

Each year, Family Voices surveys the F2Fs about the populations they serve, the initiatives and partners with which they are involved, and the sources of funding that they have to carry out F2F activities. This report summarizes the results of the 2018 F2F Activity Survey, based on responses from 51 F2Fs.

## 2018 F2F Activity Survey Highlights

### Underserved Family Groups

F2Fs reported participation in initiatives focused on reaching **underserved family groups**. The most frequent responses:

Underserved Family Groups	%
Low-income families	76%
Latino families	69%
Foster care	59%
Immigrant families	57%
Limited English Proficient families	55%
Military families/Tricare	55%
African-American families	53%
Parents with disabilities	51%
Tribal Nations/American Indian	45%
Homeless populations	29%

### 2018 Emerging Topic: Working with Underserved Families



*“Massachusetts Family Voices/F2F and the Vietnamese Health and Education Outreach Coordinator spent several months... with representatives of Mass Health explaining the need for communication with the Vietnamese community in their native language. Highlights of the collaboration include...translation of the Mass Health*

*enrollment guide into Vietnamese; Convincing Mass Health to send multiple customer service representatives to a 1:1 event for Vietnamese families; Mass Health, with the assistance of interpreters, was able to listen and solve the issues families had with ACO selection and care continuity for their CYSHCN;...The event empowered Vietnamese parents to work with Mass Health in the future and to help other members of their community... A Vietnamese mother stated tearfully this was the first time she had someone respectfully listen and help her with insurance issues.” -MA F2F*

### Specific Disability/Child Populations

F2Fs reported participation in initiatives focused on **specific disability/child populations**. The most frequent responses:

Specific Disability/Child Population	%
Developmental disabilities	96%
Children with complex medical needs	90%
Autism	86%
Adults with disabilities	59%
Newborns	53%
Disease-Specific	47%
Traumatic brain injury	43%
Epilepsy	35%
Drug affected infants	29%
Opioid affected families, pregnant women	25%

### Health Care Financing Topics

F2Fs reported participation in initiatives on **health care financing**. The five most frequent responses:

Health Care Financing Topics	%
Medicaid Waivers	80%
ACA health insurance/health care financing	59%
Medicaid - EPSDT	55%
Medicaid Managed Care	55%
Non-ACA health insurance/health care financing	49%

### 2018 Emerging Topic: Medicaid Waivers

*“With the Medicaid reform and changes to waiver services, we have been inundated with questions and concerns from families...referrals to our F2F programs have increased, especially for families who do not qualify for Home and Community Based Services, but are seeking additional support.” -AK F2F*

## F2F SPECIFIC INITIATIVES

F2Fs were asked to identify specific topic areas in which they participated in initiatives or programs. The following tables display the percent of the 51 F2Fs who indicated involvement in the specified topic areas:

Specific Topic	2018
Parent to Parent Support	90%
Care Coordination/Care Management	84%
Early Intervention	82%
Transition	78%
Early Childhood	73%
Family-Centered Care	73%
IEPs and School-based Care	73%
Cultural & Linguistic Competence/Health Equity	71%
Medical Home	71%
Early Hearing Detection and Intervention	67%
Supported Decision-Making	67%
Mental/Behavioral Health/Trauma	63%
CYSHCN Research	57%
Newborn or Other Screening	57%
Quality Improvement initiatives	55%
Improving Parenting, Parent Mental Health	53%
Adverse Childhood Experiences (ACEs)	51%
Health Care Coalitions	51%
Assistive Technology	47%
Respite	45%
Social Determinants of Health/Lifecourse	45%
Family Faculty programs	43%
Disaster Planning/Response/Preparedness	41%
Telemedicine	41%
Self-Directed care	39%

