

STRENGTHS, CHALLENGES, AND GAPS IN THE SERVICE SYSTEM



With the recent cuts in IHSS, Rosie's benefits have been cut in half. She is blind and without this in-home support, her father will now have to quit his job to care for Rosie full time.

California has many important components in place that foster implementation of a system of care for CYSHCN:

- A strong network of family organizations and a statewide chapter of Family Voices that bring community-based information, education, and support to families as well as bring the perspective of families to the design and operation of a family-centered system of care for CYSHCN.
- A dedicated pediatric provider network of physicians and other health care providers and tertiary and quaternary pediatric hospitals that are the envy of many states.
- Committed advocates for children and youth, including advocates specifically focused on improving access and care for CYSHCN.
- Publicly funded programs such as Medi-Cal that typically have exceeded the minimum required by federal law, bringing vitally needed services to low-income CYSHCN.
- Specialized programs designed specifically for special populations of children such as CCS and regional centers/Early Start.
- Child health policy and clinical researchers who are nationally known and respected to assist in design and implementation of an appropriate system of care for vulnerable children.
- Public and private foundations whose interest is focused on children with special health care needs.

At the same time, the national and global economic downturn coupled with the state's own political and budgetary problems present major challenges at the macro level to achievement and maintenance of any system of care. These challenges, which affect funding and political support for programs that serve CYSHCN, include the following:

- The impact of the global economic meltdown has had catastrophic effects on California, including double-digit unemployment (11.6% in August, 2009; *San Francisco Chronicle*, 8/8/09) and a substantial drop in revenue to the state.
- California has a huge economy (eighth largest in the world) that typically is slower to move into a recession but also slower to recover from one.
- California has severe structural budget imbalances; e.g., 55% of state revenue comes from personal income tax, as opposed to most other states that

typically have a one-third division among income tax, property tax, and sales tax. This imbalance leaves the state very vulnerable to a drop in income tax receipts such as the state is experiencing now.

- The economic situation is compounded by huge state budget deficits over the past few years that have resulted in major reductions in overall state spending, amounting to a drop in state spending of almost 20% in the last two years (California Department of Finance).
- The power of the governor and legislature to address structural imbalances is limited by California's status as the only state to require a super majority for both passage of the budget and any increase in state taxes.

As a result of these factors, California finds itself in the worst fiscal crisis in at least 20 years, with concomitant impact on funding for the services that make up the existing system of care for CYSHCN. As noted throughout this report, the recently finalized current state budget includes major reductions in many of the programs that support care for children. Details on these reductions and their impact are not yet available at the time of this report but they are expected to be profound.

Even before the current fiscal situation and its potential impact, California had major gaps in its service system that leave vulnerable children and families at risk. Major service gaps that we have identified are grouped according to the six federal MCHB core performance measures discussed earlier in this report. The service gaps are organized by measure because these measures are national goals for CYSHCN that every state is expected to meet and they help to define the service system that families and maternal and child health professionals agree must be in place for vulnerable children.

The authors wish to stress that the gaps reviewed below are not newly identified; they have been culled from existing reports and surveys concerning access to care for California's CYSHCN that have been produced by major stakeholder processes over the years and reflect the thinking of many professionals and family members. See the earlier section on "Prior Efforts Addressing CYSHCN" for a review of some of these reports indicating how thoroughly the gaps and barriers in California's system of care have been analyzed over the past decade.

Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive.

1. Families in California do not have structured and institutionalized opportunities to partner in decision-making at all levels. Although there are "moments" of partnership, at this time there is no formal infrastructure for ensuring family participation at the state or local level. For example, until recently the state and a number of county CCS programs were supporting the work of parent health liaisons. Because of state and county budget cuts, these positions have been decimated, with six counties having cancelled their contracts, and one reducing the hours of the PHL (personal communi-

My daughter, Marci, was born with a left clubbed foot. Shriners Hospital helped with surgery when she was a few weeks old. Then several weeks later, we learned her neck was not strong enough. As she grew, we found out that her arms and legs were not strong enough to do the usual things babies her age do. I realized I needed to be strong. Through her doctor we found out about a program that sends someone to our house to give her therapy and exercises. Then Marcia started having seizures. We have taken her to many doctors' appointments but no one seems to be able to really stop the seizures. She has tried many different medicines and none really seem to stop the seizures. Right now she is on two different kinds of medicine and it seems to be helping more than before, but it's still not right. I hope someone will help me help my child.

cation, T. Robinson, 10/21/09). State CMS, the Department of Developmental Services, and other state agencies often send family-oriented materials to family organizations for review, but the timeline typically has been short and the impact uncertain.

