Health Services

Services for children and youth with special health care needs are provided in a variety of inpatient, outpatient, and community settings, depending on a number of factors, including the funding source, where the child lives, services needed, and the child's medical condition and available specialists.

Children's Hospitals

While there is no formal regional system of care for CYSHCN, there are eight children's hospitals in California that provide primary, specialty, tertiary, and quaternary care. Children's hospitals provide graduate medical training for nearly 700 full time residents, 300 of whom are pediatric subspecialists, and provide almost 40% of all inpatient care for children in California.

Up to 75% of the children treated in children's hospitals are enrolled in Medi-Cal and more than half of the 698 CCS special care centers are located in children's hospitals. The eight children's hospitals provide 72% of inpatient care for children who need heart surgery, 60% of surgery for children who need organ transplants, and more than 55% of the inpatient care for children with cancer; 55-60% of their inpatients are children with serious illnesses. Children's hospitals provide over 1.5 million outpatient visits each year and over 55% of pediatric intensive care beds are located in children's hospitals. The case-mix is more than 25% higher than that of other hospitals that treat children. Managed care plans as well as PPOs and indemnity plans utilize these facilities (CA Children's Hospital Association, 2009). Appendix 6 provides a listing of these facilities.

In addition to children's hospitals, California has a number of tertiary care centers and specialized care units located within university medical centers or other hospitals within the community that have been approved as CCS tertiary hospitals.

Despite world-class facilities available to care for children with special needs in California, families experience long waits, especially for specialist care. This is the result of a shortage of pediatric subspecialists, as well as reluctance on the part of many providers to accept patients with Medi-Cal, Healthy Families, and CCS, due to low reimbursement rates and burdensome administrative

requirements. In addition, pediatric beds are in short supply, resulting in children being turned away when requests for transfers are made between community hospitals and children's hospitals. Further, there has been an overall decrease in pediatric bed supply over the last 10 years. According to an analysis of Office of Statewide Health Planning and Development (OSHPD) data, more than 800 in-patient pediatric beds were eliminated between 1998 and 2007, a 19% decrease (UPI.com, 2009). The hardest hit are rural, non-teaching hospitals, which reported an 80% loss of pediatric beds between 1992 and 2004, according to an unpublished study of the American Academy of Pediatrics (Yoshino, January 25, 2009). In addition to waits for pediatric in-patient and specialty care, families often have to travel great distances to receive this care, adding to their burden.

CCS Special Care Centers

CCS special care centers (SCC) are located throughout the state and provide comprehensive, coordinated health care to children with complex, handicapping medical conditions. There are 698 SCC in the state (Morrow, 2009). Staffed by interdisciplinary teams of experts including pediatric subspecialists, nurses, social workers, and others, the centers are organized around a specific medical condition or system. SCC are charged with evaluating each child's medical condition and developing a family-centered health care plan that will facilitate the provision of timely, coordinated treatment appropriate to each child. Although SCC provide care for a large number of diagnoses, there are CCS-eligible conditions for which there is no designated SCC, leaving some children without the comprehensive and coordinated care offered through these centers.

Keith, a young man living with a complicated health condition, was diagnosed with pneumonia at his pediatrician's office and sent home with an inadequate treatment plan. When his family contacted his pediatric pulmonary specialist, they moved heaven and earth to have him come in the following day to have a complete workup and additional medications added to his plan. Owing to the quick response of the pediatric pulmonary care team, the pneumonia was treated at home, avoiding a costly hospitalization.

Community Hospitals and Clinics

While most children with serious chronic or life threatening conditions are cared for in children's hospitals, academic medical centers, or related institutions, some receive care from community hospitals, due to geographic availability, the urgent nature of the condition, or limitations imposed by their health plans. While many community hospitals are able to care for children with common pediatric conditions, they cannot typically care for the most seriously ill children, or those with illnesses complicated by a chronic condition or other special health care need. At times, they are forced to care for children with significant care needs, as beds in children's hospitals may not be available to accept transfers.

Outpatient services are often provided in community clinics or by individual providers in the community. There are 6,157 board certified pediatricians in California, with a pediatrician:child ratio of 65.6 pediatricians per 100,000 children (American Board of Pediatrics, 2008). There are 8,015 family practice physicians in California many of whom serve children as well (American Board of Family Medicine, 2008). Nurse practitioners and physicians' assistants also provide care in outpatient settings. For some children, care is provided by general practitioners, who typically have not had any training specifically in

the care of children. For those living in rural and underserved areas, the federally qualified health centers, rural health care centers, and other safety net providers are critical to the provision of children's health care.

Pediatric Subacute Facilities

Pediatric subacute facilities provide care to children who require more medical and nursing care than can safely be provided at home. These facilities provide very intensive, licensed, skilled nursing care in acute care hospitals or in free-standing nursing facilities to patients who have fragile medical conditions.

To qualify for the pediatric subacute program, the patient must be under 21 years of age and need one of the following: tracheostomy care with dependence on mechanical ventilation for a minimum of six hours each day; tracheostomy care requiring suctioning at least every six hours, room air mist or oxygen as needed, and dependence on one of four treatment procedures (intermittent suctioning, continuous intravenous therapy or intermittent intravenous medication administration, peritoneal dialysis, tube feedings, and other medical technologies); total parenteral nutrition or other intravenous nutritional support and one of the five treatment procedures; and skilled nursing care in the administration of any three of the five treatment procedures (Medi-Cal, 2000). They may provide short or intermediate term care, while arrangements are made to return the child to the home, or they may provide long-term care. Because of their limited capacity there may be long waits, with children remaining in hospitals longer than necessary, before an adequate and available facility is located.

Home Health Care

Home health care is provided by registered nurses, licensed vocational nurses, and home health aids, most often through home health or nursing agencies. This can be short-term care, for instance to aid in recovery from an acute problem; intermediate term, checking-in on and guiding a family who is learning to care for a chronically ill child; or long-term, to assist families who need ongoing services to care for their child in the home. Included in this are children who need hospice care. Providers and families often encounter difficulties in locating home health care for children, due to poor reimbursement rates and lack of providers qualified to care for children.

In accordance with AB1745, CMS Branch and the Medi-Cal program collaborated to submit a waiver application to the federal Centers for Medicare and Medicaid Services/CMS for a 1915(c) Home and Community-Based Services waiver to allow seriously ill children to receive a range of supportive palliative care services while simultaneously receiving treatment services for their CCS-eligible medical condition. The waiver was scheduled for implementation in October, 2009, in Alameda, Monterey, San Diego, Santa Clara, and Santa Cruz counties.

Developmental and Mental Health Services

Regional Centers

The Department of Developmental Services, through contracts with 21 regional centers throughout the state, provides services to individuals who have qualifying developmental disabilities from birth until death. In addition, the Department of Developmental Services is responsible for Early Start, California's IDEA early intervention program.

Regional centers, like other publicly funded programs, are the payers of last resort. Families are expected to use other public and private resources (Medi-Cal, CCS, special education, commercial insurance) before regional center services are utilized. At times, families are caught in the middle as agencies attempt to shift responsibility for care away from themselves and to another payer. For example, parents often report tension between regional centers and school districts regarding the provision of some services such as behavioral therapies. Families also may have difficulty obtaining the denials of benefits from private insurers that are necessary to trigger access to regional center services.

Each regional center has its own community-based board of directors, responsible for overseeing the operation of its regional center. While regional centers are to provide a basic set of services—for instance, service coordination and respite care—there can be tremendous variability among regional centers in terms of program eligibility and service delivery. This can cause great frustration for families as they move from one area to another, or are aware of different benefits provided by individual regional centers elsewhere.

Mental Health Services

Publicly funded mental health services are provided to children and youth through county mental health programs, typically carved out of Medi-Cal and, in the case of serious mental illnesses, from the Healthy Families program. There may be little coordination between the plan with primary responsibility for health care and the mental health service system, resulting in barriers to access for children who need mental health care. For example, MRMIB reports very low utilization of mental health services by Healthy Families-enrolled children: between 2004 and 2007, only 3% of Healthy Families enrollees received mental health services provided through their plans and only 1% of all enrollees received treatment for serious emotional disturbance (SED) through counties (MRMIB, 2009). As is the case with regional centers, there can be tremendous variability in eligibility and service provision within and between counties. In addition, there can be considerable waits for services, at times up to several months long, shortages of qualified providers, particularly child psychiatrists, and a lack of available pediatric inpatient psychiatric beds, especially for those who have Medi-Cal.

Of particular concern is the conflict that can arise regarding service delivery between regional centers and mental health programs for children and

youth with both developmental disabilities and mental illness. Parents and providers report that regional centers do not have the capacity to serve individuals with mental health needs in addition to their developmental disabilities, and mental health programs often lack experience in dealing with patients who have a developmental disability in addition to their mental health condition.

Special Education

Each child served in special education has an individualized education plan (IEP) that maps out individual educational and related goals and identifies the services to be provided by the school district. For children with special needs, these services can include health care, therapies such as occupational and speech therapy, accommodations for the special need, and specialized approaches to education.

As mentioned above, through a California interagency agreement known as AB3632, both mental health services and California Children's Services can be offered through the county to address specific areas for children eligible for special education. Families whose children benefit from these services can be stymied to address issues that are caused by conflicting regulations and legal mandates of these agencies. In addition, because of tremendous budget pressures, tensions exist between general education and special education, between school districts and other providers of services such as regional centers and CCS, and between parents and districts, as parents seek services needed to maximize their child's education and districts are driven to limiting services due to ever tightening budget constraints.

Summary

While California has many services in place that are extremely valuable for children with special health care needs, the state does not have a true system of care for these children. Instead, the services available are a patchwork of programs located in different state departments or in the private sector, often with little formal communication or coordination among them. In addition, their disparate funding sources can put them in direct conflict with each other, as individual "systems" may seek to control their enrollment and expenditures. In one example, cost savings realized in one system as a result of innovations in another system will not be credited to the innovator, thus reducing the incentives for programs to collaborate or to make changes in the ways they organize or deliver services. Every report addressing access to care for CYSHCN in our state has commented on the need for California to address its "siloed" health, developmental, and mental health programs and to create mechanisms for the delivery of true coordinated, collaborative care.