

National Performance Measures and the National Technical Assistance Centers

A publication of the Massachusetts Family-to-Family Health Information Center @ Federation for Children with Special Needs

The Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services provides funding for 51 Family-to-Family Health Information Centers. There is one Center in each state; all are family-run. The Massachusetts Family-to-Family Health Information Center is a project at the Federation for Children with Special Needs.

Each Center provides free, confidential assistance to families raising children and youth with special health care needs (CYSHCN), professionals, and interested others around six national performance measures. The Maternal and Child Health Bureau (MCHB) established these six measures to ensure CYSHCN have access to family-centered, community-based, coordinated systems of care. These measures or outcomes are:

- 1) Family/professional partnership at all levels of decision-making
- 2) Access to comprehensive health and related services through the medical home
- 3) Early and continuous screening, evaluation, and diagnosis
- 4) Adequate public and/or private financing of needed services
- 5) Organization of community services so that families can use them easily
- 6) Successful transition to all aspects of adult health care, work, and independence

The MCHB also funds national centers that provide technical assistance to the Family-to-Family Centers (F2Fs) and others to help them work towards each outcome. This article provides an overview of the national technical assistance centers and the information and resources each provides around one or more of the performance measures.

The **National Center for Family/Professional Partnerships**, a project of Family Voices, helps the F2Fs and others work toward family/professional partnerships to ensure families can partner in decision-making at all levels and will be satisfied with the services they receive. This center also compiles the data collected by all the F2Fs and creates reports that show progress towards each of the outcome measures, numbers of families served, and how the data can be used to advance policy and program initiatives to improve systems of care for CYSHCN and their families. Each publication includes family stories that “illustrate” the work of each F2F, to highlight a particular success, and to keep families at the center of children’s healthcare. This center also publishes Friday’s Child, a monthly e-newsletter that highlights leadership in the states, provides legislative updates, and news of other partnership organizations. Learn more at <http://www.fv-ncfpp.org/>.

The **National Center for Medical Home Implementation**, a project of the American Academy of Pediatrics (AAP), helps ensure all children, including CYSHCN, have access to a medical home. Learn about national and state-specific medical home initiatives, and access a variety of tools families can use to organize medical information about their CYSHCN. There are links to other resources, including the AAP’s Healthy Children. This family-friendly Web site provides information about child development and health by age/stage. Learn more at www.medicalhomeinfo.org/.

Technical assistance around early and continuous screening is provided by the **National Center for Hearing Assessment and Management**, based at Utah State University. This Center provides information and training to families and professionals, and works to expand hearing screening

programs. There are links to programs in each state, information about the types of testing used to screen for and identify hearing loss, and family support resources. Learn more at www.infanthearing.org/.

The **Catalyst Center** works to improve health care financing for CYSHCN. This national center is based out of the Boston University School of Public Health. They work with states and other partners to expand health insurance coverage for CYSHCN, close insurance gaps due to underinsurance, and develop and share innovative financing strategies at the state and national level. Please note, they do not provide individual assistance to families around healthcare financing, but will connect you with the F2F in your state. The Web site includes a wide variety of publications, videos, and presentations about healthcare financing issues. In addition, the center has developed a State-at-a-Glance Chartbook. If you are thinking of moving and want to learn about health coverage in other states, this is a great resource. Learn more at www.hdwg.org/catalyst/.

[Note: If you want information about how national health reform – the Patient Protection and Affordable Care Act – will affect health care for CYSHCN in Massachusetts, listen to the playback of a topical conference call the Catalyst Center presented for the Massachusetts F2F at www.massfamilyvoices.org/Topical_Calls.html.]

The Institute for Community Inclusion (ICI) at the UMass-Boston is the **National Center for Community-Based Services**. They create materials for and work with Title V directors, service providers, and families of CYSHCN to ensure community-based services are easy to access. Visit the ICI Web site to learn about all their projects at <http://www.communitybasedservices.org/>.

Got Transition? is the name of the **National Health Care Transition Center**, located at the Center for Medical Home Improvement (CMHI) at Crotched Mountain Foundation. This newly funded center will work to create health care transition policies, initiatives, and health care transitions tools for professionals, youth, and families to make sure youth and their families receive the support they need to plan for and successfully move from pediatric to adult systems of care. Learn more at www.gottransition.org/.

While not a separate performance measure, cultural competence is part of the work of all the F2Fs. The **National Center for Cultural Competence** (NCCC) at Georgetown University in Washington, D.C. assists the F2Fs, and others, to help ensure programs are designed and implemented to deliver culturally competent services to families with children and youth with special health care needs. Visit the NCCC Web site to learn about their projects, and access resources and tools. Of particular interest are the self-assessment checklists for providers, which families can also use as a starting point to develop questions to ask potential providers and to assess the physical environment of the office to see if the practice will be a welcoming place and that the provider will be a good match for their child. Learn more at <http://nccc.georgetown.edu/>.

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