

DIVISION OF CHILDREN WITH SPECIAL HEALTH NEEDS
Family to Family Health Information Center Program
PERFORMANCE MEASURE DETAIL SHEET SUMMARY TABLE

Performance Measure	Topic
F2F 1	Provide National Leadership for families with children with special health needs

F2F 1 Performance Measure

Goal: Provide National Leadership for families with children with special health needs

Level: Grantee

Category: Family Participation

The percent of families with Children and Youth with Special Health Care Needs (CYSHCN) that have been provided information, education, and/or training by Family-to-Family Health Information Centers.

GOAL

To increase the number of families with CYSHCN receiving needed health and related information, training, and/or education opportunities in order to partner in decision making and be satisfied with services that they receive.

MEASURE

The percent of families with CYSHCN that have been provided information, education and/or training by Family-to-Family Health Information Centers.

DEFINITION

Numerator: The total number of families of CYSHCN receiving one-to-one services and training from Family-To-Family Health Information Centers.

Denominator: The estimated number of families with CYSHCN in the state.

Units: 100

Text: Percent

BENCHMARK DATA SOURCES

Related to Objective MICH-20: Increase the proportion of children and adolescents with special health care needs who have a system of care.

GRANTEE DATA SOURCES

Progress reports from Family-To-Family Health Care Information and Education Centers, National Survey for Children's Health (NSCH), Title V Information System

SIGNIFICANCE

The last decade has emphasized the central role of families as informed consumers of services and participants in policy-making activities. Research has indicated that families need information they can understand and information from other parents who have experiences similar to theirs and who have navigated services systems.

DATA COLLECTION FORM FOR DETAIL SHEET #F2F 1

A. PROVIDING INFORMATION, EDUCATION, AND/OR TRAINING

The estimated number of families with CYSHCN in your state: _____
(Denominator: data from the National Survey of Children's Health)

1. The total number of families served is based solely on "one-to-one" service conducted by the F2F. This includes one-to-one family navigation, consultation, counseling, information, education, referrals, case management, mentoring, and small group individualized assistance etc.

a. Total number of families receiving one-to-one services (including small group individualized assistance) and training from Family-To-Family Health Information Centers. (Numerator; unduplicated count): _____

b. Of the total number of families served/trained, how many families identified themselves as:

Ethnicity

1. Hispanic
2. Non-Hispanic

Race

1. White
2. Black or African American
3. Asian
4. Native Hawaiian or Pacific Islander
5. Native American/American Indian or Alaskan Native
6. Some other Race
7. Multiple races
8. Unknown

2. The types of services provided to families.

a. Total number of service/trainings provided to families (this will be a duplicated count): _____

b. Of the total numbers of service/trainings, how many provided:

1. Individualized assistance (Includes one-on-one instruction, consultation, counseling, case management, and mentoring) _____
2. Basic contact information and referrals _____
3. Group training opportunities _____
4. Meetings/Conferences and Public Events (includes outreach events and presentations) _____

3. Our organization provided health care information/education to professionals/providers to assist them in better providing services for CYSHCN.

a. Total number of professionals/providers served/trained (unduplicated count): _____

4. The total number of services provided to professionals/providers. This includes the duplicated count of one-to-one services and trainings, group trainings, meetings/conferences, and outreach events. This does not include social media impressions or web hits (to be reported in Q5).

a. Total number of services provided to professionals/providers (duplicated count):: _____

5. Our organization conducted communication and outreach to families and other appropriate entities through a variety of methods.

- a. Select the modes of how print/media information and resources are disseminated. (Select all that apply).
- Electronic newsletters and listservs
 - Hardcopy/print
 - Public television/radio
 - Social media platform description: _____
 - Text messaging

B. MODELS OF FAMILY ENGAGEMENT COLLABORATION

1. Our organization worked with State agencies/programs to assist them with providing services to their populations and/or to obtain their information to better serve our families.

- a. Total number of State-wide agencies/programs with which your organization has worked: _____
- b. Indicate the types of State agencies/programs with which your organization has worked: _____

	Check the box if you worked with this type of organization
Title V MCH/CSYHCN Program	
Newborn Screening Program	
Early Hearing Detection and Intervention/Newborn Hearing Screening	
Emergency Medical Services for Children	
Home Visiting	
State Medicaid	
State CHIP	
State Mental and/or Behavioral Health	
Government Housing Program	
Early Intervention/Part C	
Head Start Collaboration Office	
Other (Specify):	
None	

2. Our organization served/worked with community-based organizations to assist them with providing services to their populations and/or to obtain their information to better serve our families.

- a. Total number of community-based organizations: _____
- b. Indicate the types of community-based organizations with which your organization has worked:

	Check the box if you worked with this type of organization
Medical homes, providers, clinics, hospitals	
Provider organizations (for example, American Academy of Pediatric chapter)	

Provider training programs (for example, residency programs; schools of medicine, nursing, public health, LEND programs, social work, etc.)	
Schools (K-12, pre-school)	
Faith-based organizations, places of worship	
Condition-specific organizations (for example, United Cerebral Palsy, March of Dimes, etc.)	
Child care programs	
Local Head start	
Other community organization (Specify):	
None	

c. Of those community-based organizations, indicate if any were dedicated to specific populations

	Check the box if you worked with this type of organization
American Indian or Alaska Native	
Black or African-American	
Hispanic or Latino	
Asian-American, Native Hawaiian or Pacific Islander	
Other (please specify)	

3. Number of staff who work on Family-to-Family HIC activities _____
4. Number of near/full-time (30+ hours/week) F2F staff who are family/have a disability _____
5. Number of part-time F2F staff who are family/have a disability _____