SUMMARY HEARING REPORT

SENATE SELECT COMMITTEE ON CHILDREN WITH SPECIAL NEEDS

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

Subject: Summary Report
Informational Hearing titled "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

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PREFACE:

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The Lucile Packard Foundation for Children's Health (LPFCH) provides funding to support research and policy analysis for the Senate Select Committee on Children with Special Needs. The Foundation is a public charity, founded in 1997. LPFCH's mission is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. Through its Program for Children with Special Health Care Needs, the foundation supports development of a high-quality health care system that results in better health outcomes for children and enhanced quality of life for families. The Foundation works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University.

EXECUTIVE SUMMARY:

The Senate Select Committee on Children with Special Needs convened its first informational hearing on December 1, 2015, providing an overview of the various programs and services available to eligible children with special needs in the State of California and setting the foundation for the Committee's scope of interest moving forward.

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 first hearing centered on four key systems of care for children with special needs: physical health, mental health, developmental disability needs and education. In addition to mapping programs and services for children with special needs under these four systems of care, panel speakers also identified current challenges impacting programs and service delivery, addressed funding mechanisms for programs and services, and provided relevant data during testimony.

The hearing was organized to include representation from the state, county and local levels. Representatives from the California Department of Health Care Services (DHCS), the California Department of Developmental Services (DDS) and California Department of Education (CDE), along with representatives from various county and local agencies and nonprofit organizations provided their expertise and testimony.

The hearing generated a collection of recommendations for the Select Committee to consider and explore further. Notably, all three departments and several agencies and organizations committed to providing the Select Committee with technical assistance and data to develop a prospective California Systems of Care Report Card/Dashboard tailored to children with special needs.

INTRODUCTION:

The Senate Select Committee on Children with Special Needs held its first informational hearing entitled "Mapping the Current System of Care for Children and Youth with Special Needs in the State of California" on December 1, 2015 at the State Capital in Sacramento, California. Video of the first Committee Hearing is available at http://senate.ca.gov/media-archive# and background reports, presentations and supplemental material for this hearing can be found at http://senate.ca.gov/childrenspecialneeds.

This report highlights key takeaway points and recommendations proposed by panel speakers during the hearing. Takeaway points have been organized into the following subcategories: data, figures and trends; services and care; funding streams and allocation; challenges and barriers impacting care; and interdepartmental and interagency coordination. Recommendations put forth by panel speakers during the hearing have been organized to mirror the four systems of care and include the following subcategories: general across-systems; data and tracking; physical health; mental health; developmental disability; and education.

In addition, this report also includes hearing minutes, along with presentations, written testimony and supplemental material provided by panel speakers. Additional background information regarding legislation, programs and technical terminology cited during the hearing is also provided in the footnotes section.

The focus of the first hearing was to map out systems of care for children and youth with special needs—including physical health needs, mental health needs, developmental disability needs and educational needs—by addressing the following questions:

1. What does the current research and data tell us about children and youth with special needs?

2. What services and care are currently provided to children and youth with special needs—including health needs, mental health needs, developmental disability needs and educational needs—at the state and local level?

3. How are programs and services for children and youth with special needs funded, including by federal, state and county resources, and how is funding distributed to pay for services?

4. What are the current challenges and barriers impacting care and services for children and youth with special needs?

5. What strategy and programs are under way to coordinate with other agencies and programs providing services to children and youth with special needs, and if not, how should coordination be best addressed?

KEY TAKEAWAYS EXTRACTED FROM THE HEARING:

TO COLLABORATE ON A CALIFORNIA REPORT CARD/DASHBOARD

- The following departments, agencies and organizations committed to providing the Select Committee with technical assistance and data to develop a California Systems of Care Report Card/Dashboard tailored to children with special needs:
    - Lucile Packard Foundation for Children's Health (LPFCH)
    - California Department of Health Care Services (DHCS)
        - California's Children's Services (CCS)
        - Mental Health and Substance Use Disorder Services
    - California Department of Developmental Services (DSS)
    - Association of Regional Center Agencies (ARCA)
    - California Department of Education Special Education Division (CDE)

DATA, FIGURES, AND TRENDS

General

- Rate of disability and special needs among children is increasing; 1% increase between 2001-2011
- Slightly over 10% of children in California between the ages of 0-17 met the definition of children with special health care needs for the 2009-2010 year
- Health is the common link throughout all of the systems; including child welfare, special education and developmental disabilities
- California has a lower proportion (10.6%) of children who meet the definition of children with special health care needs compared to the national rate (15.7%) for the 2009-2010 year; difference is attributed to California's large Hispanic population whose families have traditionally demonstrated greater reticence toward identifying their children as having special needs
- Compared nationally, California ranks poorly on several health indicators, including but not limited to preventative care visits, family-centered care, proportion of parents with above average stress, care coordination, developmental screening, and receiving mental health services, etc. according to the 2009-2010 National Survey of Children with Special Health Care Needs

Physical Health

- Over last ten years DHCS has seen a 61% enrollment growth in children
- DHCS covers approximately 5 million children; 180,000 of those children are in the CCS program

