



Giving a Strong Start  
Lifting Family Voice  
Advancing Inclusive  
Communities



Empowering and supporting all Vermont families  
of children with special needs

**ANNUAL REPORT 2019**

Dear friends and families of VFN,

We are delighted to share the work of Vermont Family Network over the last fiscal year, July 1, 2018-June 30, 2019. Our staff and volunteers, with excellent support from our Board, have had such an impact across Vermont during this time. Our signature family-to-family support, information, and connections reached 1101 families and 140 professionals, lifting family voices for positive change. Our Children's Integrated Services Early Intervention (CIS-EI) program gave a strong start to 601 Chittenden County infants and toddlers and their families, often in their childcare settings. VFN's newest program, Puppets in Education (PiE), has increased VFN's reach beyond Vermont, engaging 10,170 people throughout our state, New York, Massachusetts, and New Jersey, helping all children address difficult issues like bullying and abuse. We have enhanced our collaborations with a variety of partners, endeavoring to advance inclusive communities all over Vermont and, thanks to PiE, beyond! As the state's Family Voices and Parent Training and Information Center, we have continued to be involved in advocacy efforts around early intervention programs, special education, payment reform, and budget decisions that impact families of children with disabilities and special health needs.

Our organization is in its second year of an exciting sustainable funding strategy that we are calling "VFN Thrives." Our Board and staff are building a culture of philanthropy that is inspiring on many levels. Through one hour "Meet the Family" tours a few times a month, we are able to compellingly describe VFN's mission and impact through family stories. Participants are invited to attend a wonderful annual one hour Strong Families, Strong Futures breakfast fundraiser in November. The proceeds of this event are allowing us to diversify our funding and build a future that is not so heavily reliant on grants that are typically 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 for the long run. Between last year's tours and the annual breakfast, 500 people were engaged with VFN, learning about what we do, how we do it, and why it matters.

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) 876-5315, ext. 207, or [pam.mccarthy@vtn.org](mailto:pam.mccarthy@vtn.org), and Board Chair Ellen Zeman can be reached at [zeman@champlain.edu](mailto:zeman@champlain.edu).

Onward!

All our best,







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# Family Story - The Giles Family



“They built  
a recipe  
specifically  
for and  
about  
Maddox.”

My name is Craig, and my wife Bridget and I have 2 boys, Coen who is 12 and Maddox who is 10. When Maddox was born, his development seemed like his older brother's. He showed affection, engaged with others and by 18 months had a vocabulary of roughly 25 - 30 words. Shortly thereafter, however, we noticed a pretty dramatic change. What felt like overnight, Maddox became distant and disconnected. He would focus and play with a toy for long periods of time but would no longer respond to us when we called his name. His somewhat robust vocabulary became virtually non-existent and we were completely confused.

I clearly remember a day when Bridget and I were in the kitchen and Maddox was playing with a toy on the floor. She called his name several times and he did not look up from what he was doing. Confused and wondering what was going on, I walked up behind him, bent down and clapped my hands as loudly as I could near him. Nothing. Zero reaction. He just kept playing with his toy.

Thinking that he must be having trouble with his hearing, we sought a doctor's advice and plans were put in place to have tubes put in his ears just after his second birthday. We felt relieved and grateful that there was a plan in place to help Maddox get back to his “old self.”

Just before his second birthday we took our annual trip to the beach down south. What was expected to be a fun, relaxing vacation is now seared in my brain as the worst week of our family's life. From the moment we left home Maddox was completely unable to adapt. He could not handle the plane, the activities, or the food. His tantrums were out of control and seemingly endless. Every single moment he was agitated and uncomfortable. He was unable to sleep for any period of time the entire trip, and our attempts to sooth him grew more strained as we endured our own lack of sleep. By the time we returned home a week later we knew that something more than hearing struggles were happening, and we were beside ourselves with worry.



Several years earlier in 2005 I was diagnosed with Multiple Sclerosis. While my ability to manage my disease had been good, the stress brought on by Maddox's condition certainly made that more difficult. Our pediatrician referred us to the Child Development Clinic in Burlington for an autism assessment. Bridget and I were relieved when Maddox was finally diagnosed in November of 2011. While we did not know much about Autism, at least we had a clear understanding of why Maddox was behaving the way he was, and we were able to start putting together a plan for our future. The CDC immediately referred us to Vermont Family Network where we were able to set up Early Intervention services.

