



## **The Title V MCH 5-Year Needs Assessment & Transition: A Primer for CYSHCN Programs**

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### **BACKGROUND AND LEGISLATIVE MANDATES**

The Title V Maternal and Child Health (MCH) Block Grant provides funding to states to assure that mothers, infants, and children—including children and youth with special health care needs (CYSHCN)—have access to preventive and primary health care. Over the years, Title V has been amended to reflect new knowledge and understanding of the healthcare needs of families and children, to support an ever-improving response to these needs, and to assure accountability in program implementation across the states.

Under the Omnibus Budget Reconciliation Act of 1989 (OBRA), each state is required to submit an annual report and to conduct a statewide needs assessment of the MCH/CYSHCN population every five years. In 1993, the Government Performance and Results Act (GPRA), Public Law 103-62, required Federal agencies to establish measurable goals that could be reported as part of the federal budgetary process. The Maternal and Child Health Bureau responded by identifying national performance measures, health status indicators and health outcomes on which state Title V agencies could report. These state reports are mandated as a condition of continued Block Grant funding. More importantly, state systems built on these standards help to assure that CYSHCN make successful transitions along the developmental continuum, and that young adults with disabilities are able to meet the goals at the center of the legislative intent -- having health care and insurance, working, becoming independent.

### **THE NEEDS ASSESSMENT**

The MCH Block Grant program is designed to develop effective partnerships through which federal funds address community needs and support community goals. Community learning and achievement can be reported to and disseminated by the federal health care partners. The MCH Block Grant program also advances state partnerships with other states, among state and local agencies, and between organizations and the individuals and families they serve.

In addition to satisfying Block Grant requirements, the assessment process is a core function of public health, setting the stage for policy development and programming. The process incorporates many of the 10 Essential Services of Public Health, including monitoring health status, diagnosing and investigating health problems, mobilizing community partnerships, and informing and empowering families, youth, and other stakeholders about important health issues. In assessing needs, the Title V program also is carrying out its assurance function as health systems availability, access, and quality are assessed.

The Needs Assessment focuses on the entire state MCH program. A subsection describes how well CYSHCN and their families are faring, how well services are meeting family and

youth needs and where gaps in services exist. The pages that follow provide guidance and links to resources that can help your state move through the process of building a team, collecting data, setting priorities, and reporting on your needs assessment for CYSHCN. Reporting on the healthcare and transition needs of CYSHCN is a recent mandate of the Block Grant Program so specific advice regarding steps to assure success in this new area is provided.

## LESSONS LEARNED FROM PREVIOUS NEEDS ASSESSMENT PROCESSES

A study commissioned by HRSA/MCHB of processes used by Title V agencies in the 2005 Needs Assessment identified skilled and dedicated staff members, strong partnerships, and access to and utilization of data as key elements of the process. Challenges and lessons learned include: 1) setting priorities is useful only to the extent that they are translated into benchmarks and tracked over time; 2) consultants can be useful, but they should not replace Title V staff involvement in the process; and 3) your stakeholders are often the best support for needed resources and services so they need data in a clear and useful format. A complete copy of the report, samples, and appendices can be downloaded at [http://www.mchtaproject.com/Resource\\_Page.htm](http://www.mchtaproject.com/Resource_Page.htm).

## BUILDING A LEADERSHIP TEAM

- **Start early!** The Title V 5-Year Needs Assessment can be a daunting project—start early—at least six to seven months prior to the due date for the application and report. Remember that leadership staff will be using findings and priorities from the needs assessment to allocate resources and craft the narrative of the block grant application. Include time for public comment. Some states require legislative approval prior to submitting the Block Grant, so this too should be factored into your timeline.
- **Develop a broad-based leadership team.** Involving diverse stakeholders will bring efficiency to the process and will build the collaborative relationships necessary for a comprehensive needs assessment—and successful program implementation once the Block Grant is received. Assure that your leadership team includes:

INTERAGENCY => individuals representing each aspect of the system of care (state Title V MCH and CYSHCN program staff, medical home physicians (adult as well as pediatric providers since YSHCN are transitioning to adult systems) and other service providers, public health and school nurses, mental health, foster care, early intervention, education (both special education and health education staff as many CYSHCN do not have Individual Education Plans), vocational rehabilitation, family and youth representatives and leadership organizations, insurance, state transition workgroups, etc.) ; also consider adding representatives from independent living centers; medical education programs for physicians, nurses, and other health professions; and the media;

DIVERSITY => the diversities present within your state population (cultural, gender, disability, geographic and economic);

LEGISLATORS => a legislator could be an asset to the leadership team so consider adding a legislator and/or legislative aide to the health and welfare committee; and

MCH and CYSHCN STAFFING => assign competent enthusiastic staff to coordinate the work of the leadership team. Clarify roles and responsibilities and ensure that they have adequate time to devote to the effort. Whenever possible, include an MCH epidemiologist or someone suitably qualified to assist with data collection and analysis.

- **Prepare the Leadership Team.** Plan on meeting frequently during the first four to six weeks to build team rapport, create a common vision, establish goals and objectives,

and design activities for the statewide needs assessment. Use these first meetings to familiarize the leadership team with critical documents and data, including:

The MCH BLOCK GRANT GUIDANCE:

<ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf>

CULTURAL COMPETENCY issues in the state and skills for working with individuals and groups of diverse cultures. For resources, check the National Center for Cultural Competence: <http://gucchd.Georgetown.edu/nccc>

SAMPLES - Previous needs assessments from your state, as well as examples from other states can be helpful. See [http://www.mchtaproject.com/Resource\\_Page.htm](http://www.mchtaproject.com/Resource_Page.htm).

DATA – Use state results from the National Survey of Children with Special Health Care Needs and National Survey of Children’s Health at [www.cshcndata.org](http://www.cshcndata.org) to determine areas of concern that might be a focus for the needs assessment. Look at the Behavioral Risk Factor Surveillance System, Youth Risk Behavior Survey, birth register and census data, and the percent of state SSI beneficiaries less than 16 years old receiving rehabilitative services from the state CSHCN Program. [www.hrtw.org](http://www.hrtw.org), Data Source HRTW-U for other sources of data on youth and young adults.

Types of services and means of delivery (e.g., clinics, care coordination, number of primary and specialty providers, and adequacy of funding for health care, education about rights and responsibilities for health care.

TRANSITION - Look to recent needs assessments or surveys conducted by private organizations serving CYSHCN in your state including department of workforce development, and vocational rehabilitation. Also look at state Medicaid agency and the Social Security Administration on children and youth receiving SCHIP, Medicaid, and SSA benefits for insight into the transition status and needs of this population.

- **Plan to assess the needs of all CYSHCN.** Do not limit your focus to just those enrolled in the State Title V Program. Look for disparities in access to care and use of health services among CYSHCN who are racial and ethnic minorities and other special populations. Identifying and understanding disparities is fundamental to developing solutions and improving the health status of all populations.

## PERFORMANCE MEASURES AND CORE PUBLIC HEALTH SERVICES

The MCH Block Grant Guidance identifies 18 National Performance Measures—including 6 National Performance Measures specific to CYSHCN—on which states are to report in their needs assessments and subsequent annual reports. In addition, each state is expected to identify 7-10 State Performance Measures addressing areas of particular concern that are identified through the needs assessment and on which they will report annually. Probably, one or two of these will be related to CYSHCN. These measures are aligned within a pyramid of public health services:

**Direct  
Health  
Care Services**

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**Enabling Services**

Youth transition & family support services, access to private and public insurance with adequate benefits and a medical home, referral and assistance with application for social services, transportation, translation, outreach, respite care, health education

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**Population-based services**

Universal newborn hearing screening, lead screening, immunization, sudden infant death syndrome counseling, oral health, injury prevention, nutrition, smoking cessation, outreach/public education