Specific Topic	2018
Help Me Grow	33%
Home Visiting	33%
Community Health Centers/Clinics/FQHC	31%
Bright Futures AAP Guidelines	29%
Child Welfare/Protection/Abuse & Neglect	29%
Health & Wellness Promotion/Prevention	29%
Collaborative Improvement & Innovation Network	25%
Oral Health	25%
Palliative Care	24%
Health Information Technology	18%
Opioid Misuse	18%
Research	18%
Improving Pregnancy/Birth Outcomes	16%
Reducing Hospital Re-admissions	16%
American Indian Health	14%
Family Leave Policies	14%
Other responses included Obesity Prevention/Intervention, Zika, HRSA: Mother to Baby, Public Health Crises, Domestic Violence, and Employment of People with Disabilities	

### 2018 Emerging Topic: Transition

*“Ohio F2F, in partnership with UCCEDD, has worked on multiple efforts over the last few years to address families’ needs regarding planning and preparation for a successful transition into adulthood for children and youth with special healthcare needs and disabilities. In addition to our annual Transition Bootcamp Conference in SW Ohio with over 300 attendees, we now provide monthly Transition Booster Sessions in NW, Central and SW Ohio, with an average of 30-60 attendees at each of these sessions. Most recently, we have had requests from other partners in Ohio to help them set-up their own Transition Booster Session series so that families can receive information for successful transition preparation closer to home... Our model of a Transition Booster Session series is easy to implement and sustain and is very cost effective, while at the same time very valuable to families.” -Ohio F2F*



# F2F PARTNERSHIPS

F2Fs were asked to rate their level of involvement in activities with partners (0 = none to 5 = significant). The following tables display the percent of the 51 F2Fs who indicated high levels of partnership (4 or 5) with the following organizations/programs:

Partner	2018
Other Parent-led Programs	92%
Development Disability Agency/Program	92%
Parent Training and Information Programs	90%
State Title V Program	88%
Disability Specific Organizations	86%
Early Intervention	86%
Department of Education/Schools	82%
Protection and Advocacy Agencies	80%
Universities	80%
Children's Hospitals/ Pediatric Hospital Units	78%
P2P (Parent-to-Parent programs)	78%
LEND/UCEDD/DDRC	78%
Medicaid Agency	75%
Mental Health Agency	73%
Child Advocacy Organizations	71%
Vocational Rehabilitation Agencies	69%
Mental Health Partners	67%
Health Care Coverage Advocacy Groups	65%
Regional Genetics Collaboratives	63%
Regional MCH Leadership	61%
Youth Advisory Groups/Organizations	61%
Federation of Families/Parent Mental Health	59%
Head start/Early Childhood Programs	55%
Adults with Disabilities (ADRC)	55%
Ethnic/Cultural/Racial-specific Org	55%
Independent Living Centers	53%
State Chapter of AAP	43%
SCHIP Program	43%

Partner	2018
Community Health/Rural Health Centers	39%
Integrated Systems Grantees	37%
Emergency Medical Services	37%
Health Care Quality Orgs/Programs	35%
NICHQ Learning Collaboratives	31%
Community Disaster-Preparedness Groups	29%
Foster Care Agencies	27%
Juvenile Justice Programs	27%
Oral Health Partners	27%
HMOs/Private Insurance Companies	24%
AAP (National)	22%
Child Care Agencies	22%
Faith-based Organizations	22%
Nursing Associations	16%
Father Support Groups	16%
Indian Health Services	14%
HUD/Housing	14%
Other Responses included Obesity Prevention/Intervention, Zika, HRSA: Mother to Baby, Public Health Crises, Domestic Violence, and Employment of People with Disabilities	

Top initiatives on which F2Fs reported an **increase since 2017** in their levels of partnerships with other organizations:

Partner	% increased
Ethnic/Cultural/Racial-specific Orgs	33%
Child Advocacy Organizations	29%
Community Health/Rural Health Centers	29%
Federation of Families/Parent Mental Health Group	25%
Protection and Advocacy Organizations	24%

## F2Fs Partnerships with Title V



Strong partnerships with State Title V Programs are reported by 88% of F2Fs including 55% who report that their F2F receives funding from their Title V agency, 65% of whom describe being actively involved with the Title V Needs

Assessment, 61% who indicate they participate in state consortia around MCH issues, and 55% who indicate they participate actively in the State Block grant process. F2Fs describe participation in quality improvement initiatives, training and advisory roles around many topics including complex care, care coordination, genetics, safe sleep, emergency planning, hearing initiatives, adolescent health, behavioral health, pregnancy, newborn screening, infant mortality and social emotional development.

