and DE's have provided to thousands of infants and toddlers and their families over these many years. VFN is more committed than ever to our mission as a statewide organization that empowers and supports all Vermont families of children with disabilities and special health needs. We continue to provide statewide support, information, and connection for families, and to promote strong family/professional/ community partnerships for all children. It goes without saying, VFN remains a significant resource to our transitioning CIS-EI families in Chittenden, should they wish to utilize any of our other supports and services, now, or in the future.

In FY 20, Chittenden CIS-EI:

- Served 584 children/families
- Received 423

 referrals, an
 average of 35 per
 month- an increase
 from 377 last year
 despite COVID 19



Family Story—The Barwin Family

My name is Katherine, and I'm a mom of four children. My two youngest children were adopted through DCF. My youngest daughter, Zippy, had lived several years in severe neglect prior to coming into DCF custody, and then had spent a full year in five different foster homes prior to coming to me at age five. Being very familiar with the effects of trauma, I wasn't overly worried about being able to handle her behavioral and educational challenges (ongoing night terrors, ADHD, language and learning delays, PTSD), because I knew I could provide an enriched, nurturing, stimulating environment for her, and my knowledge of the educational system would allow me to advocate for the best services that could be provided for her.

From kindergarten through seventh grade, Zip seemed to thrive. Her academic needs were addressed with a combination of home and school extra help. We enrolled her in as many enrichment activities as she was interested in doing. She had consistent after-school care with a loving and very experienced childcare provider. Yes, she was still academically challenged. Yes, she still acted developmentally very young for her chronological age. Yes, she still had inexplicable meltdowns at times, which we attributed to her early neglect and trauma. Yes, her responses to ordinary situations sometimes seemed very odd. But we were sure that, in time, she would come around.

What happened instead was a massive crash by the time she started eighth grade. She reported being bullied in school, but there was no evidence of this when forensic investigations took place. She reported that friends and teachers were saying and doing outrageous things to her, when they were not. She became very withdrawn, anxious, and paranoid and reported hearing voices and seeing things that were not there. She stopped eating and drinking, became catatonic, and had to be hospitalized for over a month. We were advised to check her for a brain tumor or other organic conditions, but nothing was identified. Eventually, she was diagnosed with early onset schizophrenia. Between eighth grade and 10th grade, she was hospitalized, long-term, three times when she would stop eating/drinking for days, and she significantly struggled in her home, school, and community settings with normal activities of daily living.

At my wits' end, I reached out to VFN for help and I was given excellent advice about special education legal requirements, as well as various avenues to get her the help she needed. I had inperson support from Vickie Crocker from VFN at our 264 meetings, in order to help ensure that all agencies were working in a coordinated fashion to meet her needs. Zippy was eventually enrolled in a therapeutic school with 1-1 support, and has since also been additionally diagnosed with Autism Spectrum Disorder. This latest diagnosis has gone a long way to explain many of her quirky interpretations about the world around her, and our team has worked together to provide excellent guidance to me about ASD-informed responses to her behaviors and thought patterns.

I have to say that, even with my extensive level of educational and child-rearing expertise, this situation was WAY beyond anything that I had ever dealt with before. Knowing that there was a local resource that I could turn to, like VFN, helped me do the right things for my daughter. It was such a relief to realize that I wasn't in this struggle alone. In addition to advising me about how I could manage my daughter's needs, VFN has also afforded me more training opportunities, as well as connected me with folks at the State level, so that I can continue to be an informed advocate, not only for my daughter, but for other children in the state who suffer from complex and life-threatening disabilities.

I know that my daughter's tough journeys will continue, but I now have confidence that she won't have to go it alone. Nor will I. VFN is a readily accessible, invaluable resource for all parents in Vermont.





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Puppets in Education

There is much to report on the success of the in-person Puppets in Education Program (PiE) from September 2019 to early spring 2020 before we rapidly shifted from live to virtual programming.

Our new "puppet mobile", thanks to Bokan Automotive in St Albans, carried staff into New York and throughout Vermont, reaching 5,706 students and 1,110 adults in 130 presentations at 33 sites. This outreach would not have been possible without the support of Upstate NY Chevy Dealers' lead sponsorship and others: Vermont Department of Mental Health; National Life Group Foundation; The Gibney Family Foundation; 100 Women Who Care of Franklin County; PiE's Community Partners: Creative Labels, The University of Vermont Children's Hospital, Advantage Learning Center, Main Street Landing Performing Arts Center, Spencer Group; Bokan Automotive in St Albans; and many generous donors.

In those six months we covered a variety of topics: Bully Prevention, Blindness/Visual Impairment, Children's Mental Health (Feelings, ADHD and Anxiety/Worry), Abuse Awareness, Friendship, Autism, Cultural Diversity, Learning Differences, Body Image, Healthy Snacking, and Tobacco Prevention.

In addition, a new Anxiety Program about stress and worry was created in response to a documented need from parents and educators. Thanks to support from the Vermont Department of Mental Health and the National Life Group Foundation, this program is the first of a three-year project to reach children in grades K-8 and their families. When we launched our K-4 program in January 2020 there were so many school inquiries that we quickly amassed a waiting list. In two short months we were able to perform and analyze the pilot program before schools shut down. Through 28 presentations we reached 1,458 children and 214 adults by early March.

We heard many honest comments about worries children feel and hold onto: making friends, trying something new, strangers in the house (!), a new school year, monsters, competition, nightmares, heights, loud places, stage fright, doing something wrong, tests, Coronavirus, a parent getting lost or being mad, busy places and not having enough food.

When schools were shuttered in March, the PiE team knew that children were anxious about the uncertainty in the world, and we wanted to give them tools for how to handle worry. Puppeteer Sarah Vogelsang-Card and her family took our Anxiety/Worry skit and created a YouTube "at-home" video edition, which was freely shared with educators and parents and has been viewed over 3,260 times: https://youtu.be/Dwu6jbf09Wg

Although not intended as a long-term solution, the video on worry gave us a launching point for a second video created in April, with Dr. James Metz and Dr. Lewis First from the University of Vermont Children's Hospital, to discuss with children what to do if they are experiencing abuse at home: <u>https://youtu.be/</u>Od-Zw1505UI

There has always been a critical need for our programs. Now more than ever our messages can help children with important tools to help flatten the "stress curve." Puppets can validate personal connections and share ideas and strategies on how to regulate internal worry and fears that they feel in their body, especially as external stressors fluctuate in the environment around them. And puppets can do so in a creative and fun way!

In February one child related to his parents, after seeing a presentation, "There are ways to squash your worry and make it smaller so that you can still do things you want to do, even if you're worried about it. Also, your worry never goes away, but you can make it small enough so that you don't realize it's there anymore. That's good to know, so that you're not disappointed when it's still there."

Puppets in Education will continue to actively engage with students online in the new and different school year. We will help children create their own strategies to decrease worry--ones that they can use now in this pandemic, and for the rest of their lives.

"The puppet show reminded me of the first day of school. I liked the calm breath and will remember that when I am worried. Come back when I am in the 2nd grade."





"It was great the students were involved and you had them practice, 'I can handle this." Seeing the worry octopus get smaller was a great visual." -School Counselor



Host Highlight-Tom Stretton

Since 2017 VFN has been offering guests the opportunity to see firsthand the impact of our work through "Meet the Family" tours. Volunteer hosts invite 10-15 of their friends/colleagues/family to experience a 1 hour event where families share how they were supported by VFN. In three years, over 600 people have learned about VFN because of the work of our hosts.

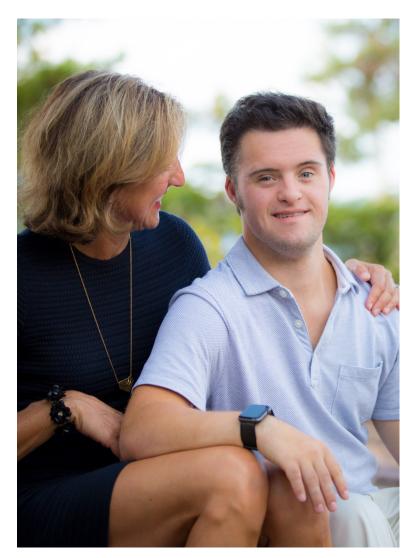
Tom Stretton is a shining example of what it means to be an advocate of VFN, and has hosted 3 tours, introducing more than 30 people to the organization. Tom came to know VFN through the support his family received around his son with a diagnosis of autism. Through sharing his own story and inviting people to tours, Tom has helped spread the word about how VFN can help families like his support their children in reaching their greatest potential. Tom has since been a dedicated member of our Board of Directors and has served as Treasurer for many years.

We are so grateful to Tom and others likes him for helping get the message out that VFN is here to support ALL Vermont families of children with special needs. If you are interested in being a host, contact us at info@vtfn.org!



"The tours that I have hosted have been a blast and a rewarding experience to see guests that might be unfamiliar with VFN become inspired within minutes."









Graduation in the time of COVID

Our son Ryan, who is 18 years old, participated in the graduation ceremony at Mount Mansfield Union High School in the Spring of 2020 as COVID-19 held an overwhelming presence in our daily routines. Ryan has full mutation Fragile X Syndrome and autism. Fragile X is the leading known cause of inherited cognitive delay and is a significant cause of anxiety, physical and occupational delays, and much more.

It took many months of creative planning in order to enable his participation in his graduation ceremony. With the support of his school team, he began to look forward to this meaningful event. Just like his peers, he wore a mask, a cap, and a gown. His sister Marin, his biggest cheerleader, helped plan his participation in the ceremony and was a major source of encouragement for him. She led Ryan to the stage and waited for him after he received his certificate. He smiled and gave a thumbs up to the photographer as his friends waved and cheered for him. It was a beautiful day filled with support from the family, the school, and our friends at the Vermont Family Network.

Ryan Kanat, 2020 MSU Graduate

-Lanie Kanat, Mom and VFN Board Member

FY20 Expenses: \$2,159,998



FY20 Revenues: \$2,224,466



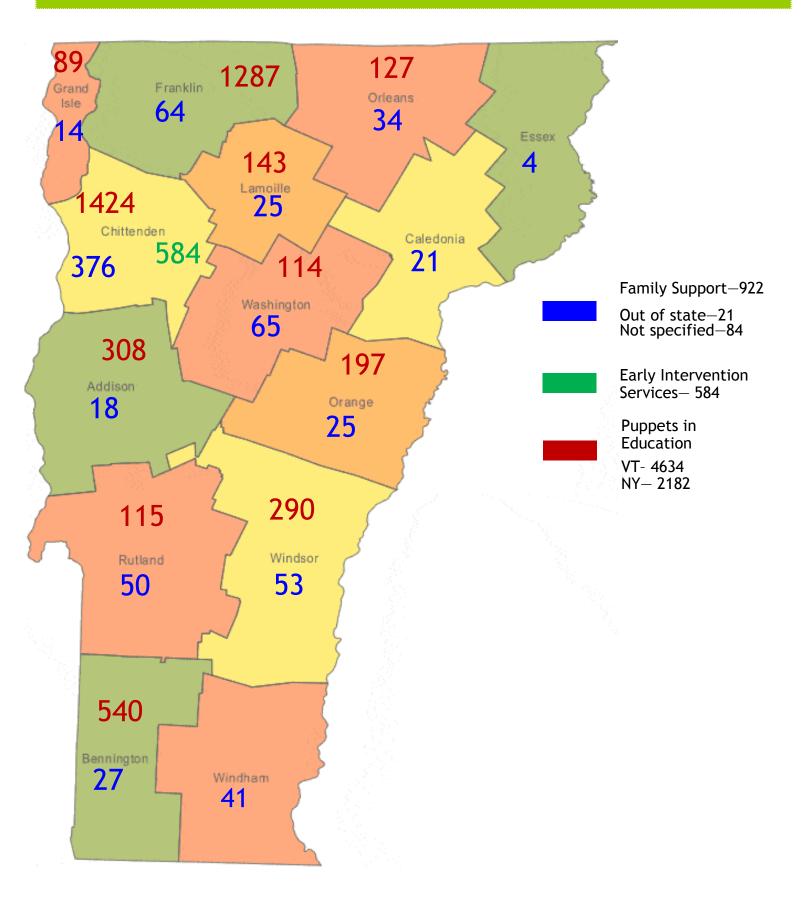


- = Federal Grants: \$304,442
- Fee for Service: \$221,172
- Direct Public Support: \$156,891
- Foundation Support: \$53,200
- Pledges, Outstanding: \$46,665

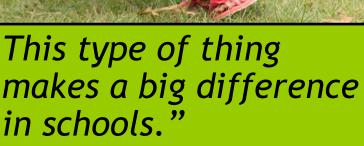




SUPPORTING FAMILIES AND COMMUNITIES IN VERMONT AND BEYOND! JULY 1, 2019 TO JUNE 30, 2020



"We have started meeting and providing services to families using telehealth platforms such as Zoom. It has been a nice transition to stay connected to the families that want continued support. One of my families was very appreciative to have this as an option because she could try out a strategy that we have been talking about while I observe and we can problem solve together what's working or not working for the child." — Early Intervention Staff Member



- Adult after seeing a puppet show





"I had help from a staff person from VT Family Network. We did a consult via phone, emailed her the IEP and then a 2 hour in-person meeting to help me with a plan on how to address school. There was no charge and I did get "most" of what was needed from the school. Lawyer was my next step but VFN educated me enough AND had my husband come to meeting for moral support." - Parent

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