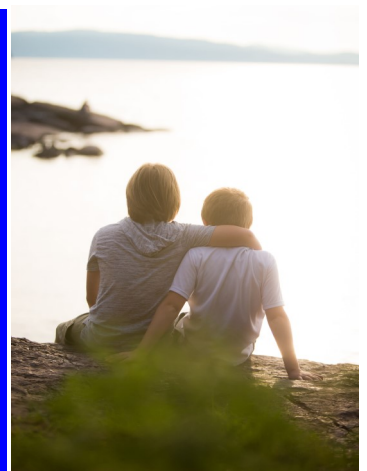
Soon after beginning Early Intervention, Bridget was diagnosed in March of 2012 with breast cancer. Her diagnosis resulted in multiple surgeries over the next year and 4 months of chemotherapy. As dark as this time felt in some ways, we were also overjoyed and amazed at how VFN was able to give my family a strong start. VFN wrapped around Maddox and our entire family, teaching us how to support and engage with him. I like to describe it as "They built a recipe specifically for and about Maddox," and then taught us the recipe and how to perfect it as time went on. The first 6 months of these services were crucial! We were trained not on how to "handle" Maddox, but rather how to understand how he experiences the world, and how to incorporate those differences in a way that was calming to him. We were finally seeing our little boy again, a little boy that we had worried was lost to an invisible diagnosis.

Our family had A LOT going on during that time. I was working and traveling a lot, still managing my MS. Bridget was recovering from surgery and going through chemotherapy, and oh yeah, we had a whole other kid we were taking care of in addition to Maddox. The fact that VFN coordinated our services and brought those services into our home made all the difference in our ability to get through such a difficult time.

Prior to VFN it seemed EVERYTHING we did simply did not work. Imagine having a child who constantly had uncontrollable tantrums. You basically become a family who does not leave your home and the isolation becomes overwhelming. Once VFN was on board, everything started getting better. With Maddox's new "recipe" we started experiencing positive steps almost immediately. It seems so obvious now that Maddox's internal clock drives his behavior, but it was VFN that helped identify the specific, unique ingredient of sticking to a schedule throughout the day being important to Maddox. It took Maddox about 2 years to regain his previous vocabulary and to start showing affection again. While the road was long, I am completely confident that without the strong start and immediate action and support from VFN staff in his first 6 months of early intervention we likely would have never seen these improvements at all.

Today Maddox is about to begin the 5<sup>th</sup> grade. He is transitioning away from having 1:1 support in the classroom and is spending more and more of his day in the classroom among his peers. He has a robust vocabulary, excellent fine motor skills and is very artistic. While he still lacks some skills around social engagement and applying certain lessons can be very hard for him, he has a very big heart and works hard to not disappoint the people around him. He is much more in tune with his emotions and can self-regulate more consistently. Bridget and I have found so much joy in learning how he thinks and seeing how he experiences the world. He has challenged us to not assume we know the best way to do something, to not always sweat the small stuff, and to just take the time to be present. VFN opened the door for us to be able to see all the gifts that Maddox has to offer.

**"Once VFN was on board, everything started getting better. With Maddox's new 'recipe' we started experiencing positive steps almost immediately."**



# Family Support Program



VFN's Family Support Program is founded on the work of its highly experienced and dedicated employees who are all parents who have "walked the walk." Several staff members have been committed to this work for over 10 years and continue on a daily basis 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 and the Parent Training and Information Center, our staff is skilled and ready to support Vermont families in this process.

Our grant funding provides families opportunities for respite, conference, and training experiences, and we collaborate with Children with Special Health Needs at the Vermont Department of Health to pay for medically necessary services and products that are not otherwise covered. VFN partnered with the Division of Vocational Rehabilitation, Vermont Federation of Families for Children's Mental Health and other organizations to support the development of a Youth Advisory Council (YAC). This Council, made up of seven young, motivated self-advocates of differing abilities, planned and implemented the first Youth Summit Conference in May 2019 which attracted 107 youth participants with disabilities throughout the state. Adult partners (including VFN) supported the Council with logistics. The YAC picked a keynote speaker, Matthew Shapiro, whose self-advocacy message could inspire youth and selected workshops on various transition to adulthood topics.

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 and 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 employees are uniquely qualified to achieve this goal.



