

DIVISION OF CHILDREN WITH SPECIAL HEALTH NEEDS

**Family to Family Health Information Center Program
PERFORMANCE MEASURE DETAIL SHEET SUMMARY TABLE**

Performance Measure	New/Revised Measure	Previous Performance Measure Number	Topic
F2F 1	Revised	70	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 with Special Health Care Needs (CSHCN) that have been provided information, education, and/or training by Family-to-Family Health Information Centers.

GOAL

To increase the number of families with CSHCN 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 CSHCN that have been provided information, education and/or training by Family-to-Family Health Information Centers.

DEFINITION

Numerator:

The total number of families with CSHCN in the State that have been provided information, education, and/or training from Family-To-Family Health Information Centers.

Denominator:

The number of families that can be reasonably served with provided federal grant funds.

Units: 100

Text: Percent

BENCHMARK DATA SOURCES

Related to Objective MICH-31: Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, coordinated systems

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 number of families that can be reasonably served with provided federal grant funds: _____

1. The total number of families served is based solely on “one-to-one” service conducted by the F2F.

a. Total number of families served/trained: _____

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

c. Total instances of service/training provided (this will be a duplicated count): _____

d. Of the total instances of service, 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) _____

e. Of the total number of families served/trained, how many instances of service related to the following issues:

1. Partnering/decision making with providers
Number of families served/trained _____
2. Accessing a medical home
Number of families served/trained _____
3. Financing for needed health services
Number of families served/trained _____
4. Early and continuous screening
Number of families served/trained _____
5. Navigating systems/accessing community services easily
Number of families served/trained _____
6. Adolescent transition issues
Number of families served/trained _____
7. Other (Specify): _____
Number of families served/trained _____

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

a. Total number of professionals/providers served/trained: _____

b. Total instances of service/training provided (this will be a duplicated count): _____

c. Of the total number of professionals/providers served/trained, how many instances of service were used to provide health care information/education related to the following issues:

1. Partnering/decision making with families
Number of professionals/providers served/trained: _____
2. Accessing/providing a medical home
Number of professionals/providers served/trained: _____
3. Financing for needed services
Number of professionals/providers served/trained: _____
4. Early and continuous screening
Number of professionals/providers served/trained: _____
5. Navigating systems/accessing community services easily
Number of professionals/providers served/trained: _____
6. Adolescent transition issues
Number of professionals/providers served/trained: _____
7. Other (Specify): _____
Number of professionals/providers served/trained: _____

3. 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
 - Public television/radio
 - Social media (Specify platform): _____
 - Text messaging

4. 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. Types of State agencies/programs - Total: _____

b. Indicate the types of State agencies/programs with which your organization has worked:

- a. State level Commissions, Task Forces, etc.
- b. MCH/CSHCN
- c. Genetics/newborn screening
- d. Early Hearing Detection and Intervention/Newborn Hearing screening
- e. Emergency Medical Services for Children
- f. LEND Programs
- g. Oral Health
- h. NICHQ Learning Collaboratives
- i. Developmental Disabilities
- j. Medicaid (CMS), SCHIP
- k. Private Insurers
- l. Case Managers
- m. SAMHSA/Mental & Behavioral Health
- n. Federation of Families for Children's Mental Health
- o. HUD/housing
- p. Early Intervention/Head Start
- q. Education
- r. Child Care
- s. Juvenile Justice/Judicial System
- t. Foster Care/Adoption agencies
- u. Other (Specify): _____
- v. None

B. MODELS OF FAMILY ENGAGEMENT COLLABORATION

1. 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. Types of community-based organizations - Total: _____

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

- Other family organizations, groups
- Medical homes, providers, clinics
- Children's hospitals
- American Academy of Pediatrics Chapter
- Hospitals - Residents, hospital staff training
- Hospitals - Other: _____
- Universities - Schools of Public Health
- Universities - Schools of Nursing
- Universities - Schools of Social Work
- Community Colleges
- Schools
- Interagency groups
- Faith-based organizations, places of worship
- Non-Profits, such as United Cerebral Palsy, March of Dimes, etc)
- Ethnic/racial specific organizations
- Community Teams
- Other (Specify): _____
- None

2. Family-to-Family Health Information Center goals/objectives were accomplished through formal and informal partnership strategies and practices.

a. Number of agreements with partners (from partners identified in items 3 and 4). Total _____

b. Indicate the type of partnership agreements that were in place during the reporting period:

- Subcontract
- Memorandum of Understanding/Agreement
- Letter of Invitation/Acceptance/Support
- Informal/Verbal Arrangement
- Other (Specify): _____

9. Our organization is staffed by families with expertise in Federal and State public and private health care systems.

a. Number of Family-to-Family FTE _____

b. Number of FTE who are family/have a disability _____