

# Overview: Mapping Systems of Care for Children with Special Needs in the State of California

## SENATE SELECT COMMITTEE MEMBERS

Senator Dr. Richard Pan, Chair  
Senator Jean Fuller  
Senator Ted Gaines  
Senator Jerry Hill  
Senator Ben Hueso  
Senator Carol Liu  
Senator Holly J. Mitchell

**Prepared for the Senate Select Committee on Children with Special Needs**

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## **PREFACE**

### **SENATE SELECT COMMITTEE MEMBERS:**

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This brief was requested and produced at the direction of the Senate Select Committee on Children with Special Needs, chaired by Senator Dr. Richard Pan. The brief provides an overview of California’s state-administered public agencies and programs providing care and services to eligible children and youth with special needs from birth up to age 21 and is also meant to offer supplemental background information to pair with the Select Committee’s first informational hearing entitled “Mapping the Current System of Care and Funding for Children and Youth with Special Needs in the State of California” held on December 1, 2015.

### **ACKNOWLEDGEMENT:**

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### **ABOUT THE AUTHOR:**

Ms. Cristina Jade Peña has focused her life’s work on advancing equitable health policy and improving access to health information and services for vulnerable and underserved populations, with an emphasis on women, children with chronic illness and disabilities, and individuals living with HIV. Ms. Peña has partnered with and consulted for various organizations, government agencies and committees including the Henry J. Kaiser Family Foundation, UNAIDS, the White House Office of National AIDS Policy (ONAP), Keep a Child Alive, the International Conference on AIDS, and the San Francisco Food Security Task Force, among others.

Ms. Peña currently serves as the Lead Consultant to the California State Senate Select Committee on Children with Special Needs and is responsible for providing the Select Committee with policy research and analysis and organizing Select Committee hearings and related activities. Ms. Peña holds a Master’s in Public Policy (M.P.P.) with an emphasis on health policy from the University of California, Berkeley and a Bachelor’s Arts (B.A.) in Communication & Journalism from the University of Southern California.

## EXECUTIVE SUMMARY

The purpose of this brief is to provide the Committee Members of the Senate Select Committee on Children with Special Needs with an overview of California’s state-administered public agencies and programs providing care and services to eligible children and youth with special needs from birth up to age 21. This brief is also meant to offer supplemental background information to pair with the Select Committee’s first informational hearing entitled “Mapping the Current System of Care and Funding for Children and Youth with Special Needs in the State of California” held on December 1, 2015.

The Senate Select Committee on Children with Special Needs, chaired by Senator Dr. Richard Pan, was established in Fall 2015 for the purpose of increasing understanding of how programs and services for children and youth with special needs are implemented and delivered in the State, and to identify ways to strengthen and integrate systems of care for children, youth and their families. The Select Committee will focus primarily on four systems of care— physical health, mental health, developmental disability care and education—for children and youth with special needs residing in the State.

Organized by system, each overview provides a summary of the public programs and services available to eligible children and youth with special needs residing in California, including the administering agency, services provided, eligibility for services, and funding mechanisms to support programs and services. When applicable, a brief description of the legislative history is also provided.

The scope of this brief is limited to public programs and services and does not explore care and services provided through privately funded entities including private health insurance, private facilities, or private education schools.

## INTRODUCTION

For children and youth with special needs in California, systems of care can provide lifesaving and transformative support and services to help them grow up healthy and nurtured. Systems of care provide a framework—anchoring state, county, and local agencies, public and private organizations, service providers, and families around common goals—to support children and youth with care and services to ensure they thrive in their home, school, community and throughout their life.

However, California’s principal systems of care—physical health, mental health, developmental disability care, and education—for children and youth with special needs are complex and often multi-layered and intertwined, leaving these children and their families at risk for missed opportunities and diminished or even adverse outcomes. Furthermore, independent of the system of care, programs and services are also multifaceted; entailing specific eligibility criteria tied to age, medical condition, residency, and financial income; are managed and delivered by various departments, agencies and organizations; and are sustained by distinct funding sources and budgets.

The purpose of this brief is to provide the Committee Members of the Senate Select Committee on Children with Special Needs with an overview of California’s four systems of care—physical health, mental health, developmental disability care, and education—and synopsis of the various state-administered public agencies and programs providing services to eligible children and youth with special needs from birth to 21 years old.

Each overview provides a brief summary of public programs and services provided throughout California, including the administering agency, services provided, eligibility for services, and funding mechanisms to support programs and services. When applicable, a brief description of the legislative history is provided.

### **SENATE SELECT COMMITTEE ON CHILDREN WITH SPECIAL NEEDS**

The Senate Select Committee on Children with Special Needs, chaired by Senator Dr. Richard Pan, was established in the Fall of 2015 for the purpose of increasing understanding of how programs and services for children and youth with special needs are implemented and delivered in the State, and to identify ways to strengthen and integrate systems of care to benefit children, youth and their families.

The Select Committee has bipartisan support and is comprised of the following members: Senator Dr. Richard Pan; Senator Jean Fuller; Senator Ted Gaines; Senator Jerry Hill; Senator Ben Hueso; Senator Carol Liu; and Senator Holly J Mitchell.

The Select Committee has interest in exploring a breadth of topics and issues impacting children and youth with special needs across four key systems of care—including physical health, mental health, developmental disability, and education. Historically, the definition used by the Health Resources and Services Administration’s Maternal and Child Health Bureau (MCHB) is applied to describe children with special needs 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;” however the Select Committee has selected to expand upon this definition to ensure all children and youth with specialty needs requiring distinct care and services are included for consideration.<sup>1</sup>

## **SYSTEMS OF CARE: PHYSICAL HEALTH FOR CHILDREN AND YOUTH WITH SPECIAL NEEDS**

### **OVERVIEW**

In California, several departments administer health programs throughout the state including the California Department of Care and Services (DHCS), the California Department of Public Health (CDPH), the Managed Risk Medical Insurance Board (MRMIB), the Department of Developmental Services (DDS) and the Department of State Hospitals (DSH).<sup>2</sup>

The California Department of Health Care Services (DHCS) is the primary state agency responsible for the provision of health care and services, including medical, dental, mental health, substance use treatment services, and long-term care for infants, children, youth, adults, and aging populations throughout the State. Eligibility for these publicly supported programs generally is tied to measures of family income.

The DHCS Children Medical Service Branch (CMS) oversees numerous programs and services in partnership with state agencies, county health departments, and hospitals to provide health care and services to children and youth throughout California. The vast majority of health services are delivered at the local community level by county and local government agencies; including county departments of health and through contract by private entities such as commercial managed care plans.

The CMS Branch is responsible for administering three major statewide programs for low-income and seriously ill children; the California Children's Services (CCS), which also includes the Medical Therapy Program (MTP); the Child Health and Disability Prevention (CHDP) program, which also includes the Health Care Program for Children in Foster Care (HCPCFC); and the Genetically Handicapped Persons Program (GHPP). The CMS Branch is also responsible for implementation, monitoring, and oversight of the Newborn Hearing Screening Program (NHSP) and special grants to serve children with special needs, such as the High Risk Infant Follow-Up (HRIF) program and the Pediatric Palliative Care (PCC) program.<sup>3</sup>

### **FUNDING**

DHCS is primarily supported by a combination of federal funds, state funds allocated from the State General Fund, and county funds.

Total expenditures estimated for DHCS for the FY2014-15 are expected to reach \$88.3 billion. Of the total budget for FY2014-15, an estimated \$575.5 million funds state operations, while an estimated \$87.8 billion supports local assistance.<sup>4</sup>

DHCS received approximately \$18.1 billion (20.5%) from the State General Funds, approximately \$56.1 billion (63.5%) from federal funds, and approximately \$14 billion (15.8%) from special funds and reimbursements for FY2014-15.<sup>4</sup>

DHCS receives federal funding through the following grants: Title V Maternal Child Health (MCH) Block grant; Title XIX—California Bridge to Reform Demonstration, also referred to as the Safety Net Care Pool (SNCP); and Title XXI of the Social Security Act.