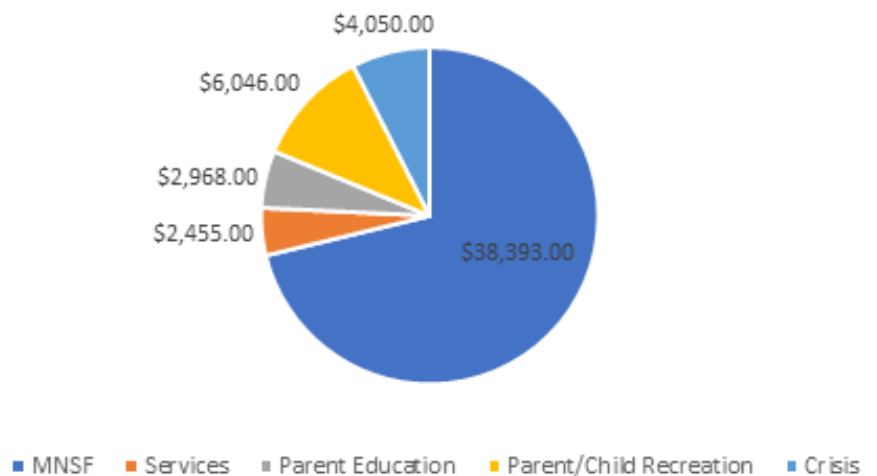
“Now instead of an angry parent, I’ll see the patient’s biggest advocate trying to get the best for their child. I’ll think more about resources to offer. This visit certainly shaped the way I practice medicine.”

-Medical Student

Top reasons families contact the Family Support program

- 1** Individualized Education Program (IEP)
- 2** Parent/Professional Communication
- 3** Parents’ Rights
- 4** Special Education Evaluations
- 5** Healthcare Financing

In FY19 we distributed \$53,912 to families for critical expenses associated with their lives as parents of children with extraordinary needs.



“Very professional and full of wonderful ideas to bring up at the IEP review for my child. It was lovely having someone so knowledgeable and caring. I’m truly happy I reached out for the help.” - 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.

Despite a year filled with an unusually high provider turnover rate, we are pleased that we filled our vacancies by the end of the summer 2019. We are excited by the high caliber of candidates we have seen and that we have been able to add competent, dedicated and supportive staff members to our Early Intervention team. Through our partnership with the UVM Early Childhood Special Education program, we were fortunate to hire some of our newest developmental educators after they had gained field experience in their Part C placements with us and in other regions. We are hopeful about having a period of more staffing stability, but without additional resources for our level funded program, turnover will continue to be a concern. In FY 19, we continued our advocacy efforts for increases to funding for all CIS services across the state, including specialized autism services. These advocacy efforts will continue into FY20, in partnership with the Parent-Child Center Network and the Winston Prouty Center.

In the early spring of 2019, the federal oversight agency of Early Intervention—the Office of Special Education Programs (OSEP)—came to Vermont for a statewide site visit and audit. They were able to hear from regional Early Intervention providers and stakeholders and learn more about how the Early Intervention system operates within our state. We found their visit to be quite supportive and they were able to recommend areas where the state and regions could make changes that will help to improve the service that is delivered to children and families.

This past year our staff received professional development in many areas including: Caregiver Coaching; Assessment, Evaluation, and Programming System for Infants and Children (AEPS); Reflective Supervision and Practice for Supervisors; Digital Security Awareness; Northeastern Family Institute's Risks and Rewards of Working with Vulnerable Populations; Communication Assessment and Intervention for Young Children with Autism; Nine East's Parent, Infant Training Program - Infants and Toddlers with Hearing Loss; and The Importance of Love in Early Childhood.

*“They are all wonderfully helpful and responsive and go above and beyond to make sure things they can help with are taken care of. We really couldn't be where we are today without their guidance, their help and various members of the Early Intervention team. An amazing program with wonderful people - we really can't say thank you enough for the support our daughter and our family have received!” - Parent*





In the most recent CIS Early Intervention Family Outcomes Survey for FFY 2018, results showed that:

92% of parents who completed the survey reported that Early Intervention helped them to understand their child's strengths, needs and abilities.

95% of parents who completed the survey reported that Early Intervention helped them to know their parental rights and how to advocate for their child.

93% of parents who completed the survey reported that Early Intervention helped them to learn how to help their child develop and learn.

