

FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS DATA REPORT:

Helping Families of Children & Youth with Special Health Care Needs & the Professionals who Serve Them



2014-2015

Family-to-Family Health Information Centers (F2Fs) provide critical, specialized support and assistance to families. F2Fs particularly help families with complex needs and those from diverse communities.

Data aggregated from reports submitted by all 51 F2Fs summarizing their work from June 1, 2014 through May 31, 2015 (FY2015), demonstrate their:

Direct Support to:

- **155,950 Families**
- **74,225 Professionals**

Estimated Overall Outreach to:

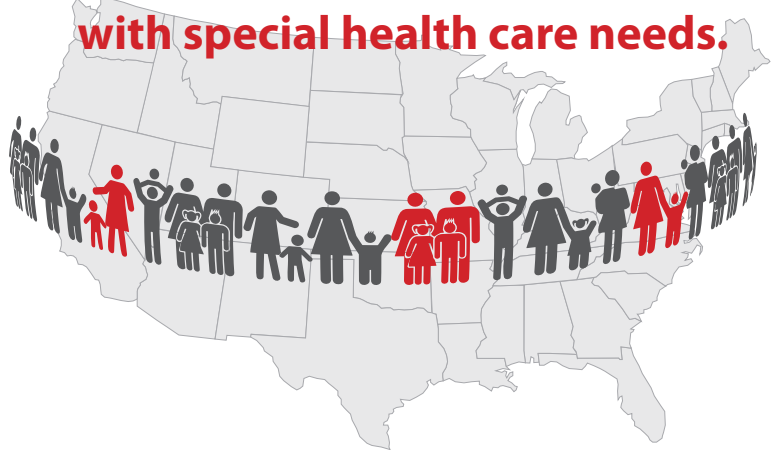
- **928,225 Families**
- **350,960 Professionals**

Impact on:

- **92% of Families Better Able to Partner with Providers & Navigate Systems**

F2Fs impact systems of care by working with community, state, and federal partners. F2Fs ensure that families are engaged in shared decision making at all levels of health care.

1 in 5 families has at least one child with special health care needs.



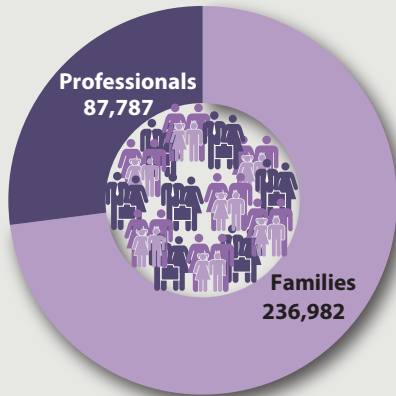
Approximately 8.8 million families in the US have a least one child under the age of 18 with a special health care need.* Of these, about 3 million families report not being able to easily access community-based services due to eligibility issues, services not available, problems getting appointments, costs of services, lack of information, and other difficulties.*

Direct Support:

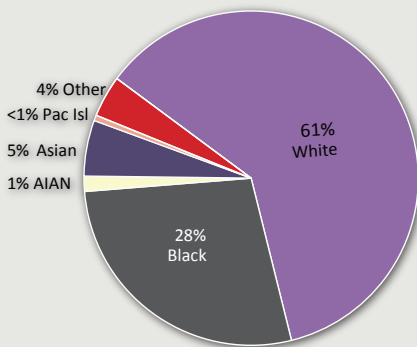
F2Fs exist in every state and the District of Columbia to provide assistance to help families and professionals address these issues. F2Fs are staffed by family members who have first-hand knowledge and training in navigating the maze of health care services for children and youth with special health care needs (CYSHCN).

F2Fs provide direct support through free one-to-one assistance and training. From June 1, 2014, through May 31, 2015, F2Fs **assisted and trained 155,950 families (unduplicated) and 74,225 professionals (unduplicated)** across the country.

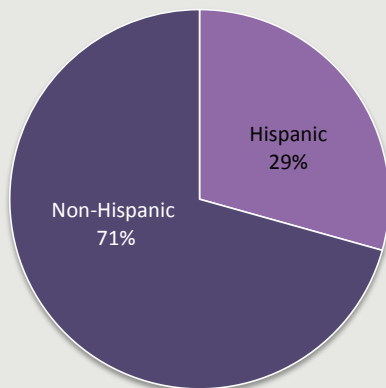
Requests for Assistance Received/Answered



Families Served by Race



Families Served by Ethnicity



OVERALL REACH of F2FS

In FY2015 F2Fs reached an **estimated 928,225 families and 350,960 professionals** through one-to-one assistance, trainings, information dissemination, and social media.**

CORE SERVICES PROVIDED

One-to-One Assistance: Families contact an F2F for help in determining their eligibility for a health care financing program, applying for programs, dealing with healthcare denials, getting referrals, identifying and accessing community support programs, connecting with peer support, and many other issues. A parent who received help from Family Ties of Nevada exemplifies the value of support from an F2F:

"Beth struggled to learn more about her son's diagnosis of autism and how best to help him. She connected with Family TIES and was provided support, information, and connections to other parents. Through this support, Beth learned about the Autism Treatment Assistance Program (ATAP) which has provided her son with Applied Behavior Analysis (ABA) therapy. Beth credits ABA therapy with significant advances in Mike's development: talking, potty training, listening, social skills, and handling noise and crowded situations. 'It has helped us be a family.'"

In FY2015 F2Fs responded to **236,982 requests for assistance from families and 87,787 requests from professionals.**

Trainings: F2Fs provide trainings through in-person workshops, online courses, webinar trainings, and other media. Frequent topics of trainings included the Affordable Care Act, Autism and Family Supports, Medicaid Programs, and Mental Health Issues for Children/Youth. In FY2015 F2Fs provided **11, 013 trainings.**

SERVING FAMILIES of DIVERSE BACKGROUNDS

National surveys indicate that more Hispanic (66.9%), Black (66.2%), and Asian (67.1%) families lack coordinated, ongoing, comprehensive care within a medical home compared to White families (51.2%).* 72% of White CYSHCN received family-centered care while only 56% of Hispanic and 52% of African American CYSHCN receive this comprehensive care.* F2Fs reach families of diverse backgrounds—hosting support groups and leadership conferences for Spanish-speaking participants, facilitating focus groups to create culturally competent materials, participating in community meetings serving diverse communities, and partnering with community brokers. F2Fs help develop the leadership skills of diverse families. The F2F Director in Iowa (ASK Resource Center) noted the impact of Family Voices' Polly Arango initiative:

"The Polly Arango grant greatly enhanced our ability to outreach to Hispanic families. ASK's Family-to-Family Mentoring Network is robust among other groups, but not with the Hispanic families in Iowa. Knowing the cost-savings that natural, family-to-family support provides, our goal is to build the infrastructure needed to sustain outreach efforts within these communities to increase both the mentoring and leadership capacities of Hispanic families."