2. There are no clear, published standards for family-centered care in the multiple systems serving CYSHCN.
3. There is no formal evaluation or tracking system to see whether families are satisfied with the services they receive.
4. Infrastructure does not exist to ensure that families or youth have ongoing access to information, education, and support for leadership that would promote their active participation in decision-making about services. Access to information is critical no matter what happens in terms of restructuring California's systems. Families will need to be informed and educated to understand their child's special health care needs, partner with professionals, navigate systems, and understand eligibility and regulations in order to secure appropriate health care services for their children.

Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home.

1. California does not have an operational definition of "medical home" for CYSHCN and it does not have clear numbers on how many medical homes really exist or a way to ensure that all CYSHCN have one. At the same time, we do know from family surveys that many families of children with disabilities do not even have a primary care provider, the first step in achievement of a medical home. In California, 42.2% of children have a medical home (CAHMI, NS-CSHCN, 2005-06).
2. There is no infrastructure to support ongoing training of and information for providers who want to implement medical homes. Several years ago state CMS embarked on development of a Medical Home Initiative for CCS children with complex medical conditions with the goal of achieving true medical homes at the local level through education of primary care providers serving CCS children, enhanced coordination between community-based providers and county CCS programs, CCS reimbursement for care coordination, and a certification process for medical homes for CYSHCN. Implementation of the initiative's first phase was derailed by budget cuts at the state and county levels and planning on the initiative has ceased.
3. There currently is no mechanism for Medi-Cal billing or other financial enhancement for care coordination in the medical home context. Particularly given the current financial climate, most pediatric providers will be unable to establish or expand care coordination activities without clear mechanisms for additional reimbursement.
4. California has an increasingly fragile provider network and continues to lose pediatric subspecialists to other states and to retirement. In addition, specialists are dropping out of participation in the Medi-Cal and CCS programs. California has been losing pediatric subspecialists steadily over the years and

the state's physician-patient ratio for pediatric subspecialists is below the national average. Many believe that this shortage is a result of low Medi-Cal (and even some private insurance plan) reimbursement rates coupled with the state's high cost of living.

Most CCS claims are handled electronically through (Electronic Data Systems (EDS), the state's fiscal intermediary for the Medi-Cal program. Many providers complain about delays in and denials of CCS claims submitted via EDS, a factor that may contribute to provider dissatisfaction with the CCS program. In addition, CCS electronic billing via EDS requires that physicians and other providers obtain Medi-Cal provider numbers through a process that can be confusing and onerous. Because one third of the state's children are enrolled in Medi-Cal, low rates and other barriers in that program can have a profound impact on the overall health of the entire pediatric subspecialty network for all children in the state (California Health-Care Foundation, 2007).

A 2007 survey of pediatric specialty care access indicated that in some areas of the state children wait months for a non-urgent new patient appointment; three months or more to see a pediatric neurologist and in one region, nine months; four to six months to see a pediatric endocrinologist; and four months to see a pediatric plastic surgeon for cleft lip and palate. The same survey also reported that in many areas of the state, pediatric medical groups have a difficult time filling open pediatric subspecialty positions, with some medical groups recruiting for open positions for one to two years. The length of time spent in recruiting was one year or more for open positions in endocrinology, behavioral/developmental pediatrics, gastroenterology, genetics, neurology, rheumatology, surgery, plastic surgery, and pulmonary medicine (Children's Specialty Care Coalition, 2007, personal communication).

5. There are long wait times for other providers serving CYSHCN, e.g., mental health professionals, particularly child/adolescent psychiatrists, and physical and occupational therapists, both among private providers and in the CCS Medical Therapy Program.
6. Health, developmental, and mental health services are more likely to be located in urban areas than in rural areas, resulting in access barriers to services based on geographic location of families and increased need for support for transportation and lodging for families who must travel to obtain comprehensive services.

Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.

1. Many families of children and youth with special health care needs do not have insurance or are underinsured.
2. Children may lose eligibility for publicly or privately funded insurance throughout the year, due to changes in income or parent employment, or family inability to meet periodic paperwork requirements for eligibility

redetermination, resulting in periods of uninsurance and lack of access to health care.

