

IMPLEMENTING COMMUNITY-BASED SYSTEMS OF CARE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

ISSUE
BRIEF

07 Measuring Progress

INTRODUCTION

States are being asked to create a comprehensive system of care for children and youth with special health care needs (CYSHCN) and their families as outlined in Healthy People 2010 and supported by the President's New Freedom Initiative. States must not only have the capacity to implement this system, but they also need to be able to measure and monitor their progress. Measurement may be used to identify child and family needs, which helps guide the development of goals for the system of care. Continued measurement is used to monitor progress in reaching these goals, the cornerstone for evidence-based decision making. Measurement results can serve as a valuable communication tool to engage key stakeholders to work toward achieving shared outcomes. Finally, measurement is needed to demonstrate program accountability as well as the need for funding to address child and family needs.

Two national surveys have set a precedent for gathering standardized data from all states on the broad population of CYSHCN:

- The National Survey of Children with Special Health Care Needs (CSHCN) is a standardized measure that reports the prevalence of CYSHCN based on the broad federal definition. This survey provides data for state-to-state comparisons of many of the core outcomes that comprise a system of care.
- The National Survey of Children's Health examines the physical and emotional health of all children, and it provides states with new information about the general health of CYSHCN as well as more detailed information pertaining to ensuring all CYSHCN have a medical home.

STATE AND COMMUNITY STRATEGIES

Additional measurement strategies are necessary in order to gain a better understanding of progress being made at the community level. State CYSHCN leaders

shared diverse and innovative strategies that they are using for more comprehensive measurement and monitoring strategies. Some examples of strategies used by the states are highlighted below:

- Health care utilization data pertaining to clients served by Medicaid, EPSDT, SSI as well as emergency room utilization and hospital discharge data have been used by states such as Florida and Oklahoma to assess both the health care needs and expenditures associated with CSHCN. Additionally, these data also can be used as an outcome measure when evaluating the effectiveness of interventions such as medical home and other care coordination approaches.
- Standardized surveys, typically used by state partner agencies, can provide valuable information pertaining to adequacy of insurance, medical home, transition, screening, and access to services. Massachusetts has collaborated in the use of the Behavior Risk Factor Surveillance System (BRFSS) to improve their understanding of health status of young adults with special health care needs. Utah has used the Consumer Assessment of Health Plans Survey (CAHPS) to compare adequacy of insurance among those with commercial insurance and Medicaid. Many states use the Pregnancy Risk Assessment Survey (PRAMS) to help measure screening and presence of a medical home for all children. The Medical Expenditure Panel Survey (MEPS) offers national data on the health for people with disabilities.
- Adding questions to existing surveys helps states to make the most of available measurement dollars. Some states purchased a larger sample size to be collected for national surveys, such as the National Survey of CSHCN, to better understand the needs and progress being made at the community or regional levels. Some states, such as Ohio, have partnered with other agencies to create an interagency survey that addresses shared goals, thus reducing the time and cost of administering multiple surveys. Other states, such as Illinois, Arizona, and Wisconsin have developed state-wide surveys, similar to the format of the National Survey of CSHCN, to capture more comprehensive information pertaining to the six outcomes based on a sufficient sample size to analyze by community or health regions.



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- Data warehousing and data integration which involve combining data from multiple agencies provide an opportunity for states such as South Carolina to measure their progress in achieving shared goals. In Oregon and Utah, data integration increases interagency collaboration by fostering confidential communication and dialogue regarding clients served and the role of various programs in comprising the broader system of care.

- Title V Clinic surveys are used by some states, such as Pennsylvania, to gain more detailed information about children and youth enrolled in their program and to measure the effectiveness of interventions.

- States have identified various strategies to address cultural competence in measurement tools used with families. The use of cultural brokers to participate in the development and review of measurement tools is an necessary first step. Some terms may not translate well from English to another language, and understanding cultural perceptions pertaining to “disability” is critical. Focus groups and individualized interviews are useful strategies to gain insights on how the system of care is working for families from diverse cultures.

- Family partners can help in the design of tools, ensuring that questions tap issues that are meaningful for families. Using family representatives in collecting survey data is beneficial because they are better positioned to develop rapport with respondents. Family participation in interpreting data provides realistic input to guide the development of useful and meaningful program policies and practices at the community and state levels. Family-To-Family Information Centers and state Family Voices directors also are implementing measurement efforts that provide another valuable source of information to guide the achievement of a system of care.

- Collaboration on these measurement strategies requires buy-in from key stakeholders, especially the support of those with position power. Colorado began by first defining

a common vision and identifying mutual benefits. Hawaii established data subcommittees to obtain relevant data and to determine other measurements that are needed. The measurement teams work on disseminating evidence-based information to the broader service system and families via issue briefs, summits, and community meetings.

DISCUSSION QUESTIONS FOR COMMUNITY-BASED TEAMS

At a series of Multi-State Meetings hosted by the Champions for Progress Center in 2004, state CSHCN staff, parent representatives, and other partners discussed the topic of Measuring Progress. The questions below can be used for discussion by interagency community teams and councils in order to share information and to build relationships.

1. What are the relevant outcomes to be measured for all key stakeholders?
2. What data do we currently have available to measure the relevant outcomes?
3. What opportunities are there to collaborate in terms of measurement, such as collecting and sharing data?
4. How can measurement information be disseminated to key stakeholders?
5. How can data be used to guide an action plan to improve the system of care?

Useful Links and Resources:

National Center for Health Statistics: <http://www.cdc.gov/nchs/about/major/slait/nsch.htm>

Measuring and Monitoring a Community-Based System of Care: www.championsforprogress.org

Assessment to Action: www.championsforprogress.org

Data Resource Center for Child and Adolescent Health: www.cshcndata.org

National Center for Cultural Competence: <http://gucchd.georgetown.edu/nccc/>



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champions @ championsforprogress.org

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