

## Getting the Word Out

### INTRODUCTION

In order to implement a system of care for children and youth with special health care needs (CYSHCN) at the community level, states are developing effective strategies for Getting the Word Out to a variety of stakeholders, such as parents and parent groups, service providers, agency administrators, and legislators. Partners are needed at all levels of the system in order to ensure that the six national CYSHCN performance measures are implemented in a coordinated, comprehensive, and culturally competent manner. Likewise, existing state and community interagency councils or networks provide fertile ground and may already be working on systems integration efforts, such as joint screening, medical home awareness, and health coverage for uninsured/underinsured.

States and communities need to develop effective methods for educating service providers about their community's overall system of care as well as helping families understand the bureaucracy and how to advocate effectively. Parents want providers to consistently ask important questions such as, "How can we help your family? What do you need most? Is what we're providing helpful for your family?" and to then act upon this information. These discussions serve to strengthen relationships and to elevate the conversation beyond what individual programs or providers can offer by connecting family needs with other resources available in the community.

### STATE AND COMMUNITY STRATEGIES

A first step in designing a successful public relations effort is to assess existing avenues and to build on established relationships. With limited dollars available, community campaigns should seek to reach out to a broad range of stakeholders.

#### 1. Move outside the box by involving unique stakeholders

- Families and youth are being paid to serve as readers/writers for State Title V block grant applications. Family input helps to redefine the needs of CYSHCN to create broader, more practical solutions.
- Communities are identifying "cultural brokers" who are viewed as credible and are better positioned to design outreach efforts for families from diverse cultural and linguistic groups.
- States are creating 211 "warm lines" where both families and providers can call for specific information about the community system. Other states are developing electronic information systems that are more easily updated and enhanced than paper-based resource guides.
- State and local chapters of national organizations often need guest speakers. Taking the time to design a standard Power Point presentation that can be used and adapted by multiple stakeholders makes it easier for individuals to educate their own colleagues as well as be available to speak to other community groups, such as businesses, churches, community recreation programs, etc.
- When other methods failed, community programs are looking for new ways for engaging fathers by going to events typically attended by fathers, such as softball games.

## 2. Capitalize on the positive energy of youth and families

- Arizona established a system of community parent groups that are used for statewide information sharing, making it easier to get the word out and gain feedback as new information and initiatives are put forth.
- In Maine, 30 families from all over the state were invited to a weekend getaway to learn about the medical home concept. Families came away with an understanding of and commitment to family involvement and advocacy.
- The state of Washington now has a training called the “Road Show” presented to families to obtain their feedback. Families are interested to learn about the system of care and the six performance measures.
- In Pocatello, Idaho, a teenage brother of a young man with disabilities designed a colorful, inviting poster for the interagency community screening clinic.
- Iowa supports a training called “Parents as Presenters” that teaches parents how to put forth a positive message of change and helps them to identify “Where I can tell my story to make a difference.” This effort gives parents every opportunity to weave their stories throughout the system and provides vital legislative input directly from families.
- A guide for parents at diagnosis of hearing delay was developed by parents in Wisconsin and is also available in Spanish—[www.infanthearing.org](http://www.infanthearing.org)

## 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 and parent representatives discussed questions similar to those below. The version below can be used as discussion questions by interagency community teams and councils in order to share information and to build relationships.

1. In what ways, if any, is our community disseminating information about the President’s New Freedom Initiative and the six CYSHCN performance measures to: parents, policy makers, other community agencies, businesses, cultural and ethnic organizations, and other natural networks for family support that exist in our community?
2. Does our community have any other stakeholder groups or public forum for promoting the President’s New Freedom Initiative and the six CYSHCN performance measures?
3. In your opinion, how effective are our community’s mechanisms for partnering with families and engaging communities from diverse cultures? On what evidence do you base your opinion?
4. List our community’s greatest accomplishments related to Getting the Word Out on the President’s New Freedom Initiative and six CYSHCN performance measures.
5. List our community’s challenges related to Getting the Word Out about the President’s New Freedom Initiative and the six CYSHCN performance measures.

## Useful Links and Resources:

### Fact Sheet on Healthy People 2010 & the President’s New Freedom Initiative:

Cultural Brokers: [http://data.georgetown.edu/research/gucchd/nccc/documents/Cultural\\_Broker\\_Guide\\_English.pdf](http://data.georgetown.edu/research/gucchd/nccc/documents/Cultural_Broker_Guide_English.pdf)

Arizona’s Report on the National Survey for CYSHCN: [http://www.azdhs.gov/phs/ocshcn/pdfs\\_files/reportcard.pdf](http://www.azdhs.gov/phs/ocshcn/pdfs_files/reportcard.pdf)

Utah’s Collaborative Medical Home Web Portal: <http://medhome.med.utah.edu/>



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A Community of Learners  
[champions @ championsforprogress.org](mailto:champions@championsforprogress.org)

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