3. Many families may qualify for insurance but because of a lack of information (on their part and that of providers), they do not access it.
4. High out-of-pocket expenses are a barrier to children receiving the comprehensive services they need. According to the Your Voice Counts survey, almost half of parents reported spending between \$500 and \$3,000 on the special health care needs of their child in the past year. One-tenth reported that they spent \$3,000 or more in that year.
5. “Adequate” insurance can be a slippery concept, since coverage that may appear adequate at first can lose its effectiveness as a result of such barriers as the payer of last resort issue (e.g., some public and private insurers require that families obtain formal denials of coverage from other insurers before paying for needed services) and long waits for access to appropriate pediatric providers.

Children are screened early and continuously for special health care needs.

1. California does not have a standardized screening tool for identifying special health care needs, nor is there an institutionalized funding/billing mechanism for administration of developmental, behavioral, and/or mental health screenings. The State Medi-Cal Managed Care Task Force on Children with Special Needs report cited earlier in this paper included a recommendation that the state develop and implement a process to identify CYSHCN using a parent-reported screener, but this recommendation has not been implemented.
2. Providers are not always knowledgeable about resources for follow-up when screening identifies problems and/or they do not refer children and families to appropriate resources.
3. Appropriate resources for follow-up once screening has taken place often are limited, particularly for children needing mental health services and for families that are non-English-speaking. The lack of services available to CYSHCN in fact may compromise providers’ willingness to screen children for special needs.

Community-based services for children and youth with special health care needs are organized so families can use them easily.

1. There is no state inter-departmental coordinating body to work toward better organization of the multiple service systems for CYSHCN ages three and up, nor are there local bodies throughout California to assist in coordinating local agencies and making community-based services easier to access.
2. There is a lack of consistency of interpretation of state regulations/laws from county-to-county and across the multiple systems serving CYSHCN that confounds families who move from one region to another and contributes to services being available in one county or region but not in another.

Born prematurely, Stuart was enrolled in California Early Start, an extraordinary early stimulation program at home that allowed him to start walking at age four, communicate better, accept new foods (other than water and formula), and increasingly tolerate a wider range of sensory input—all this while Early Start also supported the family. Now that Stuart is an adult, the regional center is helping him transition into an adult program, where he will spend most of his life learning new skills and hopefully become a productive member of society.

3. While many entities purportedly provide care coordination, there is a lack of communication among the multiple agencies serving the same child that can make care coordination difficult and shift responsibility for most care coordination to families. Oftentimes the care coordination involves a gate-keeper role for the organization's services, rather than a true coordination of all available services across agencies and providers. This lack of communication is exacerbated by confidentiality concerns that may preclude agencies from sharing important information on mutual clients.
4. Most families report that they serve as their children's care coordinators. In a recent Family Voice survey, almost all families reported that they spent time each week arranging and coordinating their children's care, and 41% spent five or more hours per week on care coordination activities.

Youth with special health care needs (YSHCN) receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

1. There is no coordinated transition process for youth who are aging out of child-focused programs, and progress toward improving the transition process in several service systems has been derailed by recent budget cuts. For example, in early 2009, the state CCS program was in the process of issuing a policy letter mandating standardized scheduled transition activities but opted instead for an information notice with suggestions for transition activities because county programs had lost too many of the staff who would have been expected to implement the transition plans.
2. There is no standardized and coordinated transition process among the multiple systems serving youth. Youth often do not receive the education and training they need to be prepared for transition, and this is particularly problematic when they are receiving services from systems with different "graduation" ages; e.g., CCS coverage ends at age 21, while special education services end when the youth turns 22, foster care ends at age 18, and health insurance may end at varying times, depending on the coverage source.
3. There are too few adult-oriented health care and other providers for youth as they age out of pediatric-oriented care.
4. Many youth transition into no insurance at all; they no longer are eligible for Medi-Cal or CCS or they age off their families' private insurance coverage. In California, 9.1% of youth ages 12-17 with special health care needs were without insurance at some point within the past year according to the National Survey of Children with Special Health Care Needs, and among those with insurance, 38.9% reported that the insurance was inadequate (CAHMI, NS-CSHCN, 2005-06). Among all youth ages 18-24 in California, 19.4% are uninsured (CHIS, 2007), many of whom are youth with special needs.
5. An emerging issue is that the success of new treatments with certain conditions seen in CYSHCN (e.g., cystic fibrosis, certain heart conditions) is enabling these youth to survive into adulthood in far greater numbers than in earlier years, resulting in a lack of adult-oriented providers familiar with the care of these conditions.