

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



Measuring Community Level Progress

INTRODUCTION

Measuring progress in the achievement of the six core outcomes for children and youth with special health care needs (CYSHCN) is essential at both the state and community levels. Efforts are best focused on measuring both the strengths and challenges individual communities face. Armed with this information, plans can be developed and implemented to address the unique characteristics of communities. The following steps delineate a process that can guide the development of effective, collaborative measurement.

STEP 1: GET ORGANIZED

Begin by bringing together key stakeholders to explore community-level measurement from a systems-level perspective, as demonstrated in the following examples:

- Defining the community of interest is an important first step to be discussed by key stakeholders. “Community” can be defined geographically, demographically and culturally, and this delineation is a necessary precursor to developing a measurement plan.

- Families are essential partners in forming a community-level team. Community councils are spearheaded by families in states such as Arizona, ensuring that coordination and measurement efforts are family-centered. This strategy encourages families to help define the community.

- Many state CSHCN programs are working collaboratively with their state early childhood comprehensive systems grants (SECCS), which focus on similar outcomes such as screening, medical home, and coordinated services.

- States such as Hawaii use distance technology (e.g. video conferencing) to facilitate collaboration with community partners.

- Cultural leaders or cultural ambassadors can be invaluable in bringing the support of underrepresented populations on board. States such as North Carolina look to other community stakeholders, such as churches, businesses and recreational facilities, to facilitate the inclusion of diverse groups.

- Communities in states such as Florida have initiated partnerships in response to the influx of bioterrorism dollars. Partnerships bring diverse community stakeholders together to assess emergency needs. This can serve as a valuable organizing group for measurement as well as general coordination to meet the needs of CYSHCN.

STEP 2: IDENTIFY EXISTING DATA

Once community-level partners are on board, begin to explore the data already available that pertains to your community and its population. Here are examples of data sources and collection strategies:

- Census data sparks stakeholder interest about the community at large. For example, identifying the number of children in the community can demonstrate the significance of the population.

- States such as Colorado and Connecticut that have a system of regional CSHCN offices use reporting systems to monitor progress on the six core outcomes. States with regional resource and referral call-in lines are collecting data when families call in on the six outcomes.

- National organizations such as Family Voices and the Family to Family Health Information Centers, are required to collect data on the needs of families. Colorado conducts a statewide “tour”, to gather information from families in different communities. This information supports program efforts to meet the needs of families, particularly those from diverse cultures.

- Communities can “piggy back” on to existing surveys. For example, communities in Wisconsin build upon an existing chamber of commerce survey by adding questions on health care needs.

- Regional level data from statewide surveys can be useful, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS). The Behavioral Risk Factor Surveillance Survey (BRFSS) can be analyzed for smaller geographic areas to provide information about transition-related issues, including those with disabilities. A subpopulation of those ages 18-14 years can be informative in guiding transition-related inquiries.

- Data on medical homes for children can be collected from community medical practices. Service coordination data can be collected by local Part C programs. Although the cohorts for these data sources do not represent the entire CYSHCN population, they can provide a snapshot of progress being made with subgroups of CYSHCN.



STEP 3: SHARE THE RESULTS

Information generated from data needs to be made relevant for various audiences. Sensitivity to the audience and the possible interpretation of the data are important considerations. How the data will be used, e.g., to support or prevent possible actions, also influences how data results are to be shared. Before you share, consider the sensitivity of data results and how it can have a potentially negative impact on the audience. For example, data that portray minorities as being less satisfied or more “needy” can harm the relationship with diverse partners. Examples of how results have been shared are featured below:

- Washington State’s CSHCN program leaders presented a “data road show,” sharing results with families and other stakeholders throughout the state. Greater stakeholder buy-in was obtained, especially from families.
- Some states use “community report cards” posted on their CSHCN website. They reflect the measurement efforts of the various communities.
- Many states have used the community data results to obtain grants. Others have found that sharing data results of mutual interest with other stakeholders has strengthened their partnerships.
- Data can be helpful in bringing elusive partners on board. One state presented judges with statistics for children with mental illness and juvenile crime, leading to more appropriate incarceration placements. Others have found that sharing data about results of mutual interest with other stakeholders has strengthened their partnerships.

STEP 4: DEVELOP AN ACTION PLAN

Data are an important component of action plans in two ways: to develop action steps for improving the service system, and to improve measurement and monitoring at the community level. Examples of action plan strategies are provided below:

- Some state Title V programs use a process to guide communities in the development of a community-level action plan in response to the community-level data, with a particular focus on achieving the six CYSHCN outcomes.

- Agency administrators, data analysts, and representatives from other community entities such as churches, recreation centers, and businesses are important to guide the implementation of a valid and appropriate measurement process.

- Family representatives can offer insights on how to recruit families as well as in selection of measurement tools for gathering valid and reliable responses.

- The cultural competence of community programs can be measured via a self assessment tool developed by the National Center for Cultural Competence. This information can be used to develop a community plan for culturally competent service delivery, such as improving outreach efforts to reach the underserved.

DISCUSSION QUESTIONS FOR STATE & COMMUNITY TEAMS:

At a series of Multi-State Meetings hosted by the Champions for Progress Center in 2005, state CSHCN staff and parent representatives discussed the topic of Building a Community-level measurement system. The questions below can be used by interagency community teams and councils in their efforts to develop their own community-based measurement system:

1. What community-level strategies are being used to measure and monitor achievements of the six CYSHCN performance measures in our state?
2. What are some ways to address gaps in measurement at the community level?
3. How can measures of cultural competence be incorporated into community-level assessment and planning? How can state-level decision makers use this information to develop supportive state policies?
4. Are there any examples of how communities are tracking or measuring the degree to which services are more integrated at the community level?
5. What models of collaboration seem to work best in conducting and getting value from measurement at the community level?

Useful Links and Resources:

Data Resource Center for Child & Adolescent Health: <http://www.childhealthdata.org/content/Default.aspx>

MCHB Title V Information System: <https://perfdata.hrsa.gov/mchb/mchreports/Search/search.asp>

M&M Project Assessment to Action: http://www.championsforprogress.org/action/docs/Assessment_to_Action_Complete.doc

The MCH Neighborhood: http://mchneighborhood.ichp.edu/index.php?pageaction=openlinkdetail&link_id=635&parent_id=58

Consumer Assessment of Healthcare Providers and Systems: <https://www.caahps.ahrq.gov>

National Center for Cultural Competence Self Assessment: <http://gucchd.georgetown.edu/nccc/selfassessment.html>

Behavior Risk Factor Surveillance System: <http://www.cdc.gov/BRFSS/>



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The work reported in this document was supported through a cooperative agreement #U42MC99241 from the U.S. Dept. of Health & Human Services Administration, Maternal & Child Health Bureau to the Early Intervention Research Institute at Utah State University