### **In FY 19, Chittenden CIS-EI:**

- Served 601 children/families
- Received 377 referrals, an average of 31 per month

*"The Team is Amazing! I feel so supported. They always make me feel like I am doing a great job. They never wasted any time connecting me to resources or finding answers to my questions or concerns!" - Parent*

# Puppets in Education

The 2018-2019 school year was a busy travel year for Puppets in Education, taking us as far south as Newark, NJ, as far west as Dolgeville, NY (close to Utica, NY), into Northern MA and to all four corners of Vermont. Puppets in Education reached 10,170 people across Vermont, NY, MA and NJ (8,463 students and 1,707 adults) through 129 presentations at 33 sites. This success would not have been possible without the support of Upstate NY Chevy Dealers' lead sponsorship and others: Vermont Department of Mental Health; Turrell Fund; our Community Partners: Creative Labels, The University of Vermont Children's Hospital, Advantage Learning Center, Main Street Landing Performing Arts Center, Spencer Group; and many generous donors.

The three most requested programs in 2018-2019: Bullying Prevention reached 5,653 individuals; Celebrating Individual Differences reached 5,003; and Children's Mental Health reached 2,513. Other topics were also in high demand: Abuse Awareness; Demystifying Autism; Healthy Bodies; and Alcohol, Tobacco, and Other Drug Prevention. We also heard from parents and teachers interested in the development of an Anxiety program for children. Of 500 adults surveyed since September 2018, 91% requested Anxiety as the #1 new program they need. We spent the spring and early summer of 2019 securing funding for this initiative and are happy to report that beginning in the fall of 2019 we will launch year one of a three-year project focused on educating children and parents about childhood anxiety.

There is a critical need for the Puppets in Education programs. For example, we heard many stories from children suffering from bullying behavior. In a grade 5 Bullying Prevention Workshop, students disclosed their personal stories: *"I get bullied because of my weight."* *"People stereotype me as a liar and it is very painful."* *"People on the bus call me stupid and it is really hurtful."* Afterward, we problem-solved strategies and solutions to help them find support and ways to keep themselves safe.

At another school students cheered while chanting the puppet's name when he roleplayed standing up to the person using bullying behavior. Students in the grades K-4 puppet presentations shared meaningful and encouraging affirmations:

*"You can make a difference. It doesn't matter how some-one looks and walks, it's still important to be friends."*

*"We all need friends because without it you cannot have happiness."*

*"We should overpower bullying with kindness."*





Within our Cultural Diversity Workshop for grades 5-8, students shared many similar stories about being harassed based upon religion and race. We also heard heartwarming statements from the K-4 students during the puppet presentation:

*"You should be friends with someone different (than you) as you can learn from them and they might need a friend."*

*"We might be different in skin tone, but we are all human with feelings."*



## Quotes from the Road:

"During the workshop I was surprised by one of the students who volunteered, as he has unique challenges and is new to the school. He was glowing during the role play."- 5<sup>th</sup> Grade Teacher

"I'm going to sit with someone I don't usually sit with today."  
- 2<sup>nd</sup> Grader

"There is no place for hate in this school."- 3<sup>rd</sup> Grader

# Supporting families from birth through their child's transition to adulthood



The  
Sanborn  
Family  
**2010**  
and  
**2019**



**Our team is primarily parents of children with disabilities and special health needs who understand the challenges and gifts our children offer. With VFN, you can:**

- ♦ Learn about your child's health, education and development
- ♦ Connect with other families
- ♦ Receive Early Intervention services birth to 3 years old in Chittenden County
- ♦ Build empathy, inclusivity, and safety through powerful puppetry
- ♦ Learn to advocate on a personal and systems level
- ♦ Ask questions about IEPs and Section 504 plans
- ♦ Teach family-centered care to future service providers
- ♦ Strengthen parent—professional collaboration
- ♦ Receive support for transition to adulthood





# A Family for 10 years!

Vermont Family Network is 10 years old! What a testament to Vermont families that include children and adults with disabilities!