* National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 01/12/2016 from www.childhealthdata.org.

** People reached through training includes an estimated count of individuals. The total of families and professionals reached may include duplicated individuals across categories.

In FY2015 F2Fs reported, on average, that about 35% of the families they served were from diverse racial populations when the family self-identifies (about 67% of families who were provided direct support self-identify). This represents approximately the same racial distribution as reported in the 2009-2010 National Survey of CSHCN which indicates that non-white families make up 40% of families who have CYSHCN. Of those families who self-identify to the F2F, **29% indicated they are Hispanic.**

METHODS USED to SERVE FAMILIES & PROFESSIONALS

F2Fs use a variety of methods to outreach, assist, and train families and professionals as shown in Chart 1 on page 7. All F2Fs provide one-to-one assistance by phone and email as well as maintain a website for broad information dissemination. At least 80% of the F2Fs host conferences, participate in community events, provide in-person assistance and training, publish newsletters, produce tip sheets and other printed materials, and use Facebook to connect to others. Fewer F2Fs maintain blogs (15), produce public service announcements (12), or have Pinterest accounts (9).

Social Media: Many F2Fs are increasingly serving families and professionals using Facebook, Twitter, and other social media tools. Data collection standards for tracking this reach were newly implemented this year. Data submitted for FY2015 includes:

- Facebook Likes: **12,360** (reported by 10 F2Fs)
- Facebook Organic Reach (total number of unique people who were shown a post): **1.4 million individuals** (reported by 11 F2Fs)
- Facebook Average (monthly) # of People Talking About Page (actual number of people who are “engaged” and interacting with that Facebook Page): **43,046 individuals** (reported by 10 F2Fs)
- Twitter followers: **3,272 people** (reported by 4 F2Fs)
- Highest Adjusted Reach of any Tweet: **7,896 people** (reported by 4 F2Fs)

Traditional Channels: F2Fs play an important role in disseminating information to the broader public, such as news about changes to programs and policies, opportunities to provide public comments, announcements on upcoming events, and stories reflecting family experiences. Last year F2Fs reported dissemination of information by:

- Listservs: reaching **173,078 families and 76,854 professionals**
- Newsletters: reaching **409,897 families and 154,638 professionals**
- Handouts and other publications: distributing over **5 million materials**

Some F2Fs use partner and public media sources to get messages out, such as the F2F in Michigan at the Michigan Public Health Institute:

“We have written articles for partner organizations reaching approximately 800 professionals through the MI Chapter of the American Academy of Pediatrics and 9,223 families through the Ludington Daily News.”

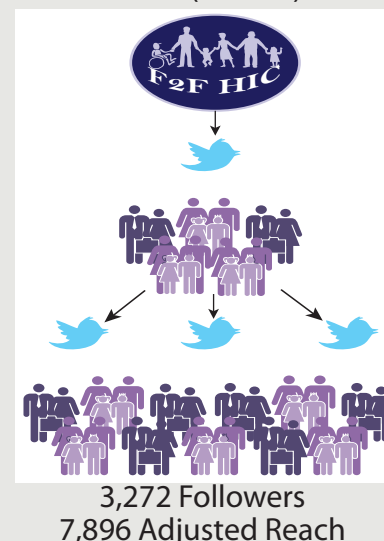
PARTNERSHIPS to IMPROVE CARE

Partners: F2Fs help families partner at the **direct care level** by giving them information and advice, bolstering their confidence, and providing tools to help them communicate with their child’s providers. At the **organization level**, F2Fs work with pediatric practices and many F2Fs serve as family faculty to nursing and medical students—helping these providers understand the value of the family as a partner. Many F2F staff also partner

Methods Most Used by F2Fs

Method	% of F2Fs
1-1 assistance by phone/ email	100
Website	100
In-person training	96
Community Events	96
1-1 in-person assistance	92
Facebook	92
Newsletters	88
Printed Materials	88
Conferences	80
Conference Calls	78
Listservs	76

Social Media (Twitter) Reach



Most Frequently Reported Important Partnerships

Partner Group with whom F2Fs reported a 4 or 5 involvement rating (0=None to 5=Significant)	% of F2Fs
Developmental Disabilities Program	98%
State Title V Program	94%
Disability Specific Organizations	90%
Early Intervention	86%
Children's Hospitals or Pediatric Units	80%
Department of Education / Schools	75%
Medicaid Agency	73%
Protection and Advocacy Agencies	73%

Examples of F2FPartnerships

- University of Arkansas for Medical Sciences
- Colorado Department of Health Care Policy and Financing
- US Department of Transportation National EMS Advisory Council
- Delaware Title V Needs Assessment
- AAP Florida Medical Home Project
- Idaho State University Traumatic Brain Injury project
- Centers for Independent Living/ Vocational Rehabilitation Agency (New Jersey)
- Native American Communities (New Mexico)
- Hispanic Community Partners Group (Nevada)
- NICU Discharge Team (Oklahoma)
- New England Genetics Collaborative
- Emergency/disaster groups (South Carolina)
- University of Utah Department of Pediatrics
- Wyoming Medicaid Waiver Redesign Committee

Involvement in Specific Initiatives

Initiatives	% of F2Fs
Transition/Youth Leadership	92%
Autism	84%
Family-Centered Care	82%
Medical Home	82%
Behavioral Health	82%
T V Block Grant	82%
Medicaid Waivers	78%
T V Needs Assessment	78%

Additional Sources of Funding that Support F2F

Funding Source	% of F2Fs
Title V	57%
Parent Training & Info Center	55%
Fundraising	53%
DOH/HHS	45%
Other Foundation	43%
State DOE	43%
Developmental Disabilities	41%

with health clinics and serve on hospital advisory boards to help implement family-centered care. Finally, every F2F partners at the **system level** to ensure policies effectively meet the needs of families.

The F2F in Virginia summarized their efforts of the past year:

“Our biggest impact has been the over 400 hours of technical assistance provided by F2F director and staff to state Medicaid and DD agency staff on the redesign of three current Medicaid waivers that serve unique populations. In the new design, everyone, regardless of disability label, would be served under an independence, support, or comprehensive waiver depending upon level of need. This is huge for our state which historically only served people with ID and served them in large congregate care facilities.”

F2F involvement with specific partner groups is shown in Chart 2 on page 8. Most F2Fs report important partnerships with their state’s Developmental Disability Program, Title V Program, disability-specific organizations, Early Intervention, and children’s hospitals or pediatric units.

Partnering Initiatives: Involvement with partner groups is often focused on sharing family perspectives and experiences to shape policies and programs to be more effective for families of CSHCN. Chart 3 on page 10 shows involvement of F2F in specific initiatives. More than three quarters of F2Fs are involved in work in the areas of transition/youth leadership work, autism, family-centered care, medical home, behavioral health, Title V block grant, medicaid waivers, and Title V Needs Assessment.

F2F PROGRAM / FAMILY ORGANIZATION SUSTAINABILITY

Each state and the District of Columbia receives \$95,700 annually to provide F2F services. Family organizations typically blend their F2F funding with other sources to maximize their impact, as shown in Chart 4 on page 12. All but 4 organizations have additional sources of funding to support their F2F work. Of those, each F2F is supported by an average of an additional 6 sources of funding, such as Title V, Parent Training and Information Center (PTI) grants, community fundraising, other grants from DOH/HHS, foundations, and developmental disability grants. 76% or 39 F2Fs reported that having the F2F grant helped their organization obtain additional sources of funding.

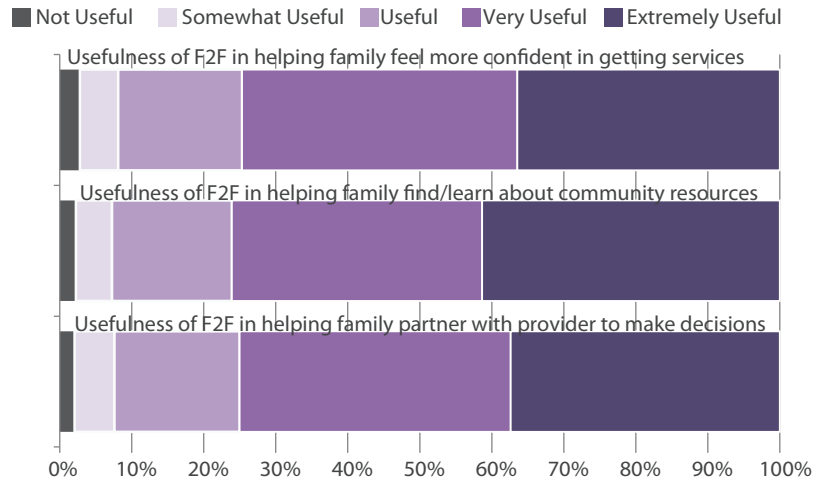
“We have strengthened our relationship with the Arkansas Title V program, which has maintained its increased funding support to the F2F program, as well as increasing our project collaborations, particularly in the areas of youth health care transition to the adult health care world. We also continue our strong relationship with Arkansas Children’s Hospital and their Research Division. They are also a on-going funding source for us, currently funding three different projects right now. These projects include a sub-contract on the HRSA funded Autism Implementation grant, a Transition project, and our on-going Neo-natal family support project.” ... AR F2F Project Director

Idaho Parents Unlimited is seeing excellent outcomes in our work with Hispanic families due in part to a partnership project with National Family Voices under a PCORI grant.” ... ID F2F Project Director

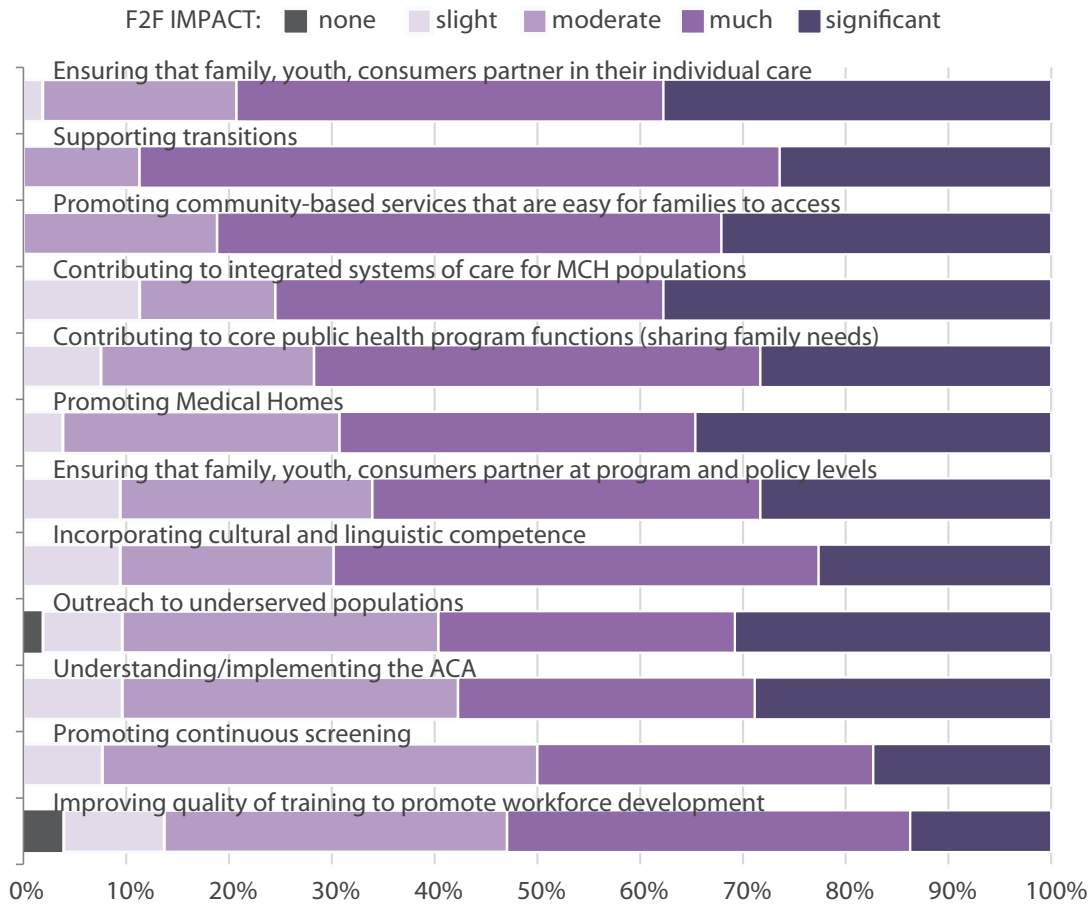
IMPACT of F2F PROGRAM

Families: Impact information is collected from families served by F2Fs based on an impact data collection protocol. The following percent of families reported the service received as useful, very useful, or extremely useful in:

- helping them partner in **decision-making: 92%**
- helping them find/learn about **community services: 92%**
- helping them feel more **confident** about getting needed health care services for their child: **90%**



Programs & Policies: F2Fs self-reported their impact in specific policy areas in their communities. The greatest areas of impact were in **promoting community based services, supporting transitions, and ensuring partnerships at the individual care level.**



Last year, of the families served by F2Fs, 14% reported they participated in committees, task forces, advisory boards, or other levels of program/policy. Of those families, **88% reported that the assistance/training they received from the F2F was useful, very useful, or extremely useful** in helping them represent CYSHCN. The F2F in Louisiana (Bayou Lands Families Helping Families) noted their work in developing new family leaders:

"We are the only agency training families regarding Medicaid Managed Care in Long-term Supports and Services (MLTSS) so they can participate in stake-holder meetings and serve on plan oversight committees. We are spearheading discussions among a number of agencies regarding MLTSS and representation for families on stakeholder groups."

WHAT FAMILIES & PROFESSIONALS SAY ABOUT SERVICES RECEIVED FROM F2FS:

Massachusetts Family Voices: Direct Assistance



"I did not know where to start applying for MassHealth. The application was in English and I can only read Vietnamese. I called Massachusetts Family Voices (MFV) for help and within a couple hours, the MFV staff sat down with me and together we submitted the MassHealth form online. MFV staff explained the information being requested each step of the way. The online application system crashed and so MFV staff called MassHealth to be sure my application was received. Then she also helped with explaining and filing a Supplemental Disability form. MFV staff made things seem so easy. My paperwork was done in a couple of hours. Thank you so much for all the work you have done."
... a Vietnamese Parent

Vermont Family Network: Leadership Training



"Interacting with others broadened my perspective beyond my own situations, spurred idea sharing and team building, and inspired me. I am not alone in this journey, and my voice matters."

... a Family Member

"I really enjoyed the presentation of the parents and learning from their stories of positive and negative experiences. As a future health care provider, it is important to be mindful of these things."

... a Nursing Student

"Thank you so much for taking the time to send me this information! It is a wonderful comprehensive list and I look forward to checking out the resources."

... a Family Member

"When working with parents I need to remember that to them it's not just their job, it's their LIFE!"

... UVM Education Student

Tennessee Disability Coalition/Family Voices of Tennessee: Direct Assistance & more



"Our son Cain was born with a rare congenital heart defect called Hypoplastic Right Heart Syndrome, which means a portion of his heart was missing. Cain had 3 open heart surgeries all before his 4th birthday. He is now 6 and thriving. Cain will always be a 'half-a-heart' kiddo, but we have learned so much during this journey. I was introduced to Family Voices of TN (FVTN) Family-to-Family Health Information Center several years ago and since then I've had the opportunity to participate in leadership trainings and connected with many family leaders. That training has enabled me to facilitate a support group, sponsored by FVTN, for families who have kids with congenital heart disease. FVTN is a wonderful resource for families!"
... a Mom

CHART 1: F2F METHODS of ASSISTANCE/TRAINING:

State	Blogs	Care Notebook	Conference Calls	Conferences	I-I Phone/Email Assistance	I-I In-person Assistance	Distance Learning	Facebook	Family Surveys	Focus Groups	In-person Training	Library/Lending Program	Listsens	Newsletters	Online Training	Parent Matching	Pinterest	Public Service Annms	Printed Materials	Community Events	Support Groups	Topical Calls	Twitter	Videos	Webinars	Website
AK	•		•	•	•	•	•	•	•		•	•		•					•	•	•					•
AL		•		•	•	•		•	•	•	•			•		•			•	•						•
AR			•	•	•	•		•	•	•	•		•	•					•	•	•		•			•
AZ		•		•	•	•		•	•	•	•		•	•	•				•	•				•	•	•
CA		•	•	•	•	•	•	•	•	•	•	•	•	•		•		•	•	•	•		•	•	•	•
CO	•		•	•	•	•		•	•	•	•		•	•	•				•	•	•	•	•		•	•
CT	•		•	•	•	•		•	•	•	•		•	•		•		•	•	•	•	•	•	•	•	•
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VA	•	•			•	•		•		•	•		•	•		•			•	•	•	•		•	•	•
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CHART 2: F2F INVOLVEMENT with PARTNERS:

Self-rating by F2F Directors of their level of involvement with specific partner groups (0=None to 5=Significant)

Partner	AK	AL	AR	AZ	CA	CO	CT	DC	DE	FL	GA	HI	IA	ID	IL	IN	KS	KY	LA	MA	MD	ME	MI	MN	MO
360 Grantees	1	1	1	1	1	1	1	3	4	3	1	3	1	1	4	1	1	1	1	1	1	2		1	5
AAP (national)	1	1	2	1	1	1	1	1	1	5	1	4	1	2	2	4	2	1	2	4	4	1	1	4	1
Adults with Disabilities (ADRC)	3	3	2	1		3	5	4	4	5	3	3	3	4	5	5		4	1	1	2	3	1	4	5
Advocacy Groups (Health Care Coverage)	2	5	3	2	4	5	5	5	4	4	3	4	5	5	5	5	4	2	5	5	2	4	5	5	3
Child Advocacy Organizations	2	3	3	3	4	5	5	5	5	5	3	3	3	5	3	5	4	3	5	5	4	4	4	4	2
Child Care Agencies	2	3	2	2	3	3	3	5	2	4	2	4	3	2	2	3	3	2	5	2	3	2	1	2	4
Children's Hospitals or Pediatric Units	3	4	5	4	4	5	5	5	4	5	2	4	2	5	5	5	4	3	5	5	5	4	2	5	5
Community Disaster-Preparedness Groups	1	4	2	4	2	3	4	1	3	4	2	1	3	2	4	5	3	2	5	2	2	3	1	1	5
Community Health/Rural Health Centers	2	3	2	2	2	2	4	5	3	4	2	3	1	4	3	5	3	2	5	3	3	4	5	3	3
Developmental Disability (DD) Agency/Pgm	5	4	4	5	5	4	5	5	4	5	5	5	4	5	5	5	4	4	5	5	5	5	5	4	5
Department of Education/Schools	3	2	5	5	4	3	5	5	2	5	5	4	5	5	3	4	5	4	5	5	5	5	2	5	4
Disability Specific Organizations	3	5	4	4	4	5	5	5	5	4	4	4	4	5	5	5	3	2	5	5	4	5	4	5	5
Early Intervention	5	5	4	5	5	3	5	5	5	5	5	5	5	5	2	5	5	4	5	4	5	3	5	5	5
Emergency Medical Services	1	1	2	1	1	3	5	3	4	3	1	3	1	1	3	3	3	2	5	3	2	3	1	2	5
Ethnic/Cultural/Racial Specific Organizations	2	1	4	4	2	5	5	5	3	4	5	2	4	4	3	5	4	3	1	5	4	4	3	5	4
Faith-Based Organizations	3	3	3	3	2	1	5	4	2	5	2	3	3	3	2	5	2	3	2	3	4	3	1	2	3
Fathers Support Groups	1	2	1	1	2	1	3	5	1	5	1	2	1	2	2	4	2	1	1	3	2	3	2	2	3
Federation of Families/Mental Health Orgs	3	4	2	2	2	3	5	1	5	5	4	4	5	5	3	5	1	4	5	5	3	5	4	3	5
Foster Care Agencies	3	2	2	3	2	3	5	4	3	4	1	4	5	3	2	3	4	2	4	4	2	3	1	3	2
Head Start / Early Childhood Programs	4	2	4	4	4	3	3	5	2	5	3	4	5	5	3	5	5	3	5	2	5	3	3	5	5
Health Care Quality Organizations/Programs	2	1	3	1	2	3	5	4	2	5	1	4	4	2	5	3	2	2	3	4	2	3	1	2	2
HMOs or Other Private Insurance Companies	1	2	1	1	2	4	3	3	2	4	1	5	1	1	3	2	4	2	1	2	4	1	1	5	2
HUD/Housing	2	1	1	1	2	1	2	5	2	3	1	2	1	2	2	1	1	2	2	3	1	3	1	2	3
Independent Living Centers	1	3	3	4	3	4	3	5	2	5	4	2	3	5	4	3	5	3	3	2	2	4	4	3	4
Indian Health Services	2	1	1	2	2	1	1	1	1	3	1		1	2	1	1	5	1	2	1	1	4	2	3	1
Integrated Systems Grantees	3	5	1	1	2	1	5	4	2	4	3	3	5	1	5	5	5	5	1	1	1	2		5	5
Juvenile Justice Programs	1	1	1	1	1	2	1	5	2	4	2	2	1	5	2	3	3	2	4	2	3	5	4	4	2
Lend Program or University Ctr on Disability Pgm	3	3	4	3	2	2	5		5	4	5	5	5	5	5	5	3	3	1	5	3	3	3	4	5
March of Dimes	2	3	1	1	1	2	1	1	1	4	2	4	1	1	2	4	1	2	1	3	1	3	1	2	2
Medicaid Agency	3	4	2	4	2	5	5	5	5	5	2	5	5	5	5	3	5	4	5	5	2	3	4	5	2
Mental Health Agency	3	3	4	3	3	2	5	5	3	5	3	4	5	5	4	4	5	4	5	5	4	4	4	5	5
Mental Health Partners	2	3	3	2	3	2	3	5	3	4	3	3	5	5	5	5	3	4	5	5	5	3	4	5	4
NICHQ Learning Collaboratives	3	2	4	1	1	3	5	2	1	4	1	4	1	5	4	1	1	3	1	5	1	3	1	1	2
Nursing Associations	1	1	1	2	2	2	4	1	2	4	2	4	1	1	3	3	2	2	2	2	1	3	1	4	3
Oral Health Partners	1	2	3	1	2	1	1	4	3	4	1	3	2	2	5	3	5	2	2	3	4	3	1	4	4
Other Parent Led Organizations	4	5	4	3	4	2	5	5	5	5	4	5	5	5	5	5	5	4	5	5	5	5	5	5	5
Parent-to-Parent Programs (P2P)	1	5	2	5	5	5	5	4	5	4	5		5	1	2	5	5	5	5	5	2	5	5	2	5
Protection and Advocacy Agencies	4	3	3	3	4	5	5	5	5	5	2	5	5	5	2	5	5	5	5	4	5	3	2	5	5
Parent Training and Information Centers (PTI)	5	4	5	5	4	4	5	5	3	5	5	4	5	5	5	4	5	5	5	5	5	5	4	5	5
Regional Genetics Collaboratives	4	1	1	2	2	3	5	1	2	4	1	5	1	5	3	5	2	5	2	5	1	3	5	4	5
Regional MCH Leadership	1	4	2	4	2	2	5	4	5	5	5	4	1	3	3	4	4	2	2	5	2	5		3	3
SCHIP Program	1	4	3	1	2	4	5	4	3	3	3	5	1	5	4	2	4	3	3	3	4	4	3	4	3
State Chapter of AAP	3	3	5	2	1	2	3	2	3	5	2	5	1	3	5	5	2	3	2	5	5	3	3	2	2
State Title V Programs	4	5	5	4	5	4	5	5	5	5	5	5	1	5	5	5	4	5	5	5	5	5	5	5	5
Universities	4	5	5	3	3	2	5	4	5	5	3	5	1	5	5	5	3	3	5	3	5	3	3	5	5
Vocational Rehabilitation Agencies	2	5	3	2	3	4	5	5	2	5	5	3	5	5	3	3	4	4	5	4	5	4	3	3	3
Youth Advisory Groups/organizations	2	4	3	2	3	2	5	5	2	5	4	2	3	3	2	5	4	3	5	5	2	3	1	3	5

Partner	MS	MT	NC	ND	NE	NH	NJ	NM	NV	NY	OH	OK	OR	PA	RI	SC	SD	TN	TX	UT	VA	VT	WA	WI	WV	WY
360 Grantees	1	1	1	3	5	1	5	5	2	1	1	4	1	1	2	2	5	1	1	1	1	5	1	1	4	1
AAP (national)	2	1	2	3	3	1	4	3	2	2	1	1	3	2	4	4	1	3	1	3	1	3	2	2	1	1
Adults with Disabilities (ADRC)	5	5	3	4	5	2	4	4	3	2	2	3	2	2	4	5	4	5	4	3	3	5	5	5	5	3
Advocacy Groups (Health Care Coverage)	1	3	4	5	5	3	5	5	2	2	5	2	2	5	5	5	5	5	5	4	2	5	3	5	3	2
Child Advocacy Organizations	5	5	4	5	5	1	5	5	4	3	5	2	3	5	5	5	5	5	5	4	5	5	3		4	4
Child Care Agencies	3	3	2	5	4	1	5	3	2	1	1	2	2	2	5	3	5	2	2	4	2	3	4	2	2	4
Children's Hospitals or Pediatric Units	2	4	4	5	5	1	5	4	3	3	5	4	5	5	5	5	5	5	5	5	5	5	5	5	3	5
Community Disaster-Preparedness Groups	1	2	2	5	4	1	5	2	3	5	2	1	2	1	4	5	2	5	2	3	2	4	2	3	2	2
Community Health/Rural Health Centers	2	2	2	3	4	1	5	4	3	2	3	1	3	2	5	5	5	3	3	3	3	4	3	3	3	5
Developmental Disability (DD) Agency/Pgm	5	4	3	5	5	4	5	5	5	5	5	4	5	5	5	5	5	5	5	5	5	5	4	5	5	5
Department of Education/Schools	3	5	4	5	5	3	5	5	2	4	5	3	3	5	5	5	5	5	3	4	5	5	3	5	5	5
Disability Specific Organizations	3	5	4	5	5	3	5	5	5	5	5	4	5	5	4	5	5	5	4	4	5	5	4	5	5	5
Early Intervention	5	5	4	5	5	5	5	5	5	3	5	3	3	4	5	5	5	5	5	5	4	5	4	3	4	5
Emergency Medical Services	1	2	2	5	1	1	4	2	1	3	1	1	5	2	4	4	1	5	5	4	1	4	2	1	5	2
Ethnic/Cultural/Racial Specific Organizations	3	1	3	3	3	1	5	4	2	2	2	2	2	2	4	4	4	5	2	3	5	5	5	3	2	1
Faith-Based Organizations	1	1	2	3	3	1	5	1	2	2	3	2	1	2	3	4	3	4	2	4	4	3	3	2	2	2
Fathers Support Groups	1	1	1	4	4	1	5	2	1	1	2	2	1	1	4	1	3	3	2	2	3	4	5	1	2	1
Federation of Families/Mental Health Orgs	2	5	3	5	5	3	5	2	3	3	3	5	5	3	4	5	4	4	2	5	5	5	3	5	1	5
Foster Care Agencies	3	3	4	4	5	1	5	2	3	2	1	3	2	2	5	2	5	2	2	3	2	3	4	3	4	5
Head Start / Early Childhood Programs	3	3	4	5	5	4	5	4	3	1	4	3	3	5	5	4	5	3	2	3	2	5	5	3	4	3
Health Care Quality Organizations/Programs	5	2	1	3	4	1	4	4	3	1	4	2	5	2	5	5	1	5	2	5	3	5	2	3	5	2
HMOs or Other Private Insurance Companies	3	2	2	4	2	3	5	4	2	3	5	1	2	4	4	3	2	3	5	4	2	4	2	3	3	2
HUD/Housing	5	1	2	2	3	1	4	1	2	1	3	1	1	2	4	1	3	3	1	1	2	4	2	1	3	1
Independent Living Centers	5	5	3	4	5	2	5	3	3	2	3	1	1	5	5	4	5	5	2	4	4	5	3	4	5	3
Indian Health Services	1	2	2	3	5	1	3	4	3	2	1	2	2	1	2	1	3	1	1	4	1	3	5	3	1	2
Integrated Systems Grantees	1	1	1	3	5	1	5	5	4	3	5	2	5	5	4	5	5	4	5	5	1	5	1	5	1	2
Juvenile Justice Programs	1	5	1	3	5	1	5	2	2	2	2	2	1	2	2	4	4	2	1	2	1	4	5	4	2	3
Lend Program or University Ctr on Disability Pgm	5	5	3	4	5	5	5	4	5	3	4	5	5	5	2	4	5	5	3	5	5	5	5	5	5	5
March of Dimes	1	5	2	4	4	2	5	2	2	2	1	2	1	4	4	3	2	4	3	1	3	2	3	2	1	
Medicaid Agency	3	5	2	5	5	5	5	4	3	4	5	5	3	5	5	5	2	5	4	5	5	5	3	4	5	5
Mental Health Agency	5	5	3	4	5	3	5	3	2	3	3	5	4	4	5	4	5	4	3	4	5	5	5	4	2	5
Mental Health Partners	2	5	3	4	5	2	5	2	2	3	3	4	5	2	4	4	5	4	4	4	5	5	5	4	2	5
NICHQ Learning Collaboratives	1	2	1	3	5	1	4	2	1	1	1	1	1	1	4	5	1	4	2	5	3	5	4	4	2	3
Nursing Associations	1	3	3	3	5	1	5	2	4	3	2	2	1	3	4	3	3	5	3	4	1	4	2	3	2	4
Oral Health Partners	1	1	4	4	5	2	5	2	2	3	3	1	2	1	5	4	5	3	2	4	2	5	2	3	4	5
Other Parent Led Organizations	5	5	5	5	5	4	5	5	5	5	5	4	5	5	5	5	5	5	4	4	5	5	5	5	5	4
Parent-to-Parent Programs (P2P)	1	5	5	5	5	2	5	5	5	5	5	5	4	5	5	5	3	5	5	5	5	5	5	5	4	5
Protection and Advocacy Agencies	5	5	3	5	5	3	5	4	3	4	3	2	1	5	5	5	5	5	4	4	5	5	4	5	5	3
Parent Training and Information Centers (PTI)	5	5	5	5	5	5	5	5	4	5	4	2	4	5	5	5	5	5	3	5	5	5	5	4	5	2
Regional Genetics Collaboratives	3	1	3	5	5	5	5	3	2	3	4	4	5	3	5	5	5	5	4	5	4	5	5	3	1	1
Regional MCH Leadership	1	3	3	3	5	1	4	5	5	5	3	3	5	5	5	5	3	5	5	2	2	5	5	3	3	5
SCHIP Program	1	3	4	5	5	2	5	4	3	2	4	2	3	1	5	5	2	3	1	4	2	5	4	3	5	3
State Chapter of AAP	3	2	3	5	3	5	5	3	3	2	2	1	5	5	5	4	2	5	3	5	2	5	4	4	4	2
State Title V Programs	5	2	3	5	5	5	5	4	5	4	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5
Universities	5	4	3	5	5	5	5	3	4	2	2	3	4	3	3	5	5	5	3	5	5	5	5	5	5	5
Vocational Rehabilitation Agencies	5	5	3	5	5	2	5	4	3	2	3	3	1	5	5	5	5	5	2	4	5	4	3	5	5	3
Youth Advisory Groups/organizations	5	5	2	5	5	4	5	5	2	2	4	2	1	5	4	5	3	5	2	3	5	3	4	2	3	2