**Infrastructure Building Services**

Needs assessment, evaluation, planning, quality assurance, standards development and information systems;  
10 Essential Services of Public Health

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In order to adequately address the requirements of the MCH Block Grant Guidance, leadership team members must have—or quickly develop—an understanding of the national and state performance measures, health status indicators, and health outcome information. The leadership team should understand the value of structuring the needs assessment—and subsequent data collection procedures—to provide data and information specific to these measures. In addition, team leaders must be able to analyze information and data in order to identify emerging issues to be addressed in the state's priority needs.

## **COMMUNITY PARTICIPATION**

Provider and community surveys, focus groups, key informant interviews and community forums are valuable tools for gathering information and data on the provision of and need for services. The more deeply local communities can be involved in the needs assessment process, the more the information gathered will represent and reflect the real concerns of the statewide population.

- **COORDINATE WITH REGIONAL AND LOCAL STAKEHOLDERS**, including county and municipal health departments and regional state health staff, Title V/CYSHCN administrative and clinical staff, community-based school personnel, Area Development Districts (ADDs), Area Health Education Centers (AHECs), and others. Their knowledge of community and on-the-ground assistance can be invaluable in finding data sources and conducting focus groups, community forums, and surveys.
- **TARGET YOUR EFFORTS** to assure the input of families, key service providers, and the children and youth whose needs are the focus of the statewide effort. Include family and youth advisory groups and develop the abilities of youth and families to find and interpret data about youth in transition, and do surveys and key informant interviews. Consider developing a matrix based on demographic data from the NS-CSHCN to ensure representation from families and youth of diverse racial, ethnic, and socio-economic backgrounds and geographic regions.

## **MANAGING TIME AND ACTIVITIES**

- **Designate a coordinator** who will be responsible for communicating with all leadership team members, tracking activities, convening meetings, and keeping records.
- **Focus on addressing the key performance standards** outlined in the MCH Block Grant Guidance: national and state negotiated performance measures, health status indicators and outcomes. The CYSHCN subcommittee will focus on the 6 National Performance Measures for CYSHCN.
- As data sources for these measures are identified and data collection processes adopted, **establish due dates and delegate leadership team members** to work with community-based partners to assure data collection is completed on time.
- **Think of the 6 National Performance Measures for CYSHCN as stepping-stones** leading to successful transition to adulthood and the adult health care system. The needs assessment will help determine how your state is performing and what needs special attention.
- If there is an interest in the impact of a specific CYSHCN health condition, **the needs assessment may include a marker condition study** focusing on the capacity of the state system to provide services to meet the relevant needs and attain desired transition outcomes

## SHARE SUMMARY RESULTS

When you have completed your CYSHCN needs assessment, develop a 1-page summary, to be included in the 2-4 page MCH program summary, which addresses the 6 National Performance Measures, lists your state's priority needs, describes the data which led to this determination of priority and the process by which the priorities were identified, describes the process and products of needs assessment partnership building and collaboration, and provides an update on changes since the last Block Grant application. Include a summary of your efforts to identify and document disparities and the measures taken to ensure representation of diverse populations reflecting the state's CYSHCN population.

Distribute this summary to:

1. Programs represented by members of the leadership team (providers and family, youth and consumer leadership groups, etc.),
2. State government leaders,
3. Health care professionals and providers of adult services,
4. State and community-based education leaders who can use the information to enhance educational services for CYSHCN, and
5. Community business leaders who can use the information to prepare for the young adults with disabilities who will be accessing adult services and joining the workforce.

## EVALUATE THE NEEDS ASSESSMENT PROCESS

Engage the leadership team in evaluating the process and suggesting ways for improving the next 5-Year Needs Assessment.

## ADDITIONAL RESOURCES

## **TITLE V/MCH NEEDS ASSESSMENT & PERFORMANCE MEASURES**

### **Technical Assistance Workshops**

<http://128.248.232.90/archives/mchb/needs2004/>

Excellent TA resource information, power point slides presentations. Look at both the January and February sessions.

### **Review of the Title V 5-Year Needs Assessment Process in the States and Jurisdictions. December 2006.** Prepared by Health Systems Research, Inc. for MHS/MCHB.

[http://www.mchtaproject.com/Resource\\_Page.htm](http://www.mchtaproject.com/Resource_Page.htm)

A detailed study of the ways in which States implemented their Title V Needs Assessments in 2005; identifies best practices and promising approaches used by states. The appendices include sample surveys, questionnaires, logic models, worksheets, priority setting tools and innovative models used by states.

## **HEALTHY & READY TO WORK NATIONAL RESOURCE CENTER**

<http://www.hrtw.org/index.html>

Offers numerous resources and links to other sites that can inform and guide efforts to build a system of care that will assure successful transitions for CYSHCN to the activities and concerns of adult life. Click on the Youth Involvement tab to find good information on assuring that youth with special health care needs participate as decision-makers and as partners. Data Sources to Know lists sites with data on youth and young adults.

## **FAMILY VOICES**

### **National Center for Family/Professional Partnerships**

[www.familyvoices.org](http://www.familyvoices.org)

## **CHAMPIONS FOR INCLUSIVE COMMUNITIES – ChampionsInC**

[www.championsinc.org](http://www.championsinc.org)

A national center designed to support communities in organizing services for families of children and youth with special health care needs (CYSHCN).

## **NATIONAL CENTER FOR CULTURAL COMPETENCE**

National Center to support the development of culturally and linguistically competent service delivery systems.

<http://www11.georgetown.edu/research/gucchd/nccc/index.html>

## **AMERICAN ACADEMY OF PEDIATRICS**

National Center for Medical Home Implementation [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)

## **CATALYST CENTER**

National Center with data on insurance for children and youth and families

<http://www.hdwg.org/catalyst/>

## **DATA RESOURCE CENTER FOR CHILD AND ADOLESCENT HEALTH**

### **Children and Youth with Special Health Care Needs Data**

<http://www.cshcndata.org>

Site includes an easy to use, interactive data query feature that allows users to view and compare state, regional and nationwide findings from the State and Local Area Integrated

Telephone Survey (SLAITS) National Survey of CSHCN and National Survey of Children's Health, educational materials, state profiles on key performance indicators.

**CENTER FOR DISEASE CONTROL - NATIONAL CENTER FOR HEALTH STATISTICS  
State and Local Area Integrated Telephone Survey (SLAITS)**

<http://www.cdc.gov/nchs/slait.htm>

National Survey of CSHCN, National Survey of Children's Health and other surveys of interest to MCH administrators.

**Behavioral Risk Factor Surveillance System (BRFSS)**

<http://www.cdc.gov/brfss>

National and state-specific results of telephone surveys focusing on health behaviors and use of health services. Provides comparison information for CYSHCN from the general population by age groups.

**The Youth Risk Behavior Surveillance System (YRBSS)**

Monitors priority health-risk behaviors and the prevalence of obesity and asthma among youth and young adults through in-school surveys.

<http://www.cdc.gov/HealthyYouth/yrbs/index.htm>

**US CENSUS BUREAU – American Community Survey**

Annual survey that provides an array of data in addition to traditional demographic data, including education, employment, disabilities broken down by age categories. Click on American FactFinder Link on the ACS homepage.

<http://www.census.gov/acs/www/index.html>

**SSI DATA ON CHILDREN AND YOUTH**

<http://www.hrtw.org/youth/data.html> Data by year and by state

<http://www.mathematica-mpr.com/surveys/survdisabledchil.asp> National survey of SSI children and families currently being done by Mathematica

[http://www.ssa.gov/policy/docs/statcomps/ssi\\_children/](http://www.ssa.gov/policy/docs/statcomps/ssi_children/) SSI Website with most current data with variety of tables