How did we get here? Some of our employees were not yet born in the 1970's and '80s when Parent to Parent of Vermont (P2P), Vermont Parent Information Center (VPIC), and Puppets in Education (PiE) were seedlings of ideas of three mothers determined to create nurturing communities for families and their children with special needs. Nancy Divenere envisioned connecting families so that no one would feel alone. The concepts of Support Parents and partnering with providers for family-centered care evolved into Parent to Parent. Connie Curtin recognized the need for inclusionary practices and expertise in Special Education as well as family partnering on IEP and 504 teams in schools. Vermont Parent Information Center offered assistance for families advocating for the academic and social needs of their children. Kids on the Block puppeteering was Mary Kay Dennison's door into children's lives to engage them in thoughtful conversations about differences and social inclusion. Now Puppets in Education puppeteers empower children to talk about difficult subjects and to change behaviors.

We're grateful for the founding parents of these organizations, and for Pam McCarthy who has nurtured the VFN organization into what we celebrate today!

Thanks to families, the merger of P2P and VPIC in 2008, and the more recent partnership with Puppets, VFN has flourished because families believe in connecting with and supporting each other. We learn together, advocate for our children's and communities' health and well-being, and embrace the goal of helping all children reach their potential.



## Saying Goodbye...

In December 2018 VFN said good-bye to a very special person, VP of Operations Holly Brooks. Holly retired after 22 years of dedicated work behind the scenes where her skill and commitment contributed to VFN's smooth operation. Holly began her career at Vermont Parent Information Center in 1997 as a part-time office assistant. It soon became clear that she was indispensable, and she was promoted first to Program Director and some years later to VP of Operations. Holly helped guide the organization through significant changes and challenges, including the 2008 merger between the Vermont Parent Information Center and Parent to Parent of Vermont. Her accomplishments are too many to list, but include assisting with the federal grant application process, developing family-friendly policies that make VFN a great workplace, coordinating the annual budget process and most importantly always, always keeping families' needs at the heart of every decision. We miss her calm presence and expertise. We are grateful for her years of service and wish her only the best as she enjoys her well-earned retirement. Holly provided a rock-solid foundation on which to build and grow for many years to come.

## Family Faculty

This year rounded off another successful year of teaching medical, nursing, health care, and education students about disability and working with families that include a child with special needs. With an amazing cast of 75 family faculty members, we presented 15 panels and hosted 72 home visits, to reach a total of 983 students. Family Faculty programs have proven to meet the curriculum requirements in college courses, as well as providing opportunities for parents to support each other and positively influence the practices of future professionals. Feedback from students and families demonstrate the positive impact that these programs are having.

*“Meeting with 3<sup>rd</sup> yr. medical students for home visits gives me hope that we will continue to have thoughtful, caring medical professionals capable of interacting effectively with their patients and families.” - MEP host family*

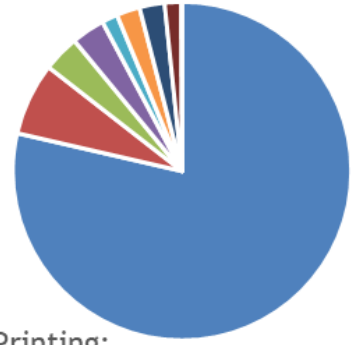
*“I was made vulnerable by my lack of knowledge, leaving me to listen most intently, with an open mind, and without an agenda. I could better hear their story that way, and pick up on the subtleties of their journey rather than the facts.” - Medical student*

As we head into the next year, we are refining our training materials for new Family Faculty members, and continuing our curriculum-based partnerships with the Larner College of Medicine and the College of Nursing and Health Sciences. Sharing family experiences will continue to contribute to more family-centered service delivery in the future, as well as offering families the opportunity to teach from the reality of their experiences.

*“We are so thankful for the services provided to our son through Early Intervention. We recognized very early on that he would need to be taught skills to meet his developmental milestones and EI has helped us along the way. Thank you to Our Whole Team!” - Parent*

## FY19 Expenses: \$2,189,190

Salaries & Benefits: \$1,720,837	Facilities: \$151,554
Program: \$76,222	Family Funding: \$69,642
IT Supplies & Support: \$33,321	Travel: \$48,875
Marketing/Fundraising: \$52,536	Supplies/Copy/Printing: \$34,586
Staff Development: \$1,617	