### *Title V Maternal Child Health (MCH) Block Grant*

The Title V Maternal Child Health (MCH) Block grant is allocated to fund services for the following populations; pregnant women, infants under 1 years old, children between age 1 years old to 22 years old, children with special health care needs (CSHCN), and others. States receiving Title V MCH funding must match every \$4 dollars of Title V MCH money granted with at least \$3 dollars of state and/or local funds.<sup>5</sup>

Furthermore, at least 30% of Title V MCH funding provided to the State must be used for children’s preventive and primary care services with an emphasis on promoting family-centered, community-based and coordinated care. An additional 30% of Title V MCH funds must be allocated to provide services specifically for CSHCN which also promote family-centered, community-based and coordinated care.<sup>6</sup>

The proposed estimated allocation of Title V MCH funds for California for FY2014-15 is \$35.3 million. Approximately \$11.1 million (31.56%) of the total Title V MCH federal allocation must be designated for preventive and primary services for pregnant women, mothers and infants; approximately \$11.5 million (32.64%) must be used for preventive and primary services for children; and approximately \$11.5 million (32.64%) must support services for CSHCN for FY2014-15. The remaining 1.8 million (5.16%) is designated for Administration.<sup>6</sup>

California must match a minimum of \$26.5 million in state funds for Title V MCH-supported programs and services during FY2014-2015.<sup>6</sup>

### *Title XXI of the Social Security Act*

In 1997, Title XXI of the Social Security Act created the Children’s Health Insurance Program to help states provide health insurance coverage for low-income children who are ineligible for the Medicaid program—known as Medi-Cal in the State of California— and are unable to afford private insurance. For every \$2 dollars of Title XXI funds California receives, the state must with \$1 dollar of state or local funds.<sup>5</sup>

### *Title XIX—Medicaid Section 1115 Waiver: California Bridge to Reform Demonstration (Safety Net Care Pool- SNCP)*

Under Title XIX—Medicaid Section 1115 waiver, also referred to as the Safety Net Care Pool (SNCP), California may claim up to \$400 million annually in federal matching funds for nine specific health programs. Programs funded by Title XIX that directly benefit children and youth with special needs include the non-Medi-Cal component of California Children’s Services, also referred to as “CCS State-

Only” or “straight CCS;” the Genetically Handicapped Persons Program (GHPP) administered by DHCS; County Mental Health Programs; and the Community Service Program administered by the Department of Developmental Services (DDS).<sup>5</sup>

Additional health programs supported through Title XIX include Medically Indigent Adults/Long Term Car Program; Expanded Access to Primary Care; AIDS Drug Assistance Programs (ADAP); Breast and Cervical Cancer Treatment Program; and Workforce Development Programs.<sup>5</sup>

## **DHCS-ADMINSTERED PROGRAMS**

### **CALIFORNIA CHILDREN’S SERVICES (CCS) PROGRAM**

Established in 1927, the California Children’s Services (CSS) program is one of the oldest public health care programs in the nation. CCS is a statewide program that provides diagnostic and treatment services, medical case management, physical and occupational therapy, and authorized medical equipment to children and youth under the age of 21 years old with severe qualifying medical conditions.<sup>7</sup>

The CCS program is largely responsible for identifying chronic or debilitating conditions through diagnostic services and programs; providing care, treatment and equipment services through case management; providing rehabilitation services through the Medical Therapy Program (MTP); and developing and enforcing quality assurance standards for specialty care centers and hospitals for children with complex conditions.

Between 180,000 to 185,000 children and youth throughout California are served by the CCS general program and receive case management services. Approximately 23,000 children and youth have accessed services through CCS MTP, and countless children are served at CCS-approved facilities that include hospitals, NICUs and Special Care Centers.<sup>8</sup>

The California Department of Health Care Services (DHCS) Children’s Medical Services (CMS) Branch administers the CCS program in partnership with 58 county health departments. In most counties, county administrators perform all case management activities for eligible resident children and youth, including evaluation, linkage to specific services and appropriate providers, and authorizing medically necessary care. For counties with populations under 2,000, also referred to as “dependent counties,” the CCS Systems of Care Division provides medical case management and eligibility and benefits determination through three CSS State Regional Offices located in Sacramento, San Francisco, and Los Angeles.<sup>2</sup>

#### Eligibility

Qualifying CCS medical conditions are generally categorized as chronic, catastrophic, congenital or disabling and include, but are not limited to, medical conditions such as cystic fibrosis, hemophilia, cerebral palsy, heart disease, cancer, infectious disease, and major traumatic injuries.

Eligibility for the CCS program is dependent on which services are being delivered. For example, to qualify for CSS case management a child must be under 21 years of age, reside in a California county, have a qualifying CCS medical condition, and must meet certain financial conditions. Financial eligibility

includes children and youth who are currently enrolled in Medi-Cal; are uninsured or underinsured and whose family's annual adjusted gross income is under \$40,000; or where necessary ongoing medical care would result in financial hardship, which is calculated as exceeding 20% of the family's annual adjusted gross income.<sup>7</sup>

Eligibility for CSS diagnostic services, including those provided through the High Risk Infant Follow-Up program (HRIF), is not dependent on financial status; however, a child or youth must meet age requirements, have a qualifying CCS-medical condition identified through a screening program or have a high likelihood of presenting a CCS medical condition, and reside in a California county. Similarly, eligibility for CSS services provided by MTP is not based on a financial threshold; however, children must meet the age and residency requirement, and have a qualifying physically debilitating condition.

Approximately 70% of CCS enrollees are eligible for the program because they qualify for full-coverage Medi-Cal; all CCS services are reimbursed by Medi-Cal. The remaining 30% of children are identified as "straight CCS" and include children and youth who are uninsured or underinsured, have partial Medi-Cal coverage, or have private insurance. Care for "straight-CCS" enrollees is financed equally with State and county funds.

### Funding

The CCS program is funded by a combination of federal, state and county funds, as well as by a small portion generated through enrollment and assessment fees paid by participating families. Funding is allocated to pay for services, provide care management, including care coordination, and for administration.

The CCS program receives federal funding from the Title V MCH Block grant; Title XIX—California Bridge to Reform Demonstration—also referred to as the Safety Net Care Pool (SNCP); and Title XXI of the Social Security Act.

The CCS general program received approximately 49.91% of funding from federal grants, approximately 46.34% from state funds and the remaining 3.75% from county funds.

The CCS general program is estimated to reach \$2.8 billion based on expenditures for FY2014-15, while CCS MTP is estimated to reach \$125 million. Of the total CCS budget, 92% of the resources are paid directly to patient care service providers.<sup>6</sup>

Funding is tied to the population served within CCS. For example, services and case management for CCS Medi-Cal eligible children are funded by a combination of State General Funds (50%) and Title XIX (50%) Federal Financial Participation (FFP) funds.

Whereas, funding for the CCS State-Only portion of the program— those children identified as having "straight CCS"— is composed of 50% county funds and 50% State General Fund. Furthermore, the CCS MTP is also divided equally between State and county funding.<sup>9</sup>

### ***CCS Medical Therapy Program (MTP)***

A specialty program within CCS, the Medical Therapy Program (MTP) provides physical therapy (PT), occupational therapy (OT) and medical therapy conference (MTC) services to children and youth (birth to 21 years) who have qualifying disability conditions, generally due to neurological or musculoskeletal disorders.

All MTP services are provided free to families whose children and youth have a medically eligible condition or disease, regardless of family income. Qualifying conditions that meet both CCS and CCS MTP eligibility include, but are not limited to, cerebral palsy, spina bifida, muscular dystrophy, rheumatoid arthritis, and spinal cord injuries and head injuries.<sup>10</sup>

MTP provides interdisciplinary coordination and medical case management for services including PT and OT, and makes recommendations for specialized equipment such as orthotics/braces, wheelchairs and other assistive devices. When requested, MTP staff also consults with schools to support school staff to address a student's therapy needs; they also can participate in the development of a student's Individual Education Plans (IEP).<sup>10</sup>

PT and OT promote independence by providing support to meet a child's mobility and ambulation needs and address self-help skills including personal care and home skills.<sup>11</sup>

### ***Funding***

CCS MTP is funded by State and county funding sources. CCS MTP received approximately \$57.0 million from the State General Fund and \$57.8 million from CCS-State Only county funds for FY2014-15 totaling approximately \$114.9 million for FY2014-15. CCS MTP does not receive funding from federal grants directly.<sup>12</sup>

### ***CCS High Risk Infant Follow-Up (HRIF) Program***

Within CCS, the High Risk Infant Follow-Up (HRIF) program functions as a transitional safety net to identify infants and children from birth up to 3 years of age who might develop CCS-eligible medical conditions after discharge from a CCS-approved Neonatal Intensive Care Unit (NICU).<sup>13</sup>

Currently, there are 120 CCS-approved NICUs throughout the State. The CCS program requires each CCS-approved NICU to provide follow-up services and screenings to discharged high-risk infants and children, and also requires that each NICU have a collaboration system or written agreement for provisions of these services by another CCS-approved NICU.<sup>14</sup>

Access to the HRIF program is limited to those infants who meet medical eligibility for NICU care or had a CCS eligible medical condition during their stay in a CCS-approved NICU, regardless of whether they were enrolled in the CCS program.

The HRIF program serves as a diagnostic service, and financial eligibility is not required at the time of referral to CCS. Medical eligibility for the HRIF program is determined by the county or regional CCS program.

Reimbursable diagnostic services include; comprehensive history and physical examination with neurologic assessment; developmental assessment; family psychosocial assessment; ophthalmologic assessment; and coordination of services. Care coordination can include assisting families in accessing care and interventions and linkage to other agencies and services.

Furthermore, HRIF programs are also considered outpatient CSS Special Care Centers (SCC) and allowed to bill for a limited range of SCC diagnostic services. There are a total of 780 Special Care Centers throughout California.

The HRIF program remains 100% supported through Title V MCH funding.<sup>15</sup>

## **CHILD HEALTH AND DISABILITY PREVENTION PROGRAM (CHDP)**

Child Health and Disability Prevention (CHDP), established in 1973, is a statewide program providing comprehensive health assessments for the early detection and prevention of disease and disability in infants, children and youth.

CHDP is administered by the CMS Branch Systems of Care Division and is operated at the county level by county health departments.<sup>16</sup>

Assessments are provided periodically or if a child presents a condition requiring evaluation. Assessments include documentation of health history, physical examination, developmental assessment, nutritional assessment, dental assessment, vision and hearing screenings, a tuberculin test, laboratory tests, immunizations, and health education.

The CHDP program also assists families with linkage to diagnostic and treatment services for medical, dental and mental health conditions identified during the health assessment. The CHDP program also partners with schools districts and schools to ensure that students have a completed health assessment 18 months before or up to 90 days after enrolling in first grade.<sup>17</sup>

### Eligibility

All Medi-Cal recipients from birth to age 21 are eligible for CHDP scheduled periodic health assessments and services based on the federally mandated Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program. CHDP services are also provided temporarily through “CHDP Gateway” to non-Medi-Cal children and youth from birth to age 19 whose family income is equal to or less than 200 percent of the federal income guidelines and are uninsured or underinsured.<sup>18</sup> Since July 1, 2003, “CHDP Gateway” automatically pre-enrolls children and youth into CHDP services at the time the patient visits a CHDP provider’s office and is considered eligible for Medi-Cal while eligibility is assessed.<sup>14</sup>

## Funding

Funding for CHDP, including for health assessments, services and administrative duties, is also tied to the population served within the program.

For low-income children from birth to age 19, who are not Medi-Cal eligible and below the poverty level, funding for CHDP services—including non-Medi-Cal health assessments and administrative duties—is primarily provided by the State General Fund, with a small portion of funding deriving from the Childhood Lead Poisoning Prevention Fund, also known as State Special Funds.<sup>5</sup> The non-Medi-Cal component of the CHDP program does not receive funding from federal grants.

For FY2014-15 CHDP received approximately \$1.4 million from state funds for non-Medi-Cal health assessments and approximately \$244,000 from state funds for non-Medi-Cal county administrative services, including to fund care coordination.<sup>19</sup>

Since CHDP also provides Medi-Cal fee-for-service health assessments as an EPSDT benefit for children and youth from birth to age 21, each local CHDP program is also authorized to claim Title XIX federal funds to match local funds to deliver EPSDT services provided by CHDP and perform EPSDT-related administrative duties.<sup>19</sup>

CHDP received an estimated \$19.8 million from Title XIX (approximately 50%) and an estimated \$19.5 million from the State General Fund (approximately 50%) to fund Medi-Cal EPSDT health assessments—totaling approximately \$39.3 million for FY2014-15.<sup>19</sup>

CHDP also received federal and state funding to support CHDP administrative duties related to Medi-Cal EPSDT services. For FY 2014-15, CHDP received an estimated \$21.8 million from Title XIX and an estimated \$11.8 million from the State General Fund for a sum of approximately \$33.7 million to support county administration for Medi-Cal EPSDT services.<sup>19</sup>

## CHDP and SB75 Medi-Cal Expansion for Undocumented Children

Senate Bill 75, signed into law by Governor Brown in June 2015, mandates the expansion of full-scope Medi-Cal benefits to children under the age of 19 regardless of immigration status effective May 1, 2016. Prior to the passage of SB75, children under the age of 19 who were ineligible for Medi-Cal either because of income and or immigration status were eligible to access medical care and services through the CCS State-Only and CHDP programs. Now that this population will be shifting to full-scope Medi-Cal benefits, CDCS is proposing to sunset the income and age eligibility for the CHDP State-Only program and instead maintain the CHDP Medi-Cal component of the program.<sup>20</sup>

### ***Health Care Programs for Children in Foster Care (HCPCFC)***

County CHDP programs are also responsible for administering Health Care Programs for Children in Foster Care (HCPCFC) in collaboration with county child welfare service agencies and probation departments. HCPCFC is a public health program, which utilizes public health nurses to provide care oversight of the medical, dental, mental and developmental disability needs of children and youth in foster care.

Public health nurses act as a consultant and liaison to social workers, case workers and probation officers to provide medical and health care case planning, linkage to comprehensive health assessments and dental care, coordination of health services for children in out-of-county and out-of-state placements, and medical education and training for foster care team members.<sup>21</sup>

Assembly Bill 1111 approved in 1999 enabled California Department of Social Services (CDSS) to appropriate State General Funds for the purpose of funding the public health nurses in meeting the health care needs of children in foster care.<sup>21</sup>

Funding for HCPCFC is split between federal Medi-Cal Title XIX funds and by State General Funds. For FY2014-15, HCPCFC was allocated a total of \$33.3 million for the HCPCFC program; an estimated \$25.1 million came from federal funds and an estimated \$8.1 million from state funds.<sup>22</sup>

### ***California Newborn Hearing Screening Program (NHSP)***

The California Newborn Hearing Screening Program (NHSP) is a statewide program to identify hearing loss in infants and provide linkage to services to develop communication skills. All hospitals with licensed perinatal services are certified and participating in the NHSP.<sup>6</sup>

DHCS also contracts with three regional Hearing Coordination Centers to develop hearing screening programs in collaboration with hospitals, perform quality assurance activities, and follow and monitor infants who need additional services.<sup>23</sup>

Infants with hearing loss identified through the NHSP are referred to the Early Start program, administered in collaboration between DHCS CMS and the California Department of Education (CDE).

Funding for NHSP is provided by a combination of state (50%) funds and federal funds (50%). The Title V MCH grant also supports services for early identification and interventions of hearing loss.<sup>6</sup> In addition, hearing screenings and follow-up services for hearing loss are also a benefit of Medi-Cal.

Approximately \$4.1 million was allocated to NHSP for contracted data management system and infant tracking and monitoring operations. DHCS was unable to provide the Select Committee with data for paid screening claims for FY2014-15.

### ***Hearing Conservation Program (HCP)***

The Hearing Conservation Program (HCP) is a statewide program administered by DHCS CMS and the California Department of Education (CDE) that provides comprehensive screening to identify hearing loss in preschoolers to age 21 in public schools, CHDP programs, and other state-supported program.<sup>24</sup>

CDE and public schools are responsible for providing hearing screenings at public schools.

DHCS provides a full-time equivalent position, at an annual cost of \$120,000, to oversee the program including but not limited to certification of school audiometrists, maintain a list of approved and registered contracting agencies to provide hearing screening services to schools, reviewing and approving school waiver requests, collecting school hearing screening data, and providing consultation and technical assistance to schools upon request.<sup>24</sup>

### **GENETICALLY HANDICAPPED PERSONS PROGRAM (GHPP)**

The Genetically Handicapped Persons Program (GHPP), established in 1975 is a statewide health care program for adults with qualifying genetic diseases; however, children and youth under 21 years of age are eligible if the family demonstrates that they have first applied to CCS and received a financial eligibility denial from CCS, and also submits proof showing out-of-pocket expenses are more than 20% of family income. Some applicants may also be required to pay an enrollment fee based on income and family size.<sup>25</sup>

GHPP is based on medical need and provides case management and coverage for approved services such as home health services, mental health, therapy services including physical therapy (PT), occupational therapy (OT) and speech therapy, and medical supplies.<sup>26</sup>

GHPP-eligible medical conditions include cystic fibrosis; disease of the blood such as hemophilia and sickle cell; disease of the brain and nerves such as Huntington's disease; disease of protein metabolism; disease of copper metabolism; and Von Hippel-Lindau disease (VHL).

The Governor's 2015-2016 budget proposed modifications to the GHPP application and eligibility process. Individuals are required to first apply to Medi-Cal and subsidized coverage through Covered California. If those individuals are found eligible for either program, they are required to enroll in those programs and receive only those specialized services in GHPP that would not otherwise be provided through Medi-Cal or their qualified health plan.<sup>27</sup>

Funding for GHPP is tied to the population served within the program. GHPP is funded through a combination of funds from the State General Fund, federal Title XIX, Rebate Special Funds, and a small portion from enrollment fees.

For FY2015-16, approximately \$128.5 million was allocated to GHPP for the State-Only, non-Medi-Cal component of the program. The program received an estimated \$112.3 million from the State General Fund, an estimated \$4.2 million from Title XIX and an estimated \$20.0 million from the Rebates Special Fund. GHPP also received a small portion of funding from enrollment fees from beneficiaries equating to approximately \$436,000.<sup>20</sup>

GHPP services provided to Medi-Cal beneficiaries are not differentiated in the Medi-Cal estimate.<sup>20</sup>

## **SPECIAL GRANT AND PILOT PROGRAMS**

### ***Pediatric Palliative Care Waiver (PCC) Program***

In 2006, California passed the Nick Snow Children's Hospice and Palliative Care Act, Assembly Bill 1745, which permitted DHCS to develop a pediatric palliative care pilot program for children eligible for full-scope Medi-Cal through federal funding provided by the Center for Medicare & Medicaid Services (CMS) §1915(c) Waiver option.<sup>28</sup>

The Pediatric Palliative Care Waiver Program (PCC) provides home-based palliative care and hospice-like services delivered by the Coalition for Compassionate Care of California and the Children's Hospice & Palliative Care Coalition. These services are provided concurrently with curative care to children and youth under 21 years of age with life-limiting or life-threatening conditions. Along with improving the quality of life for these children, the program's goals include minimizing hospitalization by allowing access to in-home palliative care and reducing long-term costs.

To be eligible for pediatric palliative services, the child or youth must be in a participating county, be under the age of 21, be eligible for full-scope Medi-Cal, have an eligible medical condition, and meet the level-of care requirement.<sup>29</sup>

To date, the PCC program is only available in 10 participating counties in California; including Fresno County, Los Angeles County, Marin County, Monterey County, Orange County, San Francisco County, Santa Clara County, Santa Cruz County, Sonoma County and Ventura, which recently implemented the program in January 2016.<sup>30</sup>

PCC services include care coordination between care services in home, clinic, school and other settings; family training and education on palliative care; respite in-home and out of home; expressive therapies such as creative art, music and massage therapy; pain and system management; and family bereavement counseling.<sup>31</sup>

The Governor's Budget for DHCS FY2015-2016 proposed expanding the program to seven additional counties. Counties expected to implement the Pediatric Palliative Care Waiver program include San Diego, Alameda, Contra Costa, San Mateo, Madera, Riverside and San Bernardino.<sup>27</sup>

### ***Neonatal Quality Improvement Initiative (NQI)***

Implemented in September 2006, the Neonatal Quality Improvement Initiative (NQI) is a statewide initiative jointly sponsored by CMS Branch and California Children's Hospital Association (CCHA), established for the purpose of reducing and or eliminating catheter associated bloodstream infections and other hospital acquired infections in CCS-approved NICU throughout California.<sup>32</sup>

The HRIF program is funded entirely through Title V MCH funding and received an estimated \$436,229 for FY2014-15.<sup>15</sup>

## **SYSTEMS OF CARE: MENTAL HEALTH FOR CHILDREN AND YOUTH WITH SPECIAL NEEDS**

### **OVERVIEW**

A number of state departments including Department of Health Care Services (DHCS), Department of Social Services (DSS), Department of Developmental Services (DDS) and the Department of Education (CDE) receive funding from the Mental Health Service Act (MHSA) to administer and incorporate—often in collaboration with local mental health departments— mental health services into existing and new programs at the community level.

Across California, county mental health departments, also referred to as Mental Health Plans (MHP), are largely responsible for designing, planning, delivering and monitoring public mental health services for children and youth at the community level.

### **MENTAL HEALTH SERVICE ACT (MHSA)**

The passage of the Mental Health Services Act (MHSA), also known as Prop 63, by voters in 2004 restructured the funding and delivery of public mental health services and programs throughout the State by authorizing the California State Department of Mental Health (DMH) to contract with county mental health departments to provide community mental health services that focus on prevention, early intervention and treatment for children, transition-age youth, adults, seniors and families. In 2012, authorizing responsibility and oversight was shifted from DMH to the Mental Health Services Oversight and Accountability Commission (MHSOAC).<sup>33</sup>

MHSA's intent is to define and recognize serious mental illness in children, youth and adults; expand community mental health services, including innovative and successful programs, to meet the needs of underserved populations; and reduce long-term adverse impact on individuals, families, and communities from untreated serious mental health illness. Furthermore, MHSA's aim is to also improve state and local funding to provide mental health services to underserved populations that may not be covered by individual or family insurance programs.<sup>34</sup>

To receive MHSA funding, counties must develop a Three-Year Program and Expenditure Plan addressing five key program components and receive approval for the plan from the MHSOAC.

The five essential program components include: Community Services and Supports (CSS), which includes children and youth; Prevention and Early Intervention (PEI); Workforce Education and Training (WET); Capital Facilities and Technological Needs (CF/TN); and Innovation program (INN).<sup>35</sup> To date, WET and CF/TN funds are no longer available to counties, however counties may transfer CSS funds to WET, CF/TN and prudent reserve. In any given year after 2007-2008, a county may transfer no more than 20% of the average amount of total funds allocated to that county for the previous five years.<sup>36</sup>

## Funding

Funding for MHSAs is provided by enforcing a 1% income tax on personal income in excess of \$1 million.<sup>35</sup> Since MHSAs were enacted, over \$8 billion dollars in new resources for the public community mental health system have been generated.<sup>33</sup>

For FY2014-15, the State distributed an estimated \$1.7 billion from MHSAs to counties to deliver mental health programs and services.<sup>37</sup>

Counties are mandated to use 80% of county MHSAs funds on the CSS program component and allocate 5% from this sum to fund INN programs. Counties are required to use 20% of county MHSAs funds for the PEI program component and also allocate 5% from this sum to INN programs. In FY2014-15 approximately \$1.3 billion was allocated to CSS, excluding INN funding; approximately \$328.6 million was allocated to PEI, excluding INN funding; and approximately \$86.4 million was allocated to INN.<sup>38</sup>

In addition to funding community mental health services and programs led by county mental health departments, MHSAs funding is also provided to the Mental Health Services Oversight and Accountability Commission (MHSOC); the California Mental Health Planning Council (CMHPC)—to finance administrative duties in support of MHSAs programs; and 15 State Interagency Partners.<sup>39,40</sup>

The 15 State Interagency Partners include the following: Administrative Office of the Courts (AOC); California Community Colleges Chancellor Office (CCCC); California State Library (CSL); Department of Aging (CDA); Department of Consumer Affairs Regulatory Boards (DCA); Department of Alcohol and Drugs Programs (DADP); Department of Developmental Services (DDS); Department of Education (CDE); Department of Health Care Services (DHCS), Department of Military – California National Guards (CNG); Department of Rehabilitation (DOR); Department of Social Services (DSS); Department of Veterans Affairs (CDVA); Managed Risk Medical Insurance Board (MRMIB); Office of Statewide Health Planning & Development (OSHPD); and Office of Statewide Health Planning & Development.<sup>41</sup>

For example as a State Interagency Partner, DDS receives MHSAs funding for FY 2014-15 through 2016-17 to support mental health services and projects at selected Regional Centers, including providing novel and specialized services and support for transitional age youth with developmental disabilities and mental health illness.<sup>4</sup>

## Agency Oversight

The passage of the MHSAs also led to the establishment of the MHSOAC, a committee tasked with providing leadership, oversight, and accountability to various programs within MHSAs, including MHSAs programs and services for children and youth.<sup>42</sup> Following the elimination of the Department of Mental Health in FY 2012-13, MHSOAC remains the only State entity responsible for oversight of the community mental health system.

When MHSOAC was initiated, the committee was responsible for the implementation of MHSAs, including review and approval of county plans for PEI services; however, following the passage of AB100 in March 2011 and AB1467 in June 2012, MHSOAC's role shifted to include providing training

and technical assistance for county MHPs, approving county-led pilot programs and projects, and reviewing all county three-year plans, annual updates and annual Revenue and Expenditure Reports.<sup>43</sup>

### *MHSA Programs and Services for Children and Youth*

The passage of MHSA not only shifted the design and delivery of public mental health services to the county level, but also identified at-risk children and youth as a priority population deserving attention, including prevention and early intervention services and support. As with adult mental health services, children and youth mental health services—including services provided by pilot programs and projects—are provided at the local level by county mental health departments which then contract with state and local providers.

MHSA sought to strengthen collaboration with child welfare, juvenile justice, education and primary health care in an effort to provide children’s mental health services. Mental health services should be designed to be individualized and developed in partnership with the child and their families, with a focus on allowing children to live at home and continue to attend school.<sup>44</sup>

MHSA identifies Seriously Emotionally Disturbed (SED) children or adolescents as “minors under the age of 18 years old, who have a mental disorder as identified in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders, other than a primary substance use disorder or developmental disorder, which results in behavior inappropriate to the child's age according to expected developmental norms.”<sup>45</sup> Furthermore, children and youth with mental health needs must also meet additional listed criteria, such as having a mental disorder that impairs self-care, school functioning, family relationships or ability to function in the community; displaying risk of suicide or violence; or meets special education eligibility requirements.<sup>45</sup>

Amendments to MHSA in 2012 provided additional clarification to mental health services for children. Under the Welfare and Institutions Code (WIC), Article 11 Services for Children with Severe Mental Illness 5878.1-5878.3 services provided to severely mentally ill children must be accountable, developed in partnership with the youth and their families, be culturally competent and individualized to meet the needs of each child and his/her family. In addition, Article 11 requires county mental health programs to offer services to severely mentally ill children if mental health services provided by public or private insurance, publicly funded programs, or other mental health programs are inadequate or unavailable.<sup>46</sup>

## **MHSA PROGRAMS**

### **MHSA Community Services and Supports (CSS)**

One of five program components of MHSA, Community Services and Supports (CSS) is designed to provide mental health services to unserved and underserved children and youth with SED and adults with Severe Mental Illness (SMI). CSS programs and services are designed and implemented at the community level by county mental health departments, which contract with providers.

CSS programs and services aim to reduce homelessness, reduce involvement in justice and child welfare systems; reduce hospitalization and frequent emergency medical care; and reduce ethnic and regional service disparities. CSS services should aim to be individualized and family-driven to meet the needs of the child and or youth.<sup>47</sup>

SED is also defined by the California Welfare & Institutions Code Section 5600.3 as a diagnosable mental disorder identified in children under 18 years old age and is severe and long-lasting enough to seriously interfere with a child's function in family, school and community environments.<sup>48</sup>

CSS services are provided through four service categories: 1) Full Service Partnerships, 2) General System Development, 3) Outreach and Engagement, and 4) MHSA Housing Programs.

CSS is the largest component of MHSA and 80% of MSHA funding is allocated to CSS programs. The majority of CSS funds must be dedicated to Full Service Partnerships. Furthermore, Full Service Partnerships are funds used to provide “whatever it takes.”<sup>47</sup>

### **MHSA Prevention and Early Intervention (PEI)**

The Prevention and Early Intervention (PEI) component centers on strategies and services for underserved populations to reduce negative outcomes resulting from untreated mental illness, such as suicide, incarceration, school failure or dropout, unemployment, prolonged suffering, homelessness, and removal of children from their homes.<sup>49</sup>

While PEI programs focus on Californians of all ages, at-risk children, youth and young adult populations were identified by all counties as the most frequently addressed population.<sup>50</sup> Most county PEI programs utilized over half of PEI funds (51%) in 2012 on children, youth and young adults (newborn to 25 years old).<sup>51</sup> MHSA requires 20% of the Mental Health Service Fund allocated to counties be spent on PEI programs.

### **MHSA Innovation programs (INN)**

The INN component allows counties to test innovative and novel mental health programs and practices for a limited duration of time. INN programs should be designed to increase access of mental health services to underserved groups and the general population, increase the quality of services and promote interagency and community collaboration.<sup>52</sup>

INN pilot projects can be tailored to address the mental health needs of diverse populations including children, transition age youth, adults, aging adults, families (self-defined), neighborhoods, tribal and other communities, counties, multiple counties, or regions.<sup>53</sup>

## **MHSA Capital Facilities & Technological Needs (CF/TN)**

CF/TN funds are allocated to strengthen or replace existing technology, improve strategies and/or purchase community-based facilities that produce long-term benefits to the mental health system and aligns with the MHSA overall goals of promoting wellness, recovery, resiliency, cultural competence, prevention/early intervention, and expansion of opportunities for accessible community-based services for clients and their families and reduces disparities among underserved groups.<sup>53</sup>

Counties received \$453.4 million for CF/TN projects and have until FY 2017-18 to expend these funds.<sup>54</sup>

While CF/TN funds are not used for the provision of direct services, however children and youth may still benefit indirectly.

## **MHSA Workforce Education & Training (WET)**

WET funds are used to develop and grow a county's workforce.<sup>35</sup>

WET program goals include increasing the number of diverse, qualified individual in the public mental health system workforce; expanding the capacity of the incumbent public mental health workforce through education and training; and strengthen the state, regional and local public mental health workforce infrastructure.<sup>55</sup>

In 2008, MHSA WET programs were transferred from the California Department of Mental Health (DMH) to the OSHPD—which became responsible for administering WET programs and developing a second MHSA WET Five-Year Plan, covering the period of April 2014-April 2019.<sup>56</sup>

Currently, \$114 million remains available to fund statewide projects over the next four years. Counties received \$216 million for local WET programs and have through FY 2017-18 to expend these funds.

As with CFTN, WET funds are not used for the provision of direct services, however children and youth may still benefit indirectly.

## **CALIFORNIA WRAPAROUND SERVICES**

In 1997, Senate Bill 163 established Wraparound services providing comprehensive, family-centered services to children and families as an alternative to placing children in high-level group home care.<sup>57</sup> In 2001, following the end of the initial pilot program, Wraparound services for children became required in all California's counties, except when the county is able to provide substantial evidence that it is not feasible to establish a Wraparound program.<sup>58</sup>

To date, 45 of 58 California counties implement Wraparound services. Counties not currently implementing a Wraparound program include: Alpine, Amador, Calaveras, El Dorado, Kings, Madera, Modoc, San Benito, Sierra, Siskiyou, Trinity, and Tuolumne. Yuba County is actively planning a Wraparound program.<sup>59,60</sup>

DDS administers approval and funding for select counties to implement Wraparound services. DSS also provides training and technical assistance to counties for planning, implementing and administering Wraparound programs and services.

Counties are responsible for the design and implementation of Wraparound services and must develop and submit a three-year Wraparound Implementation Plan for approval from DSS and county providers and administrators are required attend state-approved Wraparound training programs.

Wraparound programs provide mental health services and support as an alternative to group home care to children and youth. Wraparound services utilize the Core Practice Model (CPM), a practice that promotes intensive, individualized services and support to families to foster a safe, stable and permanent family environment that allows children and youth to thrive in their home and community.<sup>60</sup>

The Core Practice Model (CPM) is a standards of practice that emphasizes an integrated approach to working with children, youth and families who have or may have mental health needs. CPM provides a framework for all child welfare and mental health agencies, service providers and community/tribal partners working with youth and families.

### Eligibility

Children and youth are eligible for Wraparound services in select counties if they are dependents or probation wards of the court *and* placed in or at imminent risk of placement in group homes (RCL 10-14); children eligible for AB 3632 services through the education system; or adopted children who receive Adoption Assistance Program Benefits.<sup>61</sup>

It's important to note that counties have flexibility to develop additional criteria and eligibility that may be influenced by other funding sources.

### Funding

SB 163 authorizes counties to use state and county Aid to Families with Dependent Children-Foster Care (AFDC-FC) funding for Wraparound service delivery and planning.<sup>62</sup> In addition, DSS mandates that all counties implementing Wraparound Services reinvest any cost savings into further expansion or enhancement of services and resource for children and families.<sup>63</sup>

California also receives some federal funding for Wraparound services in select counties through Title IV-E, also referred to as Child Welfare Waiver Demonstration Projects, which provides states funds to test innovation approaches to deliver child welfare services.

In California, Title IV-E funds the California Well-Being Project which focuses on strengthening services and approaches for children and youth from birth to age 17, who currently are in out-of-home placement or who are at risk of entering or re-entering foster care.<sup>64</sup>

In September 2014, California Well-Being Project was approved for a five-year extension and expansion to deliver prevention and family-centered services in Butte, Lake, Sacramento, San Diego, San Francisco, Santa Clara and Sonoma counties until 2019.

Prevention services under with Project include Wraparound services which focus specifically on probation youth exhibiting delinquency risk factors and at risk for entering foster care.

Furthermore, since the Wraparound model is similar to the MHSA Full Service Partnerships service model— in that services provided must be client and family-centered, culturally competent, strength-based, and integrated and coordinated across multiple agencies, programs and funding sources— some counties also use MHSA CSS Full Service Partnerships funds to support a local Wraparound program, while other counties select to use non-MHSA funding sources.

### **MEDI-CAL: MENTAL HEALTH SERVICES FOR CHILDREN**

Administered by DHCS, Medi-Cal provides free and low-cost health coverage and services to low-income adults, families with children, seniors, persons with disabilities, children in foster care, former foster youth up to the age of 26, and pregnant women.<sup>65</sup>

In 2011, following the passage of AB102, the Medi-Cal Specialty Mental Health Services (SMHS) program, which provides mental health services for both children and adults, was transferred from the DMH to DHCS.<sup>66</sup> The general SMHS program is “carved-out” of the broader Medi-Cal program and DHCS contracts with each county’s MHP to deliver mental health services.<sup>67</sup>

SMHS services for children and youth are provided under the federal requirements of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit, which is available to full-scope beneficiaries under age 21.<sup>68</sup>

#### *Early and Periodic Screening, Diagnosis and Treatment (EPSDT)*

Enacted in 1967, the EPSDT component of Medi-Cal provides children and youth under the age of 21 with physical, mental, developmental, dental, hearing, vision and other medical screenings and diagnostic services and appropriate treatment starting at birth and offered in periodic, age-appropriate intervals throughout a child’s life and when a risk is identified.<sup>68</sup>

Federal law mandates that Medi-Cal provide a comprehensive set of benefits and services for children and must include any “necessary health care, diagnostic services, treatment, and other measures” as defined in Section 1905(a) of the Social Security Act which are needed to “correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services.”<sup>69</sup>

## MEDI-CAL MENTAL HEALTH PROGRAMS

### Specialty Mental Health Services (SMHS) for Children and Youth

Children’s Specialty Mental Health Services (SMHS) are a federal requirement of the EPSDT benefit and designed to meet the special physical, emotional and developmental needs of low-income children and youth under the age of 21.<sup>70</sup> Upon waiver approval by the Centers for Medicare and Medicaid Services (CMS), the DHCS administers SMHS through contracting with county health departments.<sup>71</sup>

Children’s SMHS includes the following services: crisis intervention; crisis stabilization; day rehabilitation; day treatment intensive; intensive care coordination; intensive home-based services, medication support; psychiatric health facility services; psychiatric inpatient hospital services; targeted case management; therapeutic behavioral services; and therapy and other services.<sup>71</sup>

Youth between the ages of 18 and 21 are also eligible to receive additional SMHS services including adult crises residential services; adult residential treatment services; intensive care coordination and intensive home-based services. In addition, children and youth up to 21 who are considered a member of the Katie A. Subclass are also eligible to receive intensive care coordination (ICC), intensive home-based services (IHBS) and Therapeutic Foster Care (TFC) facilitated through the Core Practice Model (CPM).

### Funding

FY2014-15, accrual forecast of approved claims for SMHS for children between birth to 17 years old was estimated to reach a total of \$1.6 billion. Approximately \$816 million (51%) derived from federal funds and approximately \$782 million (49%) came from county funds.

For youth between age 18-20, the FY2014-15 accrual forecast of approved claims for SMHS is estimated to total \$150.9 million. As with children, federal funds attributed to 51% of funding, expected to reach \$77.1 million, and county funds attributed to 49% of funding, expected to reach \$73.8 million.

County funds may include funds distributed from the Mental Health Services Fund, the Local Revenue Fund, the Local Revenue Fund 2011, and county general funds.

### **SMHS— KATIE A. SUBCLASS ELIGIBLE**

The class action lawsuit *Katie A. v Bonta*, filed in Federal District Court in 2002, challenged the availability of intensive mental health services provided by state and county agencies to children and youth who were either in the foster care system or at risk of removal from their families.<sup>72</sup> In December 2011 a settlement agreement was reached requiring California to provide children and youth considered to be a member of the Katie A. Subclass with “medically necessary mental health services in their own home, a family setting, or the most homelike setting appropriate to their needs, in order to facilitate reunification and to meet their needs for safety, permanence and well-being.”<sup>73</sup>

Children and youth up to 21 are considered a member of Katie A. Subclass and eligible for ICC, IHBS, and TFC in addition to children’s SMHS services, if they are full-scope Medi-Cal eligible, have an open

child welfare services case, and meet the medical necessity criteria for SMHS as set forth in CCR, Title 9, Section 1830.205 or Section 1830.210 *and* are currently in or eligible for Wraparound services, TFC, specialized care due to behavioral health need or other intensive EPSDT services, a group home (RCL 10 or above), a psychiatric hospital or a 24-hour mental health treatment facility.<sup>73</sup>

The Katie A. settlement also requires DSS and DHCS collaborate with the joint management taskforce to develop and approve training curriculum and protocols, as well as develop quality control systems to support service integration and/or coordination of mental health services facilitated through CPM.

Funding for FY2014-2015 is estimated based on forecast of approved claims to reach approximately \$53.5 million for Katie A. Subclass mental health services. State and county split funding evenly 50-50.<sup>74</sup>

### *Intensive Care Coordination (ICC)*

Intensive Care Coordination (ICC) provides targeted case management (TCM) to facilitate in assessment, care planning, coordination of services, monitoring and adapting, and transition through the assignment of an ICC coordinator. Services include supporting the delivery of medically necessary services; collaborating between the child/youth, family and child-serving systems; parent/caregiver support to meet the needs of the child; and organizing community-located care across providers and child-serving systems of care.<sup>73</sup>

ICC is reimbursed at the same rates as targeted case management (TCM)

### *Intensive Home Based Services (IHBS)*

Intensive home-based services (IHBS) are mental health rehabilitation services that are individualized, strength-based interventions developed to ameliorate mental health conditions that hinder a child or youth's function. IHBS services are developed to help children and youth build skills to successfully function in the home and community and also improve the family's ability to support their child or youth in the home and community. Services include but are not limited to medically necessary skill-based interventions; development of functional skills to improve self-care and self-regulation; education to child/youth and or family to manage mental health disorder or symptoms; and vocational support. IHBS may be provided as part of a California Wraparound process.<sup>75</sup>

IHBS is reimbursed at the same rates as mental health services.

### *Therapeutic Foster Care (TFC)*

Therapeutic Foster Care (TFC) provides individualized interventions delivered in foster family-based settings in which 1 or 2 children live with and are supervised by specially trained foster parents and supported by a team of professional and paraprofessional services providers. TFC aims to stabilize or ameliorate the youth's behavioral and or emotional disorder, and address unmet needs that present challenges. Furthermore, TFC simultaneously prepares the permanent caregiver to provide for the child in his/her home and to access needed services and support for the child, youth, and caregiver.<sup>76</sup>

# SYSTEMS OF CARE: DEVELOPMENTAL DISABILITY CARE FOR CHILDREN AND YOUTH WITH SPECIAL NEEDS

## OVERVIEW

The California Department of Developmental Services (DDS) is the primary state agency responsible for providing services and support to individuals with developmental disabilities throughout their lifetime. In addition, DDS and the California Department of Education (CED) jointly administer the Early Start program for infants and toddlers under the age of three with documented developmental disability needs or at-risk for developmental delays.

A developmental disability refers to a severe and chronic disability that is classified as a mental or physical impairment that presents before an individual reaches adulthood. Developmental disabilities include intellectual disability, cerebral palsy, epilepsy, autism, and disabling conditions closely related to intellectual disability or requiring similar treatment.<sup>77</sup>

Developmental disability services and care are largely provided by state-operated Developmental Centers, a network of 21 private nonprofit Regional Centers, and through community facilities. Under the Lanterman Act, DDS is responsible for ensuring that more than 240,000 people with developmental disabilities receive the services and support needed to live independent and productive lives.

## FUNDING

Developmental disability services for children and youth are funded through numerous federal and state funding sources, and with a small portion of funding coming from parental and program fees.

DDS received an estimated \$5.4 billion in funding for programs for FY 2014-15. Approximately \$3.0 billion was allocated from the State General Fund and approximately \$2.3 billion was allocated from federal and state reimbursements.<sup>78</sup> DDS receives reimbursements from the following federal funds; Medicaid HCBS Waiver, Medicaid HCBS Waiver Administration, Medicaid Administration, Targeted Care Management, Medi-Cal, Title XX Block Grant, ICF-DD/State Plan Amendment, 1915(i) State Plan Amendment, Money Follows the Person, Homeland Security Grant, Race to the Top, and EPSDT.

Furthermore, DDS also receives funding from the Federal Trust Fund, the State Lottery Education Fund, the Program Development Fund, the Mental Health Service Fund and the Developmental Disabilities Services Account.<sup>78</sup>

DDS received approximately \$70 million from the Federal Trust Fund, approximately \$367,000 from the Lottery Education Fund, approximately \$4.3 million from the Program Development Fund, approximately \$1.1 million from the Mental Health Service Fund and approximately \$150,000 from the Developmental Disability Account.<sup>78</sup>

### *Title XX Block Grant*

The Title XX Block Grant provides federal funding as a single grant to states for social services. Also referred to as the Social Service Block Grant (SSBG), Title XX allow states flexibility to direct block grant funds to support a wide range of social policy goals, care and services.

For example, Title XX funding can be used by the State to fund child abuse prevention, increase the availability of child care, provide community-based care and services for disabled and elderly populations and provide services to children and youth in foster care, among other social service needs.<sup>79</sup>

Title XX funding is allocated to states based on population and federal funds are available to states without requiring states to provide a matching rate.

Furthermore, federal law allows up to 10% of federal Title IV-A TANF funding to be redirected to programs funded by Title XX. For example, a portion of TANF funds are transferred to Title XX block grant to support developmental services provided by DDS.<sup>5</sup>

### *Title XIX—Home and Community-Based Services (HCBS) Waiver*

Title XIX Home and Community-Based Services (HCBS) waivers provides federal funding to support long-term care services in home and community settings rather than institutional settings under the Medicaid Program. States can use Title XIX HCBS funding to provide a combination of standard medical services and non-medical services. Services can range from case management and care coordination to home health aide, personal care, habilitation services and respite care. Title XIX HCBS can also be used to purchase specialized medical equipment and supplies, environmental accessibility adaptations and vehicle adaptations.<sup>80</sup>

DDS applied for a five year HCBS waiver for years Oct. 2011 to Sep. 2016. During the FY2014-15 waiver year, the Title XIX HCBS allocated funding for up to 115,000 individuals. Eligibility for Title XIX HCBS funded-services require individuals be eligible for full-scope Medi-Cal, have a formal diagnosis of a developmental disability that originates before an individual attains the age of 18, be a Regional Center Consumer and meet either the federal or state level of care for specific facilities.<sup>81</sup>

### *Lottery Education Fund*

California's passage of the California State Lottery Act, also known as Prop. 37 in 1984 provided a supplemental source of funding to public education. Originally, the act required that no less than 84% of total annual revenues from the sale of state lottery tickets or shares be directed to public education and that no more than 16% of those revenues be used for expenses of the lottery.

AB142 signed into law 2010 amended the State Lottery Act to maximize funding by requiring 87% of the total annual revenues of the state lottery be returned to the public in the form of prizes and contributions to education.<sup>82,83</sup>

## PROGRAMS

### EARLY START PROGRAM

Administered jointly by DDS and the DOE, the Early Start program is a statewide program that provides early intervention services to infants and toddlers, from the age of birth up to three years old, with developmental delay, disabilities or an established risk condition with a probability of resulting in a delay.

Infants and toddlers are eligible for the Early Start program if through documented evaluation and assessment they have a developmental delay of at least 33% in one or more areas: cognitive, communication, social, emotional, adaptive, or physical and motor development including vision and hearing. Infants and toddlers may also be eligible for the program if they have an established risk condition with a high probability of delayed development resulting from disease, illness, or disability.<sup>84</sup>

Early intervention services are individually determined for each eligible infant or toddler and are provided at various sites including Regional Centers for developmental disabilities; local educational agencies (LEAs) such as school districts and county offices of education; health or social service agencies; and or community family resource centers and networks.<sup>84</sup>

Services provided through the Early Start program can include, but are not limited to, case management; health services; diagnostic services; nursing services; occupational therapy (OT); physical therapy (PT); psychological services; special instruction; speech and language services; transportation; and family training, counseling and home visits.

While Regional Centers are responsible for services for all children eligible for the Early Start program, LEAs are directly responsible for services for infants with vision, hearing, and severe orthopedic impairments, as well as, low incidence disabilities.

Assessment for Early Start services is initiated through a referral, which can be made by anyone in the community, such as a parent, family member, day care providers, or medical providers. Within 45 days of receiving a referral, a child will be assigned a service coordinator and assessed. If determined eligible for early intervention services, an Individual Family Service Plan outlining priority goals and early intervention services and coordination will be developed in collaboration with the family. Furthermore, parent-to-parent support and resource information is also available through Early Start Family Resource Centers.

Evaluation, assessment and services coordination are provided for free. Public and private insurance is accessed for medically necessary therapy services including speech, physical and occupational therapies. Services that are not covered by insurance can be purchased and determined by a sliding scale or provided by Regional Centers or local education agencies.<sup>84</sup>

### Funding

DDS receives a federal grant for the Early Start Program from Part C of the Individual with Disability Education Act (IDEA), which provides states funding to develop and operate early intervention programs for families and their children from birth to age three years of age with developmental delay, disabilities

or conditions which place them at high risk of developing a disability. DDS allocates a significant portion of IDEA—Part C federal funding to Regional Centers to provide care and services locally. In addition, DDS also provides IDEA—Part C funding to local education agencies (LEAs) to support programs and services provided by schools for children with disabilities.

The Early Start program also receives reimbursements for services provided to children who are eligible for Medi-Cal.

For FY2014-15, the estimated budget for the Early Start Program is \$19.4 million. DDS received approximately \$19.1 million (98%) from IDEA—Part C grant and approximately \$341,000 in reimbursements from the competitive federal grant Race to the Top.<sup>78</sup>

## REGIONAL CENTERS

A network of 21 Regional Centers provides and coordinates developmental disability services to support individuals with developmental disabilities and families throughout California. Regional Centers are nonprofit private corporations that contract with the DDS to provide or coordinate services and supports for individuals with developmental disabilities.

Regional Centers provide a wide range of services including diagnosis and assessment of eligibility, development of an Individual Family Service Plan (IFSP) for children under the age of three or an Individual Program Plan (IPP) for children over the age of three, case management, service delivery, resource development, and outreach and community education. There is no charge for the diagnosis and eligibility assessment.<sup>85</sup>

Furthermore, Regional Centers also contract with community care facilities, vendors licensed by DSS to provide 24-hour residential care to children and adults with developmental disabilities who are in need of personal services, supervision, and/or assistance essential for self-protection or sustenance of daily living activities.<sup>86</sup>

Of the total estimated 274,696 individuals utilizing services at Regional Centers during FY 2014-15, approximately 243,414 children over 3 years old received services and approximately 31,282 infants and toddlers (birth to age 3) receive serviced from the Early Start program.<sup>86</sup>

### Funding

Funding to Regional Centers is provided by a combination of federal and state funds.

During FY2014-15 DDS allocated approximately \$4.8 billion to Regional Centers. Approximately \$2.7 billion (56%) funding is allocated from the State General Fund and approximately \$2.0 billion (41%) comes from reimbursements. The remaining 3% of funding provided to Regional Centers is a combination of funds from Mental Health Services Funds, Developmental Disability Services Account, Federal Trust Fund and the Developmental Disability Program Development Grant (PDG).<sup>78</sup>

Regional Center funding for services and administration is allocated through two budgets; an “Operations” (OPS) budget which provides funds for administration and basic operations and a “Purchase of Services (POS)” budget which provides funds to purchase or reimburse for services.

During FY2014-15, an estimated total of \$620.1 million (11%) was allocated to OPS and an estimated \$4.6 billion was allocated to POS (89%).

## **DEVELOPMENTAL CENTERS**

DDS currently operates three Developmental Centers, which are licensed and certified as General Acute Care hospitals with Skilled Nursing and Intermediate Care Facility/Mentally Retarded (ICF/MR) services and one smaller, state-operated community facility licensed as an ICF/MR facility. Developmental Centers provide 24-hour habilitation and treatment services for residents with developmental disabilities while concurrently providing support and options for transition into the local community.

Services are designed to include activities that involve all aspects of daily living ranging from residential services such as skills training, specialized medical and dental health-care, physical, occupational, speech therapies and language development to leisure and recreational opportunities. Residents under the age of 22 attend school either in the community or on-site at the Developmental Center or community facility.<sup>87</sup> Furthermore, residents of Developmental Centers also receive services by Regional Centers.

DDS has proposed to initiate the closure planning process for the three existing Developmental Centers—Sonoma, Fairview and the General Treatment Area of Porterville— over the next six years.<sup>88</sup> The “Task Force on the Future of Developmental Centers,” established by the Secretary of the California Health and Human Services Agency in response to declining populations at Developmental Centers and concerns for remaining residents recommended that the future role of the State should be to operate a limited number of smaller, safety-net crisis and residential services. Furthermore, the Task Force also recommended developing new and additional service components, including development of enhanced community behavioral homes and exploring utilization of Developmental Centers assets to provide health resource centers and community housing through public/private partnerships.<sup>86</sup>

### *Funding*

Following the expectation of Developmental Center closures, the Governor’s Budget proposes decreased funding over the next several years. Total funding for FY2014-15 is estimated to reach \$562.8 million; with approximately \$309.6 million (55%) allocated from the State General Fund and approximately \$252.4 million (44%) allocated from reimbursed.<sup>78,89</sup> The remaining 1% is generated from a combination of funds from the Federal Trust Fund and the State Lottery Education Fund.

## SYSTEMS OF CARE: EDUCATION FOR CHILDREN AND YOUTH WITH SPECIAL NEEDS

### OVERVIEW

Since the passage of the federal Education for All Handicapped Children Act (EHA), Public Law 94-142 in 1975, all public schools accepting federal funds are required to provide free and equal access to education for children with physical and mental disabilities.<sup>90</sup> In 2004, EHA was revised and reauthorized as the Individuals with Disabilities Education Act (IDEA). Part B of IDEA requires local educational agencies (LEAs) — defined as county offices of education, districts, and direct-funded charter schools— to provide children from age 3-22 with diagnosed disabilities access to free, appropriate and individualized education in the least restrictive environment to meet the students’ unique needs and prepare them for further education, employment and independent living.<sup>91</sup>

IDEA—Part C also allows for early intervention services for infants and toddlers from birth up to three year old with developmental disabilities and the vast majority of these services are provided by Regional Centers rather than schools (*see: System of Care: Developmental Disability Care for Children and Youth with Special Needs*).<sup>92</sup>

In California, 705,279 children and youth (birth to 22 years of age) accessed special education services between 2013-14 and roughly one in 10 children (11.31%) receive special education services statewide.<sup>93</sup>

Disabilities for children and youth encompass a wide range of categories including learning disabilities such as dyslexia; health impairments—including both acute conditions such as leukemia and long-term conditions such as autism; intellectual disabilities; emotional disorders; and physical disabilities such as hearing and vision impairments.

Among students enrolled in special education in California in 2014, a majority of students were identified as having a learning disability (40%), followed by speech or language impairments (22.8%) and autism (12%).<sup>94</sup> While students with disabilities such as health impairments, emotional disorders and physical disabilities make up a far smaller percentage of the population receiving special education services, programs and services for this populations are often more expensive.

### Special Education Services

California has organized the delivery of special education regionally through the establishment of Special Education Local Plan Areas (SELPA) which is best defined as a collaborative consortia of school districts, county offices of education and charter schools in proximity. Currently, 130 SELPAs administer special education services by collaborating with county agencies and school districts to provide free, appropriate and individualized education to all students with documented disabilities.<sup>95</sup> Typically SELPAs are made up of multiple school districts and charter schools, however in some cases the SELPA is a single school district, as in the case of Los Angeles.

Each SELPA is required by state law to make a “continuum of program options” available to meet the needs of students with special education needs and related services in accordance with IDEA. Program

options include regular education; resource specialist programs; designated instruction; special class; nonpublic, nonsectarian school services; instruction in setting other than classrooms where specially designed services may occur; itinerant instruction in classrooms, resource rooms, and settings other than classrooms; and instruction using telecommunication, and instruction in the home, in hospitals, and in other institutions to the extent required by federal law or regulation.<sup>96</sup>

Special education services vary widely based on the individual student's needs. Students qualify for special education services only after the school has first tried to meet the student's needs through the general education program. In accordance with IDEA, an Individual Educational Plan (IEP) is developed for all students qualifying for special education services.

An IEP is an individualized assessment developed by a multi-disciplinary team and typically includes the student's parents or caregivers, the evaluator determining the student's eligibility for services, school administrators, special education instructors, resource specialists, service providers, general education instructors, local agencies, and the student, when appropriate.

An IEP assessment determines the student's present academic and functional performance, identifies and details the educational program, services and accommodations to be provided to the student by the LEA, develops measurable academic and functional goals, and provides additional considerations such as transitional support.<sup>97</sup>

In addition to an IEP or at times, instead of an IEP, a Section 504 Plan may also be developed for students, which outlines how a student's specific needs will be met to fully support participation in school activities. For example, 504 Plans accommodations may include non-instructional modifications such as wheelchair ramps, blood sugar monitoring, or tape recorders for taking notes.

### *Mental Health Services*

In 1984, Assembly Bill 3632 mandated school districts collaborate with county MHPs to deliver mental health services to students with IEPs. In 2011, the California Legislature passed Assembly Bill 144, dissolving the state mandate between MHPs and schools, and transferring responsibility of providing mental health services to students with IEPs from the county MHPs to LEAs across the state.

As a result of this new legislation, LEAs are solely responsible for developing and delivering mental health services to students with IEPs to meet their needs in accordance with IDEA; some LEAs and SELPAs have selected to continue to partner with MHPs to deliver mental health services for students with IEPs.<sup>98</sup>

### *Charter Schools*

Since the Charter Schools Act (SB 1448) was signed into law in 1992, the number of charter schools throughout California has increased from 31 operating charters in 1993 to roughly 1,230 charters to date. In 2014-15 charter schools in California served an estimated 581,100 students.<sup>99,100</sup>

While charter schools are a relatively new model of education in California, charter schools have been documented as serving a lower proportion of students with disabilities compared to public school.<sup>101</sup> Some factors identified attributing to the lower enrollment of student with disabilities at charter schools include parental choice and student need, location and a charter's capacity to develop and run special education programs. As charter schools continue to expand, greater emphasis on how charter schools can meet the needs of students with disabilities will be needed.

### Private Schools

Under IDEA, Local Educational Agencies (LEAs) must expend a proportionate share of IDEA—Part B funding to provide special education and related services for students with disabilities in private schools that are selected by the family.

Furthermore, LEAs are required to consult in a timely and meaningful manner with private school administration and families to aid in the development of special education and related services at a private school. However, a selected private school does not guarantee the right of the student with a disability to receive some or all of the special education and related services that the child would receive if enrolled in a public school.<sup>102</sup>

## **FUNDING**

Public education, including special education programs and services, are subsidized by a combination of federal, state and local funds. Total funding— generated from federal, state and local funding sources— for Kindergarten through Grade 12 education is projected to reach \$76.6 billion for FY 2014-15.<sup>103</sup>

### Federal Funding

Under IDEA, federal resources are distributed to states through three grant programs (Part A, Part B and Part C) and several discretionary grant programs to fund special education.<sup>5</sup> In order to be eligible for funding, states must serve all children with disabilities between the ages 3-21 and must provide free appropriate public education to children with disabilities ages 3-5.<sup>104</sup>

CDE receives federal grant funding annually from IDEA, which covers approximately 11.5% of the costs of special education services compared to state funding which contributes approximately 46% of expenditures.<sup>105</sup>

California's Legislature and the Governor provide the guidelines for how funds are allocated through the annual Budget Act.<sup>106</sup> IDEA requires federal funds provided to the state must be largely directed to LEAs, with a small portion used for state-level administration and activities such as monitoring, enforcement, addressing personnel needs, and providing technical assistance to LEAs. California no longer calculates IDEA grants strictly on a per-pupil basis.<sup>107</sup>

### State Funding

State funding for public education is generated through the State General Fund and local property tax revenues. California's public school budget receives 40% of the State's General Fund resources and Education the largest program in the State budget. The FY 2014-15 State budget estimated more than \$45 billion General Fund resources for K-12 education and child development.

The California budget also allocates \$60.1 million Proposition 98 General Fund to be invested in recommendations proposed by the California Statewide Special Education Task Force to improve service delivery and outcomes for all disabled students, with an emphasis on early education.<sup>108</sup>

During the FY 2012-13, school districts and charter schools spent \$10.7 billion on special education services; averaging approximately \$22,300 per student with disabilities compared to \$9,600 per student without disabilities.

California distributes federal and state special education funds to Specialized Education Local Plan Areas (SELPA's).

## CLOSING

California's systems of care—physical health, mental health, developmental disability care and education—provide programs and services that are life-saving and life-changing for children and youth, as well as, for their families. This brief offers just a snapshot of the complex nature of these programs and subprograms, which often provide coexisting and overlapping care and services to this specialty population. Furthermore, this brief also offers a glimpse into the multifaceted funding streams, eligibility criteria, and organization and delivery of select programs and services.

As the Select Committee begins to explore and examine these four systems of care, along with the programs and services available to children and youth with special needs more closely during the 2016 year, it is imperative to recognize there is great opportunity to further strengthen and integrate these systems to fully support this unique population.

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