CHART 3: F2F INVOLVEMENT in SPECIFIC INITIATIVES:

F2F Directors self-reported their F2F's involvement in specific initiatives, such as developing curriculum/materials, making presentations, serving on committees, etc.

State	AK	AL	AR	AZ	CA	CO	CT	DC	DE	FL	GA	HI	IA	ID	IL	IN	KS	KY	LA	MA	MD	ME	MI	MN	MO
Asthma								•		•					•										•
Autism	•		•	•	•	•	•	•	•			•		•	•	•	•	•	•	•	•	•	•	•	•
Adverse Childhood Experiences (ACEs)	•				•	•							•		•					•					•
Affordable Care Act (ACA)		•	•	•	•	•	•	•	•	•		•		•	•	•			•	•			•	•	•
Assistive Technology	•				•				•				•		•		•		•		•	•		•	•
Child Welfare/Abuse&Neglect/Prevention	•				•										•	•						•			•
Chronic Care					•				•						•	•									•
Cultural/Linguistic Competence	•		•	•	•	•	•		•	•		•	•		•	•	•		•	•	•	•		•	•
Emergency Preparedness		•		•	•	•	•	•		•			•		•		•		•		•				•
Domestic Violence					•					•					•										•
Early Hearing Detection&Intervention	•				•		•								•			•			•	•			
Early Periodic Screening Diagnosis/Treat.	•			•	•	•	•		•			•	•	•	•	•			•		•	•		•	•
Epilepsy					•		•		•	•			•		•						•		•	•	•
Family-Centered Care	•	•		•	•	•	•	•	•	•		•	•	•	•	•			•	•	•		•	•	•
Federally Qualified Health Centers	•	•			•	•		•	•						•	•					•	•		•	•
Foster Care					•				•	•			•		•		•				•				•
Health Exchanges			•	•	•	•			•	•			•			•		•							•
Health & Wellness					•			•				•	•		•	•	•		•			•		•	•
Health Information Technology (HIT)					•	•							•								•				
Home Visiting			•		•							•										•			•
Diverse Families				•	•	•			•	•	•		•	•	•	•	•	•		•	•			•	•
Pregnancy/Birth												•			•										
Limited English Proficiency (LEP)	•			•	•	•		•	•	•			•	•	•	•				•	•			•	•
Medicaid	•	•		•	•	•			•	•	•	•	•	•	•	•				•	•	•		•	•
Medicaid Buy-in					•	•			•			•							•					•	•
Medicaid Managed Care		•		•	•	•			•	•	•	•	•	•	•	•			•					•	•
Medicaid Waivers	•		•		•	•		•	•	•	•	•	•	•	•	•	•	•	•	•		•		•	•
Medical Home	•	•	•	•	•	•	•		•	•		•		•	•	•			•	•	•	•	•	•	•
Behavioral Health	•		•	•	•	•		•	•	•		•	•	•	•	•	•		•	•	•	•		•	•
TriCare/Military	•			•	•	•			•				•		•	•					•				
Obesity														•	•			•							
Other Disease-Specific	•				•				•			•	•		•	•					•				
Other Health Care Financing	•				•	•			•						•										
Palliative Care	•				•	•										•									•
Parents with Disabilities	•			•	•	•	•				•				•		•					•			•
Private Insurance	•				•	•			•				•		•	•								•	•
Provider Training	•	•	•	•	•	•	•	•		•		•	•		•	•				•	•		•	•	•
Quality Improvement Initiatives		•	•		•	•	•					•		•	•	•				•	•	•			•
Reducing Hospital Readmissions					•	•			•							•									•
Respite	•		•		•			•	•				•	•	•	•								•	•
State Children's Health Insurance (SCHIP)						•			•	•			•		•	•			•						
State Consortiums on MCH		•				•	•		•			•	•	•	•						•				•
Title V Block Grant	•	•	•	•	•	•	•		•	•		•			•	•	•	•	•	•	•	•	•	•	•
Title V Needs Assessment	•	•	•	•	•	•	•		•	•		•		•	•	•			•	•	•	•	•	•	•
Transition/Youth	•	•	•	•	•	•	•			•	•	•	•	•	•	•	•	•		•	•	•		•	•
Tribal Nations	•			•																					

