DIVISION OF CHILDREN WITH SPECIAL HEALTH NEEDS

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

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<th>Performance Measure</th>
<th>Topic</th>
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<td>F2F 1</td>
<td>Provide National Leadership for families with children with special health needs</td>
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F2F 1 Performance Measure

Goal: Provide National Leadership for families with children with special health needs
Level: Grantee
Category: Family Participation

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<th>GOAL</th>
<th>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.</th>
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<tr>
<td>MEASURE</td>
<td>The percent of families with CSHCN that have been provided information, education and/or training by Family-to-Family Health Information Centers.</td>
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| 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

<table>
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<tr>
<th>A. PROVIDING INFORMATION, EDUCATION, AND/OR TRAINING</th>
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<td>The number of families that can be reasonably served with provided federal grant funds: ____________</td>
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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
### 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 healthcare systems.

   a. Number of Family-to-Family FTE ______

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