# F2F FUNDING SOURCES AND BUDGET

In addition to the F2F grant, 47 F2Fs across the nation attracted support from 33 other funding sources in 2018. By leveraging the modest federal funds from the F2F grant into additional support from other sources, F2Fs are able to extend their impact on their communities. On average, each F2F gained additional funding from six different sources and sought funding from three other additional sources. Although some of these attempts were not successful, each indicates an opportunity for future growth.

## F2F Additional Funding Sources

F2Fs reported **funding sources they receive in addition to the F2F grant.**

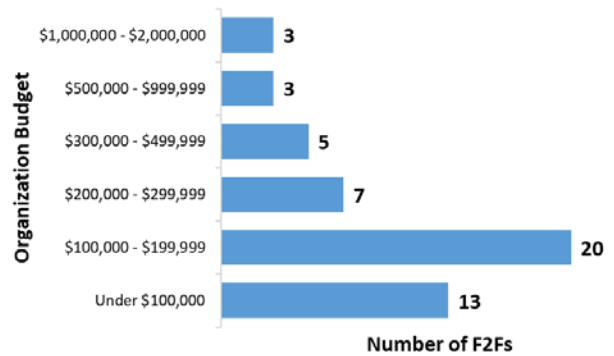
Funding Source	Funded	Sought
Community Fundraising/Donations	33	3
Title V/MCH Block Grant	27	7
Parent Training and Information (PTI)	25	5
Other Foundations	25	5
State Dept. of Ed	24	5
State Developmental Disability Council	24	5
EHDI Grant	15	5
Other federal funds from HHS	14	4
LEND, UCEDD, DDRC	13	7
Federal or state mental health agencies	12	8
Head Start /Early Childhood/EI	12	9
State Parent-to-Parent (P2P) State	12	9
Grant/contracts from a university	12	5
Fee-for-service reimbursement	9	6
Other State Title V Program	8	5
Medicaid Managed Care Providers	7	7
State Medicaid Agency	6	10
Grants/contracts from Hospitals	6	8
United Way/Combined Federal Campaign	6	5
Federal/state emergency preparedness	5	5
Other non-Medicaid State agencies	5	8
AAP Chapter	3	4
ACA Navigator	2	9
Healthcare Plan/Conversion Foundation	2	7
Private Insurance Provider	1	4
Juvenile Justice System	1	6
FQHCS/Community Clinics	0	6

Other funding sources: Vocational Rehabilitation, Foundations for the Arts, Health Authorities, Center for Disease Control, Federal Administration on Intellectual and Developmental Disabilities

## F2F Annual Activities Budgets

F2Fs were also asked the amount of their total annual budget that is spent on F2F activities. The graph below depicts their answers. In addition to the F2F grant, **approximately 75% of F2Fs receive funding from other sources to support F2F activities.**

**Total Annual F2F budgets for F2F Activities (Including F2F Grant)**



## 2018 Impact: Vermont



*“In the past year we have expanded our connection and impact at our state Children’s Hospital significantly, with the help of funding from our F2F grant we hired someone to do this. We have partnered with our state Protection and Advocacy organization to push for compliance in high tech care for children, which has fallen astray due to a nursing shortage. Our impact has been shared widely in a down to earth way during our ‘Meet the Family’ tours where attendees hear moving stories about family experiences with Vermont Family Network - including accessing services, connecting to other families, and working successfully with professionals.” –VT F2F*