State	MS	MT	NC	ND	NE	NH	NJ	NM	NV	NY	OH	OK	OR	PA	RI	SC	SD	TN	TX	UT	VA	VT	WA	WI	WV	WY
Asthma				•	•		•								•	•				•						
Autism		•		•	•	•	•		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Adverse Childhood Experiences (ACEs)			•	•			•							•	•	•						•				
Affordable Care Act (ACA)	•			•	•		•	•	•	•	•		•	•	•	•	•	•	•	•	•	•	•	•	•	•
Assistive Technology		•		•	•		•					•	•	•	•					•	•	•			•	•
Child Welfare/Abuse&Neglect/Prevention			•	•	•	•	•					•			•	•	•	•		•	•	•		•	•	•
Chronic Care	•			•			•					•			•	•	•			•		•		•	•	
Cultural/Linguistic Competence	•			•	•		•	•	•	•	•	•			•	•	•	•		•	•	•	•	•	•	•
Emergency Preparedness	•			•	•		•			•		•	•	•		•			•	•			•	•	•	•
Domestic Violence				•														•								
Early Hearing Detection&Intervention			•	•	•	•	•		•	•	•	•			•	•	•	•		•	•					
Early Periodic Screening Diagnosis/Treat.	•			•	•		•		•		•	•			•	•		•		•		•	•	•	•	•
Epilepsy				•	•	•	•		•	•										•				•		•
Family-Centered Care	•		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•		•	•	•	•	•	•	•
Federally Qualified Health Centers				•	•		•		•	•							•			•		•	•			
Foster Care			•	•	•		•		•		•				•	•	•			•				•	•	
Health Exchanges	•			•	•		•			•			•		•	•						•	•		•	•
Health & Wellness	•		•	•	•		•		•		•	•	•		•	•					•		•	•	•	•
Health Information Technology (HIT)							•									•									•	
Home Visiting				•			•					•	•		•	•		•		•		•		•	•	•
Diverse Families			•	•	•		•		•	•	•	•		•	•	•		•		•	•	•	•	•		
Pregnancy/Birth				•			•			•		•				•			•			•				
Limited English Proficiency (LEP)			•	•	•		•			•		•	•			•				•	•	•	•	•		
Medicaid	•		•	•	•	•	•	•	•	•	•	•	•	•	•	•				•	•	•	•	•	•	•
Medicaid Buy-in				•							•					•		•		•	•			•	•	
Medicaid Managed Care	•		•		•	•	•	•	•	•	•	•	•	•	•	•			•		•	•	•	•	•	•
Medicaid Waivers		•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•		•	•	•		•	•	•
Medical Home	•		•	•	•	•	•		•	•	•	•	•	•	•	•			•	•	•	•	•	•	•	•
Behavioral Health	•	•		•	•	•	•		•			•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
TriCare/Military				•	•		•			•		•			•	•			•	•	•		•		•	•
Obesity				•			•			•					•	•				•			•			•
Other Disease-Specific				•	•	•	•					•				•				•		•		•	•	•
Other Health Care Financing				•	•		•	•					•	•	•	•						•				
Palliative Care				•								•			•					•		•				
Parents with Disabilities			•		•		•	•			•	•			•	•		•						•		•
Private Insurance			•	•	•	•	•			•		•	•	•	•	•			•	•	•			•	•	•
Provider Training	•		•	•	•		•	•	•	•		•	•	•	•	•			•	•	•	•		•	•	•
Quality Improvement Initiatives	•			•	•	•	•					•	•		•	•				•		•		•	•	•
Reducing Hospital Readmissions				•			•													•		•				
Respite	•			•	•		•		•	•	•	•			•	•	•			•	•		•	•	•	•
State Children's Health Insurance (SCHIP)			•	•	•		•		•			•		•	•					•	•	•		•	•	•
State Consortia on MCH				•	•		•		•			•			•	•	•			•	•		•	•		•
Title V Block Grant	•			•	•	•	•		•	•	•	•	•		•	•	•	•	•	•	•	•	•	•	•	•
Title V Needs Assessment				•	•	•	•		•	•		•	•	•	•	•			•	•	•	•	•	•	•	•
Transition/Youth	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Tribal Nations				•						•		•				•	•						•	•		

CHART 4: ADDITIONAL SOURCES of FUNDING that SUPPORT the WORK of the F2F

State	AAP - State Chapter	ACA Navigator	Adults w/ Disabilities	Conversion Foundation	Developmental Disabilities	DOH/HHS	EI/Head Start/Early Childhood	Fee for Service	Fundraising	LEND-UCEED-DDRC	Medicaid Provider	Other Foundation	Parent Training & Info Ctr	Parent-to-Parent	Private Insurance HMO	SAMSHA/Other MH	SIG - Autism/Other DD	SIG - Integrated Sys for CSHCN	SIG - Evidence-Based Pgms	State DOE	State Exchange	Title V	United Way
AK								•				•	•							•			
AL									•													•	
AR																	•	•				•	•
AZ					•		•	•	•			•	•	•						•		•	•
CA					•		•		•			•	•							•			
CO									•									•					
CT									•	•				•									
DC						•			•			•	•										•
DE																							
FL													•										
GA					•	•	•		•			•	•	•				•		•		•	•
HI	•		•		•	•				•												•	•
IA									•			•	•								•		
ID									•			•								•			
IL								•															
IN		•							•			•				•		•					•
KS				•	•	•	•		•			•	•	•									
KY																							
LA					•		•					•											•
MA												•	•					•		•		•	•
MD	•					•			•			•	•				•	•		•		•	•
ME					•	•						•	•	•		•				•		•	•
MI																							
MN			•			•	•		•			•	•			•		•		•			
MO		•			•		•	•		•		•		•				•	•			•	
MS			•		•	•	•			•													•
MT					•	•	•	•			•	•	•			•							•
NC							•		•			•	•							•		•	
ND		•				•			•			•								•		•	•
NE									•	•		•	•							•			
NH						•			•			•					•			•		•	
NJ	•	•	•	•	•	•	•	•	•	•	•	•	•	•		•	•	•	•	•	•	•	•
NM			•	•	•	•	•		•	•		•	•	•								•	•
NV			•		•				•	•	•	•	•					•				•	
NY					•							•	•										
OH																							
OK					•	•			•	•	•	•		•		•						•	
OR																							•
PA	•				•	•		•	•	•		•			•				•	•			•
RI		•		•		•	•		•		•	•			•			•	•	•		•	•
SC	•	•			•	•	•		•			•	•			•				•		•	•
SD					•	•				•		•	•					•		•		•	
TN						•				•				•				•				•	
TX					•		•			•							•		•				
UT						•			•			•				•		•				•	
VA						•				•							•	•		•		•	•
VT			•		•	•	•	•	•			•	•	•			•	•		•		•	•
WA					•				•					•									
WI						•												•				•	
WV										•		•					•	•				•	•
WY						•				•												•	