

KEY STAKEHOLDERS¹

INDIVIDUALS

Christina Bethell, PhD, The Child and Adolescent Health Measurement Initiative

Lynn Kersey, MA, Maternal and Child Health Access

Paul Newacheck, DrPH, University of California, San Francisco

Paul Wise, MD, Stanford University

Cecily Betz, RN, PhD, USC Keck School of Medicine, University of Southern California, University Center of Excellence in Developmental Disabilities at Children's Hospital Los Angeles

Debra Lotstein, MD, MPH, David Geffen School of Medicine

ORGANIZATIONS

Association of Regional Center Agencies

ARCA) represents 21 regional centers in California that provide services to more than 200,000 Californians with developmental disabilities. Regional centers are nonprofit organizations that contract with the state Department of Developmental Services. This public-private nonprofit partnership results in the expenditure and monitoring of more than two billion state and federal dollars for people with developmental disabilities and their families.

Robert Baldo, Executive Director ■ <http://www.arcenet.org/>

American Academy of Pediatrics (AAP)

The AAP is a professional membership organization aimed at attaining optimal physical, mental, and social health and well being for all infants, children, adolescents, and young adults. In California, there are four AAP Chapters, comprising District 9. There are over 5000 board certified pediatrician members of all 4 California regional chapters. The organization focuses on advocacy on behalf of children and education of its members.

Kris Calvin, Executive Director ■ <http://www.aap-ca.org/>

California Budget Project

The California Budget Project engages in independent fiscal and policy analysis and public education with the goal of improving public policies affecting the economic and social well being of low- and middle-income Californians.

<http://www.cbp.org/>

¹ These are individuals and organizations that have been consistently involved in CYSHCN issues over several years.

California Children's Hospital Association

The Association works with state and national leaders in government and private industry to address issues impacting the hospitals' ability to provide the best care possible to the children of California, especially those with special and complex medical conditions. The eight private, not-for-profit regional children's hospitals are regular members of the association and the chief executive of each of these hospitals is a member of the association's board of directors. The five University of California children's hospitals and the Children's Center at Sutter Sacramento are associate members of the Association.

Diana S. Dooley, President & CEO ■ ddooley@ccha.org

California Premature Infant Health Coalition

The coalition exists to create a strong unified voice in California to help reduce the rate of premature births and improve outcomes for children born prematurely and their families. The coalition provides a sustainable setting to network, share best practices and other information, address policy, resource and systems change, and help keep decision-makers and the general public educated and knowledgeable about prematurity.

<http://capihc.blogspot.com/2009/03/organizational-structure.html>

Children's Regional Integrated Service System (CRISS) Project

Since 1996 CRISS has worked to create a regional seamless system of care for CCS children in Northern California. The current CRISS region encompasses 25 counties. CRISS membership includes the region's county CCS programs, major pediatric provider organizations and pediatric institutions, California's statewide family support organization, and the local family support organizations in the region.

CRISS activities focus on:

- Promoting seamless access to care for children in the region through regional planning and collaboration;
- Building a stronger, more consistent regionwide program by reducing intercounty variation in medical decision-making and other arenas;
- Promoting family-centered care through conferences and workshops and support for medical homes, parent health liaisons, transition planning, and other strategies;
- Supporting the provider network through reducing barriers to authorizations and timely payment; and
- Identifying and addressing critical policy areas for the CCS program and the children and families it serves.

Laurie Soman, Project Director ■ Lsoman6708@aol.com ■ <http://criss-ca.org/>

Children's Hospice and Palliative Care Coalition

The Children's Hospice and Palliative Care Coalition is a social movement led by children's hospitals, hospices, home health and grassroots agencies, and individuals to improve care for children with life-threatening conditions and their families.

Lori Butterworth, Executive Director ■ <http://www.childrenshospice.org/>

Children's Specialty Care Coalition (CSCC)

CSCC is a nonprofit organization representing more than 1,000 pediatric specialists in California, dedicated to educating and advocating for access to quality health care for California's children with special health care needs. The organization's objectives include educating the public and decision-makers about the importance of ensuring appropriate, high quality health care for children with special health care needs, providing and exchanging information on new developments and pending legislation in the area of financing and the provision of pediatric care programs for children with special health care needs, and increasing awareness.

Erin Aaberg Givens, Executive Director ■ <http://www.childrens-coalition.org>

Disability Rights California

Formerly Protection and Advocacy, Inc., Disability Rights California exists to advance the rights of Californians with disabilities.

Catherine Blakemore, Executive Director ■ <http://www.disabilityrightsca.org/>

Family Voices of California

Family Voices of California (FVCA) is a statewide grassroots clearinghouse for information and education about ways to assure and improve health care for children with disabilities and chronic conditions. FVCA was established through the linkage of Family Voices National and the Family Resource Centers Network of California.

<http://www.familyvoicesofca.org/>

Family Resource Centers Network of California

In California, Early Start Family Resource Centers are part of the Early Start Program. Staffed by families of children with special needs, family resource centers offer parent-to-parent support and help parents, families, and children locate and use needed services. They offer support services and resources in many languages, which may include newsletters, resource libraries, Websites, parent-to-parent groups, sibling support groups, warmlines, and information and referral for parents and professionals.

Linda Joy Landry, Chair ■ LindaJoyLA@aol.com ■ <http://www.frcnca.org/>

Los Angeles Partnership for Special Needs Children/CCS Workgroup

The mission of LAPSNC is to improve the health and well being of children with special needs in Los Angeles County by improving the systems of care for these children, advocating for clients served by LA County CCS, assisting with the provision of high quality services, advocating for improved systems of care at the county, state and federal levels, serving as a resource for other public and private entities serving CYSHCN, and assisting in educating providers and consumers regarding systems of care. Members of LAPSNC include major pediatric hospitals, health plans, LA County Department of Health Services, the local chapter of the American Academy of Pediatrics (AAP), and advocates. LAPSNC provides oversight and funding for the CCS Workgroup, and LAPSNC activities are carried out by Workgroup members.

Kathryn Smith, Chair ■ Kasmith@chla.usc.edu

March of Dimes

The March of Dimes is an organization dedicated to improving the health of mothers and babies by preventing birth defects, premature birth and infant mortality through advocacy, research, community services, and education.

California: (415) 788-2202 ■ <http://www.marchofdimes.com/home.asp>

National Health Law Program (NHeLP)

The National Health Law Program is a national public interest law firm that seeks to improve health care for America's working and unemployed poor, minorities, the elderly and people with disabilities. NHeLP serves legal services programs, community-based organizations, the private bar, providers, and individuals who work to preserve a health care safety net for the millions of uninsured or underinsured low-income people.

<http://www.healthlaw.org/>

State Council on Developmental Disabilities (SCDD) and Area Boards

The SCDD is an independent state agency to ensure that people with developmental disabilities and their families receive the services and supports they need. SCDD is composed of individuals with disabilities and their family members, and representatives of state agencies that provide services to individuals with developmental disabilities. SCDD includes 13 area boards that serve the consumer population of California. The mission of the area boards is to protect and advocate for the civil, legal and service rights of persons with developmental disabilities and to ensure that the services and supports they use are of the highest quality.

<http://www.scdd.ca.gov/>

State Interagency Coordinating Council (ICC) on Early Intervention

The ICC, appointed by the Governor, is comprised of parents of children with disabilities, early intervention service providers, health care professionals, state agency representatives, and others interested in early intervention. The ICC provides advice and assistance to the Department of Developmental Services regarding the statewide system of early intervention to achieve the full participation, cooperation, and coordination of appropriate public agencies in the state. It also offers a forum for public input.

<http://www.dds.ca.gov/EarlyStart/ICCOverview.cfm>

Western Center on Law and Poverty

Western Center advances and enforces the rights of low-income Californians to the basic necessities of life by working statewide for systemic change. Through legislative and administrative advocacy and impact litigation, we improve the lives of our clients. And by working closely with and supporting legal and social services organizations, we ensure that our work is responsive to the most critical human needs, while enhancing the capacity of community-based organizations to work in their neighborhoods.

<http://www.wclp.org/>