- DHCS uses 10 different subpopulations of children to analyze programs and trends
- Cost averages: ≈ $240.00 PMPM[1] for children
    - Developmentally disabled population: ≈ $1,800.00 PMPM
    - CCS population: ≈ $1,400.00 PMPM
- Approximately a quarter (24%) of overall cost is spent on 1% of population (the very complex subpopulations, including developmentally disabled & CCS populations)
- Expenditures and needs differ greatly depending on the population of children:
    - Foster care population: 62% of the spend was in the Short-Doyle[2] system, which is for mental health coverage
    - CCS subpopulation: 25% of spend was for acute hospital costs, only 3% was for Short-Doyle (mental health) and 28% was for pharmaceuticals
- Emergency Department (ED) room rate visits per 1000
    - CCS populations: ≈ 47 visits per 1000
        - CCS child without Asthma: ≈ 41 visits per 1000
        - CCS child with Asthma: ≈ 82 visits per 1000
    - All populations of children: ≈ 21 visits per 1000
    - 1% subpopulation (developmentally disabled populations & CCS populations): ≈ 65 visits per 1000
- CCS constitutes 2% of enrollment but 51% of all the acute inpatient days
    - CCS inpatient utilization is almost 3.5x higher than the developmentally disabled population and 13x higher than any other disabled population
- ***In Progress***: DHCS is currently developing the 2015 Healthcare Effectiveness Data and Information Set (HEDIS)[3] dashboards which includes general child-focused measures; commitment to share data and dashboards with the Select Committee

Mental Health

- ***In Progress:*** DHCS is currently developing dashboards for the mental health programs and services at the state and local levels to meet federal CMS requirements linked to the renewal of a 5-year grant provided through the 1915(b) Freedom of Choice Waiver;[4] commitment to share data and dashboards with the Select Committee
- ***In Progress:*** DHCS Mental Health and Substance Use Disorder Services is currently developing a Performance Outcome System to collect data on children; commitment to share data and dashboards with the Select Committee

Developmental Disability

- Regional Centers[5] serve close to 290,000 individuals and their families; this number continues to grow every day and as an entitlement program, once individuals are found eligible for services they are entitled under California law for the rest of his or her life, unless it is found that the original diagnosis was incorrect

- Regional Centers currently serve 135,000 children at a cost of approximately $500 million annually; 98% of children live at home with their families

Education

- In 2014-2015, over 666,000 of California's 6.2 million students (Kindergarten through 12th grade) were identified as receiving special education
- Approximately 10.7% of California's school age populations receive special education
- The percentage of students receiving special education has increased from 10.1% to 10.7% since 2010-2011
- Sacramento City Unified School District (SCUSD) special education department serves between 6,300 - 6,600 students with special needs within a given year

SERVICES AND CARE

General

- Health is the common link throughout all of the systems, including child welfare, special education and developmental disabilities
- Children with special needs and their families require unique support:
  - Readily available principle contact
  - Planned, accountable services
  - Multiple system involvement
  - Access to skilled professionals
  - Special accommodations
  - Prevention of progression & comorbidity
  - Family-centered services & support
  - Readily available & shared records
  - Coordinated or integrated services
- Care coordination is necessary when care systems are not integrated
- The parent is the *bridge* between every silo and it's a hardship to navigate the system
- Family Empowerment Center (FECs)[6] or an entity similar to FECs can help families navigate systems of care including navigating CCS and Medi-Cal

Physical Health

- CCS arranges, coordinates and authorizes payment for specialty medical care for eligible children (birth to 21 years of age) at CCS designated centers
- CSS is made up of two program components:
  - Administrative Case Management Program
    - Collaborates with the care-team to ensure child receives care that meets CCS standards

    - Medial Therapy Program (MTP)
        - Provides direct outpatient rehabilitation services within the home environment and public schools throughout the community
        - *MTP eligibility required independent of CSS eligibility
- Variation exists among CCS County Programs
    - Some counties have more enhanced services, such as a specific transition program to help youth move into adult care

Mental Health

- Through the authority of the 1915(b) Freedom of Choice Waiver, DHCS contracts with all the state counties to provide specialty mental health services within communities
- DHCS' primary responsibility is to provide oversight and monitoring of county mental health programs; DHCS conducts annual external quality reviews and triennial whole-system reviews
- Counties are required to provide a range of services for the provision of the specialty mental health services to individuals who meet medical necessity criteria; mental health services include:
    - Individual
    - Group
    - Assessment
    - Planned Development
    - Medication support
    - Psychiatric support
    - Crisis intervention
    - Crisis stabilization
    - EPSDT
    - Targeted case management for psychiatric in-patient
- The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program[7] is available to those with Medi-Cal under the age of 21, and provides mental health services for children and youth
- Medical necessity is fairly low for children; includes mild to moderate mental health needs ranging from basic socialization to school services to more severe services, such as, crises services for children in need of hospitalization
- California mandates "least restrictive environment" for mental health services
- Variability among counties regarding how county mental health centers collaborate with school districts, Local Education Agencies (LEAs)[8] and Special Education Local Plan Area (SELPAs)[9]

Developmental Disability

- Entitlement system for individuals with developmental disabilities; individuals who qualify receive services for life through the Regional Centers
- Disabilities must originate prior to 18 years old and disability must be expected to be lifelong and a perceived handicap to the individual
- Qualifying disabilities include:
    - Intellectual disabilities
    - Autism
    - Epilepsy
    - Cerebral palsy
    - Other disabilities that are similar to or require the same or similar services to intellectual disability
- DDS contracts with 21 private nonprofit Regional Centers throughout the state of California to provide services and support to individuals with developmental disabilities and their families
- Services include:
    - Intake & Assessment
    - Case management
    - Assistance with referral to other programs
    - Funding services through the Regional Centers directly
- Regional Center case managers are assigned to each client and collaborate with families to develop an Individual Service Plan (ISP)[10] for children under 3 years old or an Individual Program Plan (IPP)**Error! Bookmark not defined.** for those over 3 years old; these plans outline the types of services and funding of services provided by the Regional Center
- Regional Centers provide early intervention services through the Early Start program to infants and toddlers under 3 years old; intensive services are typically provided within the family home and meant to help ameliorate limitations on the social, mental and physical well-being of the child
- Regional Centers have three primary goals:
    - Help infants and toddlers catch up to their peers
    - Help children to stay with their parents at home
    - Help adults with developmental disabilities to be as independent as possible

Education

- Children qualify for special education and related services if an Individualized Education Program team determines that the student has a disability and because of that disability needs special education and related services; generally, this means that their disability affects their ability to access and make progress in general education curriculum

- Special Education services include:
    - Identifying children with special needs
    - Evaluation and Assessment
    - Development of an Individualized Education Program (IEP)[11]
    - Annual review
    - Special Academic Instruction provided in mainstream classes, resource rooms and or special classes
    - Related services; including transportation, language and speech therapy, occupational therapy, behavioral intervention services, health and nursing type services etc.
- Students become eligible for special education services through a multi-disciplinary assessment process and must meet an eligibility criterion for one of the 13 eligibility classifications[12]
- On average it will cost at least 2x more to educate students with special needs compared to students in general education
- Examples of medical care school nurses may provide to students:
    - G-tubes/tracheostomy tubes; trach-care and suctioning
    - Ventilator care, breathing treatments, nebulizers, inhalers
    - G-tube meds and oral meds
    - Diabetes management
    - Anaphylaxis prevention and management
    - Schools have to store meds in refrigerators and locked cabinets
    - Train personnel to help students with medications

FUNDING STREAMS AND ALLOCATION

General

- Systems of care — including Medi-Cal California Children's Services program, Mental Health, Developmental Disabilities, Special Education and Child Welfare—function in silos; systems are run by separate agencies, have separate budgets, and have separate regulations

Physical Health

- DHCS spent $10 billion on children age 0-18 for the calendar year 2011
- ***In Progress:*** DHCS to apply for federal funding to establish Health Homes through the Affordable Care Act (ACA) Section 2703 Medicaid State Plan; [13] DHCS to release a State Plan Amendment for public comment (date TBD)
- DHCS spends over $3 billion on CCS services
- CCS services are primarily paid through Medi-Cal; majority of CCS children have full scope Medi-Cal (75-80%) vs. CCS children not covered by Medi-Cal (15-18%)

    - CCS children not covered by Medi-Cal: Funding split between Federal funds, State funds (DHCS) and County funds (17.5%) to cover program costs
- Title V the Maternal and Child Health Grant (MCH),[14] provides DHCS $8 million, which is distributed to the counties to help fund care coordination
- Child Health and Disability Prevention (CHDP) receives federal and state funding; excluding county funding

Mental Health

- Multiple funding sources:
    - 2011 Realignment;[15] established a behavioral health subaccount for EPSDT specialty mental health, Medi-Cal, and other substance issue disorder services

    - The Mental Health Services Act (Prop. 63);[16] 1% tax on millionaires
    - 1999 Realignment;[17] a percentage of sales tax revenue and vehicle licenses fee
    - Federal Funds
    - County General Funds
- In Colusa County, mental health services provided by the "Schools First Program" on school sites is primarily funded by EPSDT and MHSA funding

Developmental Disability

- DDS receives approximately 58% of funding from the State General Fund and 42% from Federal funds; equates to $2.78 billion in state funding and $1.97 billion in federal funds
- Federal funding sources include:
    - Medicaid
        - Including: 1915 (c) Home & Community-Based Services Waiver (HCBS)[18]
    - State Plan Amendment Funds
    - Title IV Temporary Assistance for Needy Families (TANF) funds[19]
    - Federal Grants
        - Including: IDEA Education Grant[20] to fund the Early Start program
        - Including: Title XX Social Services Block Grant Program[21] under the Social Security Act
- Federal funds require California share in the cost of services using state funds
- DDS allocates funds to Regional Centers based on historical trends; Regional Centers use the funding to purchase and provide services through their contracted community service providers
- Under law, Regional Centers are required to seek out generic services first before providing services directly; Regional Centers therefore rely heavily on Medi-Cal, CSS and other programs before purchasing services

- Funding is allocated into two components:
    - Operations; Supports case management services and regional center operations
    - Payment for Services; Supports individual services and supports

Education

- California provides approximately $4.46 billion for special education services; 73% of these funds are from state sources and 27% are from federal sources;
  *Note: General Education Funding not included in this figure[i]
- Over last five years, federal funds have decreased and state funds have increased
- Special education funding is distributed through the Special Education Local Plan Areas (SELPAs)
- Special Education Local Plan Areas (SELPAs) are geographically organized for funding and services; SELPAs are a single district or a group of districts that are a sufficient size and scope to be able to provide an array of services that students with disabilities may need
- State general funding for CDE special education: ≈ $3.25 billion
    - Special Education Funding, also known as AB602; ≈ $2.7 billion
    - Educationally-related Mental Health Services Funding: ≈ $361 million
- Federal funding from the Individuals with Disabilities Act (IDEA) for special education: ≈ $1.2 billion
    - IDEA mental health funds: ≈ $69 million
- Examples of programs and services funded by federal funding grants:
    - Family Empowerment Centers
    - School age programs
    - Pre-school programs
    - Pre-school local entitlement
    - Transportation funds for state special schools
    - Instructional materials funding
- Federal funds, including IDEA and grant awards, use a three-part formula established by Congress:
    - Part 1: Base-amount established in 1999
    - Part 2: Overall general student population of the school
      *Note: Not based on number of children with disabilities but rather overall general student population of the school
    - Part 3: 15% of funding is based on students identified as living at or below the federal poverty line (FPL)

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[i] Post-hearing, Mr. Drouin provided the following clarification: "Special education students are also general education students, so it is expected that general education funding would cover some of the educational costs for students with disabilities."

CHALENGES AND BARRIERS IMPACTING CARE

Physical Health

- Transition to 18 years old and 21 years old is poorly coordinated and requires numerous re-evaluations and assessments by each program
- Low Medicaid/Medi-Cal reimbursements are restrictive; limiting the quantity of general and subspecialty provides and negatively impacting access to services
- Derek, a 20-year-old who has received CCS services since birth, asks why transitioning youth can't remain on CCS until 26 years of age, as with private health insurance under the ACA, which now extends health coverage for young adults up to 26 years old under a parent's health plan

Mental Health

- Limited number of children's mental health providers in Medi-Cal provider, further limiting access to services and shifting need to county mental health centers
- Question raised: Does the low percentage of CCS children receiving mental health services (3%) reflects an unmet need or is low percentage due to the high costs associated with physical/medical care when compared to mental health care?
- Limited number of children's mental health providers in Private Health Insurance Networks, further limiting access to services and shifting need to county mental health centers
- Poor and or lack of communication and coordination between children's mental health providers (including child physiatrists and therapists) and health insurance providers (including HMOs); Example provided of psychiatrist who recommended child receive an electroencephalography (EEG) for a potential seizure disorder and negotiation with the HMO took 6 months regardless of referral and medical reasons provided by the psychiatrist
- Congregate Care Reform;[22] concern regarding increased demand on mental health services and particularly higher end services at the local and regional level and lack of preparation for increased demand
- AB3632[23] was defunded by former Governor Arnold Schwarzenegger[24] in 2011 through the passage of AB114, [23] which ended the state mandate requiring a partnership between county mental health centers and schools to deliver mental health services to students with IEPs; as a result of AB114, school districts are now entirely responsible for developing and delivering mental health services to students with IEPs, which has led to variation in the delivery of mental health services—including type of services, quality and frequency—to students with IEPs across schools throughout the state.[ii]

[ii] Post-hearing, Mr. Drouin provided the additional response: "[AB114] is a change in how services are delivered, but the CDE believes that there have not been any significant negative consequences resulting from this change…and rather, [AB114] provided greater flexibility in how services are delivered and who delivers them.

- Poor record keeping and sharing for foster children and children with mental health needs; foster parents, social workers, probation officers, and treating mental health providers often have limited to no information on a child's mental health history, including past trauma and past treatment

Developmental Disability

- Regional Centers underfunded for decades and worsened under the Great Recession; the system has sustained over $1 billion in cuts during the Great Recession alone
- Halt in funding to start new developmental disability programs and services for children and other special populations
- Shrinking number of specialty providers available for Regional Centers to contract with
- Growing autism epidemic; increased need for services
- Developmental services need to be restored to meet current and growing demand
- All California Regional Centers are currently non-compliant regarding statutorily established caseload ratios; California assures the federal government that it will maintain a caseload ratio of 1:62 for some populations and the inability to meet caseload ratios is seriously jeopardizing the continuation of federal funding

Education

- Federal funds have decreased and state funds have increased, requiring the school district to contribute a substantial and a growing amount of funds in each fiscal year to provide the IEP mandated services to students, which can significantly impact a district's budget health
- Although schools can bill for LEA Medi-Cal benefits, schools and school districts don't have access to the funds for full scope EPSDT Medi-Cal reimbursements as county mental health does
- General education teachers are now more responsible for students requiring special education
    - General education teachers and administrators are not always aware of the intricacies of physical health and mental health issues
    - General education teachers and administrators are not always provided proper training and education related to physical and mental health issues
- High turnover rate of school-based and community mental health counselors
- Poor interagency coordination between schools and other agencies
    - ie: Agency-scheduled meetings often held during school hours
    - ie: School-scheduled meetings often held late in the afternoon/evening, after school/work hours
- Limited or lack of special education teachers available to district/schools
- Shortage of child psychiatry; many children have emotional disturbances and they are often

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Many LEA and County Mental Health collaborations continue, and some have been strengthened since the change."

very complex and underserved
- Families are not provided extra supplies for school and often times, schools have to reuse g-tubes, feeding bags and extension tubes, and syringes

INTERDEPARTMENTAL & INTERAGENCY COORDINATION

Physical Health

- CCS coordination happens to the greatest extent between the Medical Therapy Program (MTP) and special education
    - Therapists go to classrooms to consult with teachers on child's needs
    - Attend IEPs, if requested

Mental Health

- DHCS mental health specialty coordinates with:
    - Department of Social Services; related to foster care and use of psychotropics
    - Mental Health Services Oversight and Accountability Commission[25] and the Crisis Services' Workgroup
    - Child Welfare Council;[26] related to the Priority Access Project[27] to support family reunification
    - Office of External Quality Review
    - Office of Juvenile Justice and Delinquency prevention
    - Attorney General's Office on Defending Childhood Initiative
- Limited communication and coordination identified between CCS and children's mental health providers

Developmental Disability

- DDS coordinates with:
    - Interagency Coordinating Council for Early Intervention
        - Includes representatives from the Department of Health Care Services (DHCS), Department of Social Services (DSS) and the Department of Education (CDE), service providers, family members and others
    - Local coordination through the Regional Centers provided by case managers to help families navigate the system and obtain the services that they need
    - Other services Regional Centers may assist with include coordinating and purchasing of medical adaptive equipment and whatever the unique needs of the individuals require to help the person remain in the family home

Education

- Special education services are provided by a large number of agencies; this includes:
    - 133 Special Education Local Plan Areas
    - 1,700 Local Education Agencies,
    - 58 Counties of Offices of Education
    - 2 state schools for deaf
    - 1 state school for the blind
- Local Education Agencies contract with nonpublic agencies, certified by the Department of Education, to provide services
- Some Local Education Agencies also contract with County Mental Heath Plans and Community-based Mental Health Agencies

KEY RECOMMENDATIONS PUT FORTH BY PANEL SPEAKERS:

GENERAL ACROSS-SYSTEMS' RECOMMENDATIONS:

- **Establish Benchmark Standards for Systems of Care**; to improve systems of care, departments and agencies must identify, define and agree upon "standards for systems of care" to use as a benchmark to guide, measure, and compare program performances across systems of care
- **Incorporate a Child and Family-Centered Approach**; California needs a more child and family centered approach, a whole-child model to assess all the child's need when planning care and implementing and coordinating services
- **Improve Early Identification of Children with Special Needs**; cultural sensitivity and greater understanding is needed to address California's diverse populations, including the state's large Hispanic population whose families have traditionally demonstrated greater reticence toward identifying their children as having special needs
- **Increase Medi-Cal Provider Reimbursement Rates**; California's poor reimbursement rates for Medi-Cal providers are resulting in a loss of local and statewide pediatric providers and subspecialists, negatively affecting access to care and treatment
- **Assign a Primary, Consistent Contact or Coordinator**; families and caretakers need a "lead contact/coordinator" who can provide continuity of care, is conversant with the needs of the child and family, maintains an ongoing relationship with the family and can help the family effectively navigate across systems and programs as the child transitions to young adulthood
- **Strengthen the "Transition-Aging Out" Phase Across Programs**; transition to 18 years old and to 21 years old is poorly coordinated, requires numerous re-evaluations and assessments by each program, and often leaves families with limited support, options and guidance post-21 years of age
- **Strengthen Back-End Coordination between Departments, Agencies and Programs**
- **Expand number of Family Empowerment Centers (FECs);** ******High Need: Rural Communities and Rural Counties*

DATA AND TRACKING SPECIFIC RECOMMENDATIONS:

- **Collect Data to Illustrate Overlap of Services within Systems of Care;** collect and share data between departments and agencies to capture overlap of services
- **Capture and Share Real-Time Data to Improve Systems**; must have ability to collect real-time data, similar to the CPQCC model,[28] to measure health outcomes and demonstrate the systems' effectiveness

PHYSICAL HEALTH SPECIFIC RECOMMENDATIONS:

- **Strengthen Communication and Coordination between Primary and Subspecialty Pediatric Providers;** consider financial models which incentivize providers to coordinate; hybrid solutions such as regional distributed networks among willing local general pediatricians; and or federal grants such as funding by the ACA Section 2703 Health Homes model and Title V funding for coordination
- **Strengthen Communication and Collaboration between CCS Providers and Mental Health Providers;** including County Mental Health Plans' Providers, Medi-Cal Managed Health Plans' Mental Health Providers and Community-Based Mental Health Providers

MENTAL HEALTH SPECIFIC RECOMMENDATIONS:

- **Increase Number of Children's Mental Health Providers in Medi-Cal Managed Care Provider Networks**; **High Need: Rural Communities and Rural Counties*
- **Increase Number of Children's Mental Health Providers in Private Health Insurance Plan Provider Networks**; **High Need: Rural Communities and Rural Counties*
- **Enact Legislation Similar to AB3632**; establish provisions to provide funding to foster partnerships and collaboration efforts between county mental health plans and schools
- **Establish a Continuum of Care in Child Mental Health**
- **Develop a Mental Health Passport or Mental Health Record for All Foster Children and Children with Mental Health Needs**
- **Strengthen Coordination and Access for Mental Health Services for Children and Youth**
- **Strengthen Coordination between Children's Mental Health Providers and Private Health Insurance Plans**; Coordination between the child psychiatrist at the clinic and the private health insurance plans, such as HMOs, is a big problem
- **Expand Mental Health Services for Children through EPSDT Funding**

DEVELOPMENTAL DISABLITY SPECIFIC RECOMMENDATIONS:

- **Increase Funding by 10% immediately to Regional Center Purchase of Services and Operations Budgets**; funding to stabilize Regional Centers across California and support service delivery systems and meet case ratio compliance of 1:62
- **Increase Funding by an Additional 5% Annually to Regional Center Purchase of Services and Operations Budgets**
- **Broaden California's State Statute Definition for a Developmental Disability**; Cal. Welf. & Inst. Code § 4512 is archaic and provides a narrow definition for developmentally disabled persons, excluding many developmental conditions and disabilities and therefore limiting access to Regional Center services for those individuals with certain developmental disabilities not recognized under current law

- **Enact Legislation to Remove Sunset on Autism Insurance Mandate (SB946);**[29] Set to sunset January 1, 2017, SB946 requires health care service plans and health insurance policies issued, amended or renewed after January 1, 2012, to provide coverage for behavioral health treatment for pervasive developmental disorder or autism.

EDUCATION SPECFIC RECOMMENDATIONS:

- **Increase State and Federal Funding to Serve Students with Special Needs**: In many districts as much as 50% of the budget comes from the local district and that can be devastating to a district, especially in a small, rural area; **High Need: Rural Communities and Rural Counties*
- **Amend State Law to Permit LEAs and or SELPAs Access to Full-Scope EPSDT Medi-Cal Reimbursements**; Although schools can bill for LEA Medi-Cal benefits, schools don't have access to the full-scope EPSDT Medi-Cal reimbursement as county mental health does
- **Increase Funding to Ensure Specialists Are Available and Accessible to Students with Special Needs**; Funding desperately needed to provide adequate number of specialists including, but not limited to, speech and language specialists, school psychologists, school nurses, counselors and special education instructors **High Need: Rural Communities and Rural Counties*
- **Strengthen Communication and Coordination between General Education Instructors, School Staff and School Administrators Regarding Students with Special Needs**; Establish consistent and ongoing individual counseling for the student which includes their families, general education teachers, administrators and staff
- **Fund School Nurses to Assist with Coordinated Care Support and Services to Students with Special Needs and their Families;** **High Need: Rural Communities and Rural Counties*
- **Provide Supplemental Medical Supplies and Equipment to School Nurses for Spare Use**; Families are not provided extra supplies for school and often times, schools have to reuse g-tubes, feeding bags and extension tubes and syringes; feeding pumps and nebulizer machines have to travel back and forth with students because they only get one
- **Provide Appropriate Special Education Training to All General Education Instructors and School Administrators and School Staff**
- **Mandate All School Districts Have a School Nurse(s);** currently there are school districts without school nurses further exacerbating challenges in the delivery of related health care and services to students in those districts

HEARING MINUTES:

Opening

Senator Dr. Richard Pan, Committee Chair

Committee Chair Senator Dr. Richard Pan began the three-hour hearing recognizing that while parents and caregivers are typically the primary overseers of children, the State of California plays an important and major role in a child's life from providing education through public education systems and supports offered by special education to providing healthcare through the Medi-Cal program— which covers close to half of all children in the state— to providing developmental services and mental health services.

Dr. Pan stated the leading focus of the first hearing was to map out California's current systems of care, including programs and services provided to children with special needs. The Committee will explore four key systems of care including physical health, mental health, developmental disability and education and examine the various layers and interfaces between these care systems.

Dr. Pan proposed that often the leading question at hand from the family perspective is simply: *How do I best take care of my child and ensure my child gets the help they need?*

A parallel question put forward by Dr. Pan: *How do we make all these systems connect and work together to ensure every child has every opportunity to achieve their potential?*

Dr. Pan also stressed that while there are more formal definitions used to describe children with special heath needs such as the definition put forward by the federal Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB), the Committee aims to look at children more broadly, and include not only children with particular medical needs but also developmental, mental health and physiological or environmental stresses.

Dr. Pan identified that the overarching goal of this Committee is to identify opportunities to:

- Improve the current organization and systems of care for children with special needs
- Reduce fragmentation between systems of care for children with special needs
- Better support families and their children with special needs
- Develop better systems and services so that every child will have the opportunity to thrive

Presentation: "Overview Systems of Care: What does the current data show?"

Comments by Dr. Pan: I'd like to thank the Lucile Packard Foundation for Children's Health for their ongoing leadership in addressing the needs of children with special needs and also the Foundation's support in providing this Committee with background information and technical support to advance our work.

Presenter: Edward Schor, MD, Senior Vice President for Programs and Partnerships, Lucile Packard Foundation for Children's Health

Dr. Schor used power point slides concurrently with the presentation (See Appendix A).

Systems of Care

- Takes a system to address the care for children with special health care needs and there are multiple components of that system (e.g.: Education and Child Care; Health; Family Support and Advocacy; Recreation & Community; Care Coordination; Legal & Financial; Social Services; Developmental Disabilities and Long-Term Care)
- Public systems of care— including Medi-Cal: California Children's Services program, Mental Health, Developmental Disabilities, Special Education and Child Welfare—are managed by separate agencies, have separate budgets, and have separate regulations
- Fragmentation of services is built into the systems of services; thus coordinating among systems, not to mention integrating their services is incredibly difficult and complex

Argument for Integrating Systems

- Although many children are receiving services from multiple programs from these various departments and disciplines, ironically, there appears to be very limited data on the frequency or extent of overlap or duplication of services
- Coordination will be difficult unless we identify the commonalities and shared responsibilities

Special Needs of Special Needs Children

Dr. Schor presented the list below of systemic needs that children with special needs have:

- Readily available principle contact—Every child needs a person that they contact that gets them into the system
- Planned, accountable services—Services need to be planned and people need to be accountable for those services
- Multiple system involvement—Must acknowledge that multi-systems are involved
- Access to skilled professionals—Must have skilled professionals available
- Prevention of progression and comorbidity—Must all think about preventing progression, whether that's progression of health problems, progression of mental health problems, progression of social problems, etc.

- Special accommodations –Must be able to offer some special accommodations, whether that is longer to take a test or the provision of a wheelchair
- Family-centered services and support—Everybody agrees we need family-centered services and that families need a variety of supports; we need to build a system that actually assures those services
- Readily available and shared records— If we are going to integrate programs and coordinate programs, we must have data and records that are readily available and are indeed shared
- Coordinated or integrated services –The reason you need care coordination is because you don't have integration; so care coordination is a necessary bandage to partially compensate for the lack of integration

Key Components of a High Performance System for Special Needs Children

- Must take a whole child, comprehensive coordinated approach to care
- Must have service plans that are integrated and must share the information with all providing services to the child and family
- Must have meaningful family involvement
- Mush have adequate number of well-trained professionals
- Must have equity of access to good quality services—currently there is inequity of access to services based on geography, race and ethnicity, income, etc.
- Must have transparent monitoring of these systems to ensure we have high quality of services

Special Needs with Health Components

- Health is a the common link throughout all of the systems including child welfare, special education and developmental disabilities
- Children get into the child welfare system because of their own or their parents mental illness, substance abuse, post-traumatic stress disorder, chronic illness
- Health is linked to special education through prematurity, genetic and congenital disorders, mental illness, and chronic illness
- Health is linked to developmental disabilities through prematurity, genetic and congenital disorders, neurologic disorders
- Central to the work of all of these systems and to the need for their services is poverty and its consequences

Trends and Data for Children with Special Health Needs

- Increase in the number of children with special needs by 1% between 2001-2011
- Rates of Disability in Children: 2001-2002 year rate of children with disability was 6.87% compared with 7.95% for the 2010-2011 year
- Slightly over 10% of children in California between the ages of 0-17 meet the definition of children with special health care needs for the 2009-2010 year
- California has a lower proportion (10.6%) of children who meet the definition of children with special health care needs compared to the national rate (15.7%) for the 2009-2010 year

- Analysts attribute difference between California's proportion of children identified with special needs and national rates to California's large Hispanic population; Hispanic families are reticent to identify their children as having special needs. Consequently, when they are identified, they have more advanced health problems.
- Rates for children with more complex, higher levels of special needs in California run parallel to national rates, however for children with less severe special needs rates in California are substantially lower compared to national rates
- Recommendation: Must do a better job of early identification of children in California if we are going to intervene effectively and reduce long-term costs.

California's Quality of Health Care System for Children with Special Health Care Needs

*Source: National Survey of Children with Special Health Care Needs, 2009/2010

- California ranks poorly on several health indicators compared nationally, according to national survey
- Indicators for this survey were developed to measure failure of access to good primary care rather than sub-specialty care specialists
- California's Rankings of Concern:
    - 50th in having preventive care visit
    - 50th in family-centered care
    - 50th in proportion of parents with above average stress
    - 46th for care coordination
    - 45th in developmental screening
    - 43th in receiving needed mental health services
    - 36th for transition to adult care

Focus of Lucile Packard Foundation for Children's Health (LPFCH)

- LPFCH has identified four key priorities for it's work:
    - Care Planning and Care Coordination
    - Family Participation and Advocacy
    - Self-Management Support
    - Disparities in Quality of Health Care

Standards for Systems of Care for Children with Special Health Care Needs

- Must identify the standards for systems of care and use as a benchmark for comparison
- Must benchmark expectations for the performances of systems, not solely child outcomes
- List of core system standards of care from the report "Standards for Systems of Care for Children and Youth with Special Care Needs" published March 2014. Although designed to improve health care systems, most of these categories apply to systems outside of health:
    - Screening, assessment & referral
    - Eligibility & enrollment
    - Access to care

- Medical home and care coordination
- Community-based services
- Family-professional partnerships
- Transition to adulthood
- Information technology
- Quality assurance & improvement
- Insurance & financing

How State Agencies Can Use System Standards

- First must identify and agree upon standards
- Must identify children with special needs as a unique population in policy and programs; cannot just assume these children's needs with be meet by a broad categorical program
- Must identify and reference national system standards to both as design and improve system
- Must monitor adherence to standards; nobody reaches 100% and standards can be an important tool to assess performance and identify where improvement is needed
- Standards allow assessment of system capacity and performance comparison of performance among systems
- Standards can act as a guide for where you might need technical assistance is needed to improve performance
- If all systems are using standards, this promotes creation of partnership among all stakeholders—families, providers, community service providers, policy makers—to figure out how best to monitor the access and quality of services

Comments and Questions proposed by Dr. Pan for Dr. Schor: The slide where California ranks is a bit disturbing—a lot of 50ths; reminds me of our Medi-Cal rates. The Annie E. Casey Foundation also ranked California 40th overall for children, not just children with special needs.

Question 1: How easy or difficult was it for the Lucile Packard Foundation for Children's Health to get the data to assess where California is in comparison with national rates? If we had a goal, to create a dashboard or a standard across all the systems, such as a report card to illustrate how California is doing for children with special needs, is that possible?

Answer: We haven't done it. We are at the stage of presenting this. The grantee, the Association of Maternal and Child Health Programs, which is national Title V, has been developing assessment tools, which take these standards and turns them into an assessment instrument that can be filled out.

I suspect some of the standards we have good data for, some we don't. Standards can be the basis for a report card for how we are doing and they can be selected based on the availability of data,

although there ought to be some selection process, which doesn't solely select on availability of data; there are a lot of important things we don't have data on that we need to look at.[iii]

Follow-up Comments by Dr. Pan: We will be hearing from various agencies and perhaps we should be asking can we come up with the data for the things we don't have. We should be choosing the benchmarks for the things that are important and then figuring out how do we get the data so we can actually measure our performance.

Question 2: Do you have additional comments for why California in particular is ranked so poorly?

Answer: Medicaid reimbursement plays into that. Most of the measures we are low on are not measures related to special health care needs or specialty care, although there are some included. Most of the measures on which California does poorly suggest that children with special needs are not getting high quality primary care and that we have two systems—we have a CCS system and a Medicaid system -- that are not linked in any particular way. Therefore, poor performance on most of those measures identify problems obtaining high quality preventative care and having a regular source for care; others are a reflection of separation for those key programs and the failure to be able to reimburse adequately for those primary care services that are so necessary.

Question 3: Are there particular states you would hold up as better models that we should be looking toward for how they organized their system of care or are performing better?

Answer: There are some but I'm not able to identify at the moment. In general, you find that Iowa and Massachusetts and there are others; sometimes it reflects reimbursement levels. One of the advantages California should have is that our coverage of children's health care, theoretically is very high. So the issue of access to services relates not to coverage, but to what that coverage can buy when reimbursement is low.

Follow-up Comments by Dr. Pan: We may follow up with you on some of the models for reimbursement and we appreciate your presentation. Thank the Foundation for the support of this Committee

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[iii] Post-hearing, Dr. Schor provided additional clarification to his response: "We haven't yet done an assessment of the performance of California's systems. At this time, we are offering the compendium of standards as a resource for the state and health plans. Our grantee, the Association of Maternal and Child Health Programs, which is national organization representing state Title V programs, has been developing assessment tools, which uses the standards to create a self-assessment instrument that can be used by state programs or health care organizations. For some of the standards we have good data, for others we don't. Standards can be the basis for a public report card to convey how systems or programs are performing; their contents can in part be based on the availability of data, but some of their contents should include information on functions that are important even though data is difficult to obtain."

Presentation: "The Family Perspective"

Presenter: Wendy Longwell, Parent, Family Voices of California

Wendy Longwell shared family photos concurrently with the presentation (See Appendix B)

- My son Derek was born in 1995 with Spina Bifida, hydrocephalous, and bilateral clubbed feet and there have been other diagnoses added since his birth
- My son is very active; he might be in a wheelchair but he is not wheelchair bound. He is involved in disabled sports and is involved in various activities
- From the family perspective; it is very time consuming, very frustrating to deal with all the different systems and navigate through the different systems
- Derek has been involved in every system mentioned today
- Throughout the years, had to learn how to navigate the different systems; for example, in the case of special education, mental health is not part of the IEP, and yet mental health is linked to community, home, and school and yet mental health isn't part of the school system
- Everybody functions in their own silos and the parent is one to bridge between every silo
- That's why I keep binders of Derek's history so I can share with the different silos, whether it's school, mental health, CCS, doctors that we get referred to, I always have Derek's binder with me because nobody shares this information. I'm the only one that has all the information to ensure they have the most relevant information to treat my son correctly
- Recent changes have made making this more challenging; for example, before managed Medi-Cal came in, I could call the primary medical provider and have Derek seen within a day or same day. Now I call and it is a 6-week wait. To give you an example of why this is not ok for my son; he doesn't have feeling in his lower legs, and he has a wheelchair that has a metal plate for where his feet rest and that metal plate can cause ulcers on his feet. This happened with my son and I called Derek's primary care doctor and it was a 6-week wait, I called the wound clinic, it's a one-week wait, so better, but Derek is still going to end up in ER, so I left several messages. I know what Derek needs, he needs Bactrim DS and I need it now so Derek doesn't end up in the ER. We went down to UC Davis to see Derek's neurologist and asked the urologist to write a prescription for Bactrim DS and that prevented Derek from going to the ER.
- It's a hardship as a parent trying to navigate the system now

<u>Examples of Challenges with Transition</u>

- Derek is 20, and he is in the process of transitioning from CCS
- When he turned 18 years old, everybody wanted to re-evaluate him to see if he still qualified for the services, as if Spina Bifida was cured because he turned 18 years old
- The time and commitment to do all the evaluations—through the school, through SSI, through the Regional Center—every single entity we were connected with had to do some kind of re-evaluation when he turned 18 years old and of course he still qualified
- Turning 21 years old is the next big transition

- At 21 years old, Derek will lose CCS; Derek attends meeting and has asked why he can't keep CCS until 26 years of age like with private insurance which now extends health coverage for young adults up to 26 years old age under a parent's health plan
- For example, I'm working with the Medi-Cal system to find a pain management provider outside the CCS program and Derek's primary care provider filled out the referral for the pain management provider still has not returned my call
- When I wanted to look at switching my adult son's care to Stanford from UC Davis, I called CCS and from the time I called CCS, they set it up for second opinions at Stanford and Derek had his initial appointment within 6 weeks after that initial call with CCS
- CCS works very well, makes it so much simpler; its one phone call verses how many other calls. It's nice to know you have someone you can call that knows who you are, knows your child and what their needs are. I don't have that with Medi-Cal.
- Medi-Cal has care coordinators but you get a different one each time and they don't know your child and what they really need. So the parent has to educate each person, each time you call
- Very important as a parent to know you have a main contact point person. Besides CCS, the other person I would say I have is the Regional Center and I can call and they know who my son is and they can help out

Examples of Care Coordination

Wendy Longwell presented a "Care Map" concurrently with the presentation (See Appendix C)

- Overwhelming and amazing to see all the different entities a parent has to deal with to make sure your child has all the care that they need
- Must troubleshoot; for example, coordinating between physician and the supply source to ensure Derek has the supplies he needs, the prescription has been sent by the physician, the supply source has received the prescription and the supply order has been approved and will be shipped in a timely manner
- I can spend all day coordinating everything that Derek needs because no system makes it easy. For example in one day after taking three kids to school:
    - Helped Derek get ready for a doctor's appointment
    - Scheduled 3 appointments
    - Scheduled 1 surgery appointment
    - Made 1 wheelchