The future of children with special health care needs and their families is at a crossroads as a result of a number of pressing factors: ever-increasing numbers of children with special health care needs due to lifesaving interventions and early identification; the push toward full inclusion and optimal independence for individuals with disabilities and chronic conditions; the increasing cost of health care; the public debate to reduce health care costs and lower taxes; the decreasing availability of specialty care providers; the lack of access to comprehensive care coordination; and recent service cuts for vulnerable populations.

Children and youth with special health care needs (CYSHCN) are caught in the throes of this perfect storm; their well being is at risk. With that in mind, the Lucile Packard Foundation for Children's Health has requested a paper that provides an overview of the current system of care for children with special needs and their families in California, as the state contemplates changes in how these services are organized and delivered.

This report begins with an overview of the health and related systems designed to serve children with special health care needs. This section includes publicly and privately funded services, as well as those specific to certain populations. Detailed information about each service system is located in the appendices at the end of the report, and referenced in the text. The next section of the report consists of an analysis of the strengths and gaps within the current service system, and their impact on families. The report ends with a summary and recommendations for addressing some of the primary concerns in the current system of care.

WHO ARE CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES?

Children and youth with special health care needs are defined by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration, U.S. Department of Health and Human Services (US DHHS), as:

> *"...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."*

This definition was deliberately designed to be broad and inclusive, to reflect the characteristics held in common by children with a wide range of

diagnoses. As discussed in the sections to follow, the various publicly funded agencies do not base eligibility for services and programs on this broad federal MCHB definition, and instead tend to base their program eligibility on very specific conditions and diagnoses. In many instances, a single child with multiple special needs receives services and case management from a variety of public programs—for a complex medical condition, a developmental disability, a specific mental illness, and for special educational needs—while at the same time receiving basic health care via public and/or private health insurance.

The National Survey of Children with Special Health Care Needs (NS-CSHCN) provides a consistent source of national and state level data on the size and characteristics of the population of CYSHCN. This survey, sponsored by MCHB and carried out by the Centers for Disease Control and Prevention's (CDC) National Center for Health Statistics, provides detailed information on the prevalence of CYSHCN in the nation and in each state, the demographic characteristics of these children, the types of health and support services they and their families need, and their access to and satisfaction with the care they receive.

The 2005-06 survey reported that 13.9% of U.S. children have special health care needs, and 21.8% of households include at least one child with a special health care need. According to the NS-CSHCN, children with special health care needs comprise 9.9% of children in California (US DHHS, 2007; The Child and Adolescent Health Measurement Initiative (CAHMI), NS-CSHCN, 2005-06), or approximately 964,200 children. This represents 5.6% of children from birth through age five, 11.7% of children ages 6-11, and 12.4% of children ages 12-17 in California (CAHMI, NS-CSHCN, 2005-06).

Children and youth with special health care needs, like all children in California, represent a diverse population in many ways. Children with special health care needs in the state are ethnically diverse; 47.7% are White (non-Latino), 10.5% are Black (non-Latino), 29.1% are Latino, and 12.7% are multiple or other race/ethnicity (CAHMI, NS-CSHCN, 2005-06). In California, 14.4% of CYSHCN live in families that primarily speak a language other than English at home (CAHMI, NS-CSHCN, 2005-06). Many children with special health care needs live in families with incomes that are at or near poverty, with 18.3% of CYSHCN in California living in families with incomes under 100% of the federal poverty level (FPL), and 39.5% living under 200% FPL (CAHMI, NS-CSHCN, 2005-06). (The FPL in 2006 was $20,000 for a family of four, according to US DHHS, 2009.)

In California, CYSHCN have better rates of insurance coverage than the general child population. However, according to the NS-CSHCN, 3.1% were uninsured at the time of the survey and 8% were without insurance at some time within the past year (US DHHS, 2008). The predominant form of insurance is private insurance, with 63.6% having private insurance only, 26.2% receiving public insurance only, and 7.1% receiving both public and private insurance (CAHMI, NS-CSHCN, 2005-06).

Special populations within the broader group of CYSHCN face greater difficulties accessing health, developmental, behavioral, and educational services. These populations include children in poverty; children whose parents

do not speak English; children in foster care and other out-of-home care; and adolescents, including emancipated and homeless youth.

MCHB CORE PERFORMANCE MEASURES

In 1998, the federal MCHB established a goal for state Title V programs for children with special health care needs to provide and promote family-centered, community-based, coordinated care for CYSHCN, and to facilitate the development of community-based systems of services for these children and their families (MCHB, 2008). MCHB has identified six core outcomes which promote this system of care, also mandated by Healthy People 2010 (a comprehensive set of disease prevention and health promotion objectives promulgated by DHHS, Office of Disease Prevention and Health Promotion) and the New Freedom Initiative (an Executive Order to remove barriers to community living for people of all ages with disabilities and long-term illnesses).