## FY19 Revenues: \$2,310,699

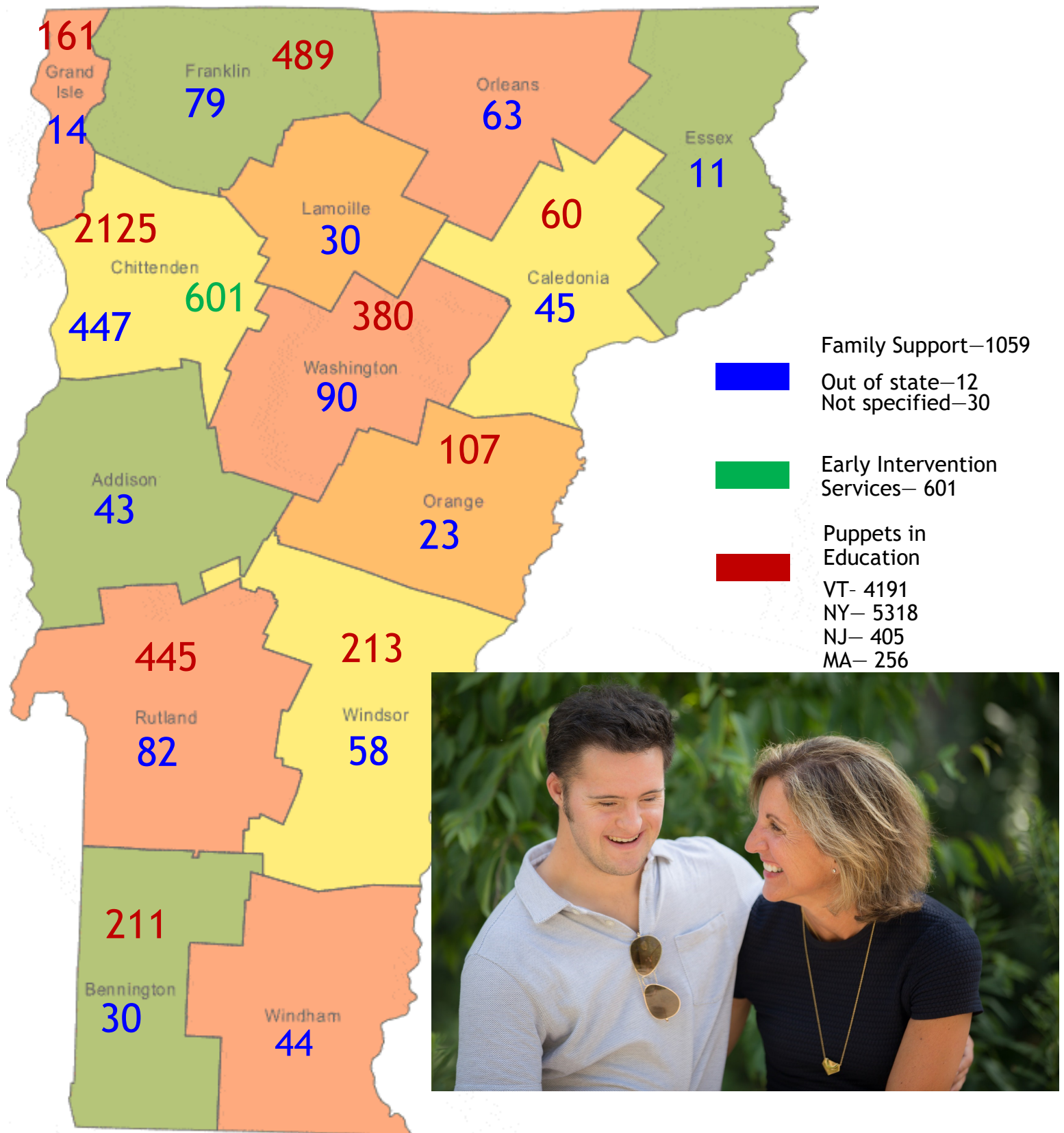
State Funding \$1,467,427	Federal Grants \$279,134
Fee For Service \$263,495	Direct Public Support \$152,722
Pledges Outstanding \$106,471	Foundation Support \$34,500
Miscellaneous \$6,950	





# SUPPORTING 11,872 FAMILIES IN VERMONT AND BEYOND!

JULY 1, 2018 TO JUNE 30, 2019





“No matter how hard it gets, don’t let it hurt your heart.”

- 3<sup>rd</sup> Grader

“I have and always have found the services at VFN excellent... user friendly, supportive and so useful” - Parent



“We would literally not be where we are without the services we have had access to. They are all wonderfully helpful, responsive, and go above and beyond to make sure things they can help with are taken care of. We really can't say thank you enough for the support our daughter and our family has received!” - Parent