



“We Can Do It”

Highlights of the March 2001 Conference

Background

To assess the health care experiences of children with special health care needs (CSHCN), Family Voices and Abt Associates, Inc. surveyed 954 parents of CSHCN in California. This effort extended a national survey of over 2,200 families conducted by Family Voices and Brandeis University in 19 other states. The survey was sent to randomly selected families from California Children's Services (CCS) mailing lists and the membership lists of California Family Resource organizations in Los Angeles, San Diego, Sacramento and Fresno counties, and two rural areas in the state.

In 2000 Family Voices of California conducted interviews of 6 managed care organizations to explore how managed care organizations serve children with special health care needs. The results of the two studies revealed specific areas of concern for families of CSHCN. Family Voices of California with support from the Packard Foundation, the California Health Care Foundation and advocates held a conference entitled “We Can Do It,” to focus on 3 of the major areas of concern identified by families: Access to Providers, Access to Information and Coordination of Services.

The conference brought together families, advocates, agencies, funders, and other professionals to look at the **challenges** families face in existing health care systems; to identify **what is working** currently for children and families; and lastly to reach consensus regarding concrete **strategies for improvement**. This report reflects points on which the group came to consensus.

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Challenges

Access to Providers

- Lack of ancillary services for children and families such as home health care
- Shortage of pediatric specialists resulting in lengthy waits for specialist appointments
- Long waits to see mental health specialists
- The quality of care for children with mental health issues is lacking (assessments and treatment)
- Children in the juvenile justice system often do not have timely access to appropriate quality care for their special needs which could potentially keep them out of the criminal justice system
- Lack of transportation and childcare impede access to services

Access to Information

- Many families lack basic information about their child's disability and their rights
- Often, professionals do not think families are ready to learn about services. Families are angered if they feel information has been withheld which creates an adversarial relationship.
- The role of various state agencies is confusing. Interpretations can vary within an agency as well as outside of agencies
- Lack of access to written materials that are family centered, culturally appropriate and in their language

Coordination of Services

- Different service systems have different eligibility criteria and procedures making it very complicated for families using multiple systems
- Payers try to shift cost responsibility to other programs/funders leaving children un-served in the process
- Categorical funding may impede coordination and integration of services



Highlights of What Is Working

- Family Resource Centers provide parent-to-parent support in hospitals and ICU's and provide family centeredness training to professionals in the community including doctors, residents, interns and medical students
- Children's Regional Integrated Service System has helped to standardize procedures for California Children Services across counties in the Bay Area
- When locally based professionals (including Family Resource Centers) have an opportunity to come together and get to know each other or share the same work space, it encourages flexibility which makes services work better for families such as the "Early Start Round Table" where agencies come together to expedite services

Strategies for Improvement

(Summit participants reached agreement on the following strategies)

1 Families are the best resources for their children

Families should be recognized as the best resources and experts for their children. Families should be given information early and often in order for them to make educated decisions. They should be given the assistance they need in order to support their child/youth.

2 Create a system of payer of first resort

Early intervention is key to stopping further disabling conditions. Services should not be delayed due to confusion about which agency should pay for which service. There should be a payer of first resort and agencies should work behind the scenes to determine who pays for what. Families should not be placed in the middle to negotiate who the payer will be, between agencies. A seamless system for services should include periods of transitions.

3 Build the capacity of providers

Build the capacity of providers by supporting an increase in the rate of reimbursement for home health care providers, mental health providers, and medical providers, including pediatric specialists. Provide trainings to providers on family centered care. Trainings should be presented as a parent and professional partnership to model collaboration.

4 *Build the capacity of agencies*

Build the capacity of agencies to serve children with special health care needs by supporting endeavors such as Alameda County's risk factor form tied to a risk-adjusted primary care capitation rate. Lower the ratio of consumers to case managers so that case managers can be more effective. There should be a case manager at each insurance company who specifically works with families of children with special health care needs. Improve, strengthen and expand the CCS System. Support projects such as Children's Regional Integrated Service System, which improve the capacity of agencies working across counties. In addition support the enhancement of data collection systems within agencies and the ability of systems to manage information across agencies.

5 *Build capacity of parent-to-parent services*

Build the capacity of Family Resource Centers' parent-to-parent support in California. Support the model of a Health Liaison in each Family Resource Center and Network across the state. This includes the model of local CCS offices contracting with local FRC's to provide input and education on family centered care. Support the Family Resource Centers' model of parent-to-parent support in NICU and in hospitals.

6 *Support coalition building*

Support models that bring individuals, agencies, providers and family members together at the local and state level. These efforts help to coordinate services for families. This includes models such as the Medical Home model, the round table focusing on family referrals, Early Start Local Interagency Coordinating Area which brings together different agencies to ensure coordination of services for families, and the Mental Health System of Care model that ensures wrap around services. This also includes the idea of a statewide group that looks at children with special health care needs.

7 *Support the distribution of information*

Support the distribution of information to families and the professionals who serve them by increasing online information, by building websites, creating and distributing a map of services, and by providing more Telehealth Trainings and trainings on the Health Care Connections Manual.

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