

OVERVIEW OF SPECIAL POPULATIONS WITHIN CYSHCN



DOLESCENTS

California is home to 1.73 million teens ages 12-14 and 1.78 million teens ages 15-17, as well as 3.7 million youth ages 18-24 (CHIS, 2007). This is an ethnically diverse population, with 29.3% of adolescents 12-18 years identified as Latino, 36.5% White, 7.5% African American, 9.8% Asian, 0.7% Native American, and 16.3% Other/Multiracial (CHIS, 2007).

Of the teen population, 12.4% have a special health care need (CAHMI, NS-CSHCN, 2005-06). Youth with special health care needs (YSHCN) face numerous challenges, especially as they begin the transition to adulthood. These challenges include identifying resources to assist in transition planning, obtaining adequate health insurance, locating adult-focused practitioners able to provide ongoing primary and specialty care, preparation for employment and/or post secondary education, and learning self care skills associated with the special health care need. While many service systems provide limited assistance in the transition to adult living, a lack of a comprehensive planning structure, an inadequate supply of appropriate health care providers, lack of independent living skills, and potential loss of health insurance combine to make this a challenging developmental period. Additionally, YSHCN are challenged by loss of program eligibility that is variable—at age 21 for CCS, age 19 for some types of Medi-Cal, and up to age 22 for special education services.

CHILDREN AND YOUTH IN FOSTER CARE

As stated earlier, there are 64,838 children in foster care in California. Many children in foster care have special health care needs, displaying higher rates of chronic medical, mental health, and developmental problems than other children from similar socioeconomic backgrounds, and have greater utilization of physical and mental health and developmental services (AAP, 1994). For example, several studies of children entering foster care have found that almost 90% of these children had physical, developmental, or mental health needs, with more than half displaying two or more problems; almost 10% had one or more mental health conditions; and almost a quarter demonstrated concerns on developmental screening (Leslie, et al., 2005; Chernoff, Combs-Orme, Risley-Curtiss, & Heisler, 1994). Their poor health reflects their

exposure to poverty, poor prenatal care, prenatal infection, prenatal maternal, substance abuse, family and neighborhood violence, and parental mental illness prior to their removal from their parents (Simms, Dubowitz, & Szilagyi, 2000).

The special health care needs of these children are complicated by the instability of their home life. Children come into out-of-home placement because of abuse, neglect, or abandonment, and then often undergo multiple placement changes while under the care of child protective services. These changes in placement may necessitate disruptions in usual health care and other provider relationships, loss of medical records, and gaps or duplications in care. Foster parents may be unaware of the type of care needed for a particular condition, or may not know where to seek services. This instability can result in lack of health care continuity and poor health outcomes (Chisolm, Scribano, Purnell, & Kelleher, 2009).

Despite the availability of health care through Medicaid and other funding sources, as well as laws and policies that mandate appropriate care, numerous systemic and direct service barriers prevent many children in state protective custody from receiving adequate health care (GAO, 1995). California's children in foster care have health coverage through Medi-Cal, but it can be challenging for foster parents to find willing primary and specialist providers who accept Medi-Cal and will provide services to the child. Many children in foster care are also clients of other programs, such as CCS, regional centers, and special education. Transition is a particularly perilous stage for many children in foster care: in addition to transitions they must make out of other service programs, they age out of the foster care system itself at age 18.

HOMELESS FAMILIES

The term "homeless children and youth" means individuals who lack a fixed, regular, and adequate night-time residence. This definition also includes children and youth who are sharing the housing of other persons due to loss of housing, economic hardship, or a similar reason; children who may be living in motels, hotels, trailer parks, shelters, or awaiting foster care placement; children and youth who have a primary night-time residence that is a public or private place not designed for or ordinarily used as a regular sleeping accommodation for human beings; children and youth who are living in cars, parks, public spaces, abandoned buildings, substandard housing, bus or train stations, or similar settings; or migratory children who qualify as homeless because they are children who are living in similar circumstances listed above (California Department of Education, 2009). During the 2005-06 school year, there were 292,624 homeless children in California, the 10th largest population in the nation (Hubert, 2009).

Homeless children face numerous health problems and parents more often rate their health as fair or poor. Hospitalization is more common and homeless children are more likely to be seen in the emergency department. Health problems seen more frequently among homeless children include infectious diseases, injuries, elevated blood lead levels, mental health and behavioral

problems, developmental lags, obesity and malnutrition, anemia, dental caries, immunization delays, asthma, vision problems, and child abuse (National Health Care for the Homeless Council, 2009). Homeless children and youth access services from special education, regional centers, California Children's Services, and other programs serving children with special health care needs. Service eligibility can be difficult since they do not have a permanent residence, and communication with them can be difficult as mail is often undeliverable or providers cannot reach them.

FAMILIES EXPERIENCING OTHER CHALLENGES

In addition to the challenge of caring for a child with special needs, families face a variety of barriers in navigating the various systems which require communication and advocacy skills to access services. In California, 3.8% of CYSHCN are immigrants and 39.7% have parents who are immigrants¹ (Centers for Disease Control and Prevention, National Center for Health Statistics). Additionally, more than 14% of families of children with special health care needs speak a language other than English at home (CAHMI, NS-CSHCN, 2005-06). In California, only 38.7% of families who needed interpreter services usually or always received these services, making communication with medical and other service providers challenging (CAHMI, NS-CSHCN, 2005-06).

Further, cultural norms or past experiences often dictate how families interact with systems. Some families may have emigrated from countries where "negotiating" with government officials is not accepted, and, in fact, dangerous, and therefore may not feel comfortable advocating for themselves or their children. Even many English-speaking families are not comfortable with or know how to advocate on behalf of themselves and their children. Some may have had previous negative experiences with government or other agencies, such as having their children taken away from them, and may perceive that they have been treated disrespectfully, and have given up negotiating with these agencies.

Families living at or near poverty have many competing demands, chiefly finding and/or maintaining employment, and they do not have the time or money to negotiate the systems of care. Many children in California live near or in poverty; 39.6% of all children and 37.3% of children with special health care needs live in families with incomes under 200% of the federal poverty level (\$22,050 for a family of four) (CAHMI, NS-CSHCN, 2005-06). Further, 17.9% of families with a child with special health care needs report spending \$1,000 or more in out-of-pocket expenses for medical care for their child and 15.5% report having financial problems related to expenses for their child's care. Thus families living with minimal financial resources bear a heavy financial burden in caring for their children with special needs (CAHMI, NS-CSHCN, 2005-06).

¹Estimates are weighted to account for population characteristics including probability of being selected, telephone lines, and other demographic variables. The wide confidence intervals reflect a small weighted sample.