Cultural competence is not a performance measure, but MCHB has included it as a guiding principle, which goes across all performance measures (Goode, T.D., et al, 2007). This guiding principle and the six outcomes are designed to give the states and MCHB a way to measure progress on achieving their goals. Progress toward achievement of the core outcomes is measured in several ways. The National Survey of Children with Special Health Care Needs (NS-CSHCN), as discussed above, provides information about CYSHCN in all 50 states and the territories by conducting telephone interviews with at least 3,000 families in each state, with in-depth interviews of 750-850 families per state specifically addressing the core outcomes. The survey was conducted in 2001 and 2005-06. In addition, California monitors some of the core outcomes as part of its Title V needs assessment process.

Tracking these core outcomes provides valuable information about a state's progress in achieving a family-centered system of care. Below is a summary of California's progress from the 2005-06 NS-CSHCN (US DHHS, 2007).

MCHB Core Outcomes	% CYSHCN Achieving Outcome in California	% CYSHCN Achieving Outcome in U.S.
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.	46.6%	57.4%
Children and youth with special health care needs receive coordinated, ongoing, comprehensive care within a medical home.*	42.2%	47.1%
Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.	59.6%	62.0%
Children are screened early and continuously for special health care needs.	62.7%	63.8%
Community-based services for children and youth with special health care needs are organized so families can use them easily.	85.3%	89.1%
Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.	37.1%	41.2%

* *The American Academy of Pediatrics describes the medical home as a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. Additionally, the American Academy of Family Physicians (AAFP), the American Academy of Pediatrics (AAP), the American College of Physicians (ACP), and the American Osteopathic Association (AOA) have produced Joint Principles of the Patient-Centered Medical Home.*

(Note: The MCHB performance measure for early and continuous screening is the rate of parents reporting that their child with special health care needs received routine preventive medical and dental care in the past year. Data from the 2007 National Survey of Children's Health showed that California children receiving a structured developmental screening in the past year lagged behind the national average more significantly for children ages 10 months to 5 years (14% of young Californians compared to 19.5% nationally) (CAHMI, NSCH, 2007). This rate of screening varied by insurance type; those screened were 15% of children in California with public insurance coverage, 14% of children with private coverage, and 10% of children who are uninsured (CAHMI, NSCH, 2007).

CALIFORNIA'S "SYSTEM OF CARE"

When Henry was born, physicians doubted he would survive the first 24 hours. When he was three, his parents were told he was retarded and would require special education classes the rest of his life. When he was five years old, he had logged hundreds of hours in physical, occupational and speech therapy. He'd received the best care by pediatric subspecialists. At 15 years old, he is enrolled in accelerated courses in a college prep high school program. This year, he will compete in the Junior Olympics with his water polo team. He is a walking, talking testament to early intervention.

Terms like "system of care" are often used to refer to the panoply of services available to CYSHCN in California. In fact there is no "single system" but rather a complex "series of systems" that exist independently of each other, occasionally overlapping and sometimes conflicting. Publicly funded services include basic health services for children, often regardless of any special health care needs but where eligibility typically hinges on family income, such as health coverage via Medi-Cal. As described later in the report, the state also administers specialized services organized by a child's particular medical or other condition (e.g., California Children's Services, or CCS, for children with specific medical diagnoses; county-based mental health services for children; regional centers for persons with developmental disabilities; special education; foster care). Some of these programs have financial eligibility criteria while others do not. Also, services are available in the private sector for those with employer-based or privately purchased health insurance coverage.

Many children use both public and private systems, depending on their conditions, needs, and individual programs' eligibility criteria. These coexisting, overlapping, and contradictory systems and funding mechanisms result in an extraordinarily complex maze of services, dueling eligibility criteria, and financing approaches that can confuse even the savviest advocate, and result in delayed or denied services for children and major financial outlays for families. Ultimately, the success of children and youth with special needs in accessing services in the "system of care" is dependent on families' abilities to negotiate this maze.

Some examples of the extent of service use by children with special health care needs in California can be seen from the following statistics:

- California provided special education services to 678,105 individuals, newborn up to 22 years of age as of December, 2008 (CDE, 2008).
- As of December, 2007, 80,272 children ages 3 through 17 were clients of regional centers in California, and another 18,383 young adults ages 18-21 were clients of regional centers (DDS, 2007).

- In 2006, 56,000 births, or 10.7% of all California live births, were premature, with a significant number having multiple medical and developmental special needs (March of Dimes Peristats, 2009).
- 64,838 children were in the foster care system in California as of December, 2008 (Needell et al., 2009); children in foster care are regarded as a specific population within CYSHCN because of their high prevalence of physical, developmental, and mental health needs, as documented in a number of studies (Leslie, etc., 2005; Chernoff, Combs-Orme, Risley-Curtiss, and Heisler, 1994).

We note that at the time of this writing, as a result of the state's desperate financial situation, everything connected with these "systems," from eligibility to, in some cases, their existence, is fluid, and there could be major changes in the coming year. We also recognize the potential impact of federal health care reform, which could result in significant redesign of the health care system nationally, with repercussions for public and private health care coverage in our state.