

Defining a System of Care for CYSHCN

INTRODUCTION

Children and youth with special health care needs (CYSHCN) are those who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson et al., 1998). This definition focuses on services needed rather than on diagnostic characteristics. It helps identify health risk broadly based on the concept of inclusion rather than exclusion. It recognizes the connectivity among physical conditions, developmental processes, emotional well being, and behavioral expression of each of these areas in a child's life as well as the impact on the family.

Children who meet this definition should receive services and support through a community-based system of care as: a "comprehensive spectrum of...health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and their families" (Stroul and Friedman, 1986 p. 3). Such a community-based system is necessary to ensure that no child is left behind and that mandates of the President's New Freedom Initiative are met. Six CYSHCN performance measures describe the basic ingredients necessary for ensuring community-based systems of care.

1. Families of CYSHCN will partner in decision making at all levels and will be satisfied with the services they receive.
2. CYSHCN will receive regular ongoing comprehensive care within a medical home.
3. Families of CYSHCN will have adequate private/public insurance to pay for the services they need.
4. Children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized in ways that families can use them easily.
6. Youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence.

STATE & COMMUNITY STRATEGIES

During a series of Multi-State Meetings sponsored by the Champions for Progress Center that were held in 2004, state CSHCN teams that included parents and youth discussed and reported several strategies that have helped them improve their system of care for CYSHCN. Meeting participants acknowledged that some form of state system already exists although it may be fragmented, targeted toward a particular group of children and families, or have other characteristics that keep it from being family-centered, community-based, and universal. State teams that are actively building community-based systems of care are using a four-step model to facilitate their work.

STEP 1. Building Partnerships. Identifying and recruiting needed partners to build the system of care precedes strategic planning efforts. Some states have hosted statewide meetings to rejuvenate their systems building efforts and to create a common level of understanding and implementation planning across state agencies. These meetings may have been coordinated through coalitions such as the state office of education, a University Center for Excellence in Developmental Disability, state chapters of the American Academy of Pediatrics, and family organizations. Typically, a core interagency group has organized the planning, received input from constituents at each level of the system, and made it happen. Common themes have emphasized making sure that the right partners are on board, designing a plan that will work within the constraints and resources available, looking at the system as a whole rather than just one performance measure, and making sure that they create the capacity to measure their progress at the



community levels. State Incentive Awards provided through the Champions for Progress Center have helped states focus on their objectives and to get the partners to the table.

STEP 2. Developing a Strategic Plan. Through MCHB Block grants and other mechanisms, state teams need to develop realistic flexible plans to guide systems change activities. Using participatory models to develop these plans helps to ensure that all of the partners in Step 1 are part of the planning phase.

STEP 3. Implementing the Plan at the Community Level. In order for services to be organized so that families can use them easily, the partners and the plan developed must strive to implement the plan via community-based services. This means that services and supports are coordinated at the community level and every effort is made to ensure that families have access to the range of needed services.

STEP 4. Measuring and Monitoring Progress. Without appropriate measurement and monitoring strategies that are used routinely, the partners will not understand whether their plan is working and meeting the needs of consumers as they had hoped. Data are important because they can both identify successes as well as help to spot problems areas, leading the way to strategies that can be more effective.

DISCUSSION QUESTIONS FOR STATE & COMMUNITY 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 reflected on the implementation of community-based systems of care for CYSHCN. The questions below can be used for discussion by interagency teams and councils in order to share information and to build relationships.

1. How will our state/community know whether there is an effective community-based system of care for CYSHCN in place? How will we know it when we see it in action?
2. How can our state/community promote the synergy across the six performance measures to create a system?
3. What constitutes best practices in implementing a system of care and how can it be measured and monitored as part of a continuous quality improvement (CQI) effort?
4. Does our team have active, frequent communication among our partners that helps shape our systems building activities?
5. To what degree has our council fostered family participation/leadership in our systems building efforts?
6. Is there a strategic plan for systems building efforts? Was it developed with all key stakeholders involved in the process?
7. Does the system we envision provide for supports and services in our state/community for all families in a manner that makes them accessible, appropriate, and affordable?

Useful Links and Resources:

American Academy of Pediatrics (AAP): <http://www.medicalhomeinfo.org>

Child & Adolescent Health Measurement Initiative (CAHMI): <http://cshcndata.org/>

Communities Can: http://gucchd.georgetown.edu/programs/ta_center/communities_can

Family Voices: <http://www.familyvoices.org>

Healthy & Ready to Work (H&RTW): <http://www.hrtw.org>

National Center for Cultural Competence (NCCC): <http://gucchd.georgetown.edu/nccc/index.html>

National Center for Financing for CSHCN: <http://cshcnfinance.ichp.ufl.edu>

National Newborn Screening and Genetics Resource Center: <http://genes-r-us.uthscsa.edu/>

National Center for Hearing Assessment and Management (NCHAM): <http://www.infanthearing.org>

Building a System of Care for CYSHCN: <http://www.championsforprogress.org/rmph/index.cfm>

What's a Community To Do?: <http://www.championsforprogress.org/main/distanceLearning.cfm>

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