

Family, Youth & Professional Partnerships in Decision-Making

INTRODUCTION

Systems of care for children and youth with special health care needs (CYSHCN) have undergone some major transformation within the past 15 years. Prior to that time, most systems of care were based either on the medical model or community support model. Families were often caught in the middle without the opportunity to give input or to be part of the decision-making process for their children. Through the work of the Maternal and Child Health Bureau (MCHB), a vision for systems of care for CYSHCN was developed that

“Families of CYSHCN will participate in decision-making at all levels of care and be satisfied with the services they receive.”

incorporates a system of care that is community-based, comprehensive, coordinated, family-centered, and culturally competent.

To implement this vision, MCHB identified

one of its six performance measure as follows: Families of CYSHCN will participate in decision-making at all levels of care and be satisfied with the services they receive. This measure recognizes that families, not professionals, are the constants in the child's life, the most important decision-makers about their own child's health care, and pivotal in creating a system of care. Family members, including those representative of culturally and linguistically diverse communities, must have a meaningful and consistent role in systems development at the state and community levels. Family

participation as equal members on state and community interagency teams helps to keep discussions open, honest, and focused on those who really matter—children and families—rather than getting sidetracked by professional boundaries and turfism.

STATE AND COMMUNITY STRATEGIES

At the federal level and in many states and communities, the involvement of families and youth in decision-making has reached a tipping point; in other words, there's no going back! The advantages of involving consumers in both personal decision-making as well as public policy-making are now being acknowledged across agencies and professional disciplines. Some basic principles for involving consumers will help to ensure the success in engaging families at all levels of the system.

- When recruiting families, make sure that there are clear, concise expectations for their involvement and that the goal of their involvement is clear and meaningful.
- Build on individual talents and interests. Provide opportunities for families to be involved in whatever level is comfortable for them.
- Recognize that individual family representatives may need to take a break periodically from committee work or other activities—leave the door open for them to return as life settles down.
- Be on the lookout for cultural brokers to help families get involved, especially families from diverse backgrounds.
- Compensate families for their participation in meetings or conferences, reviewing the State Block Grant, etc. Do not tamper or change family opinions – value what families say.
- Weave parent stories into training curriculums for both families and professionals.
- Families should be supported in their communications with legislators. They should be provided with information to substantiate the message so that it is valued and respected.

The following examples highlight only a few of the many efforts happening all across the nation to ensure family and youth involvement in building systems of care for CYSHCN.

- Connecticut family representatives are integrated into CSHCN programs. Families are asked to write their own “Block Grant” report from the family perspective.
- Colorado involves families at different levels. For example, parents are involved in parent teams for pediatric medical practices; each regional office has a parent coordinator; at the state level, a Family Action Team provides information and input on state-level policy with seed money from the Developmental Disabilities Council.
- Maine developed a coalition called Youth Educators and Advocates of Maine (YEAME) <http://www.umaine.edu/cci/service/maineworks/yeame/> to focus on transition, policymaking, and obstacles such as transportation and access to programs. Youth provide needed input to revise state-level policies and application forms for programs.
- The state of Kansas conducted a Youth Speak, training providers to increase partnership opportunities for youth and families.
- Florida hosted a mental health conference that focused on children and youth. Youth were active participants and helped to develop, design, and run the conference.

DISCUSSION QUESTIONS FOR COMMUNITY-BASED TEAMS

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

1. What types of training/support efforts occur (or are planned for) in our community/state to ensure that families and youth partner in decision-making?
2. Describe any public or private efforts for training/supporting families and youth from all cultures as decision-makers at the policy level. Have there been any parallel efforts to train board and council members in cultural competence?
3. What mechanisms, if any, help to ensure that youth have knowledge and skills to advocate for services that meet their needs and preferences?
4. What are the greatest accomplishments in our community/state related to ensuring families and youth partner in decision-making?
5. What are the greatest challenges in our community/state related to ensuring families and youth partner in decision-making?

Useful Links and Resources:

Family Voices: www.familyvoices.org.

Kids As Self Advocates (KASA) as part of Family Voices: www.fvkasa.org.

National Center on Cultural Competence: www.gucdc.georgetown.edu.

Florida Institute for Family Involvement (FIFI): www.fifionline.org.

Parents Reaching Out (PRO): www.parentsreachingout.org.

Alabama Children’s Rehabilitation Services: www.rehab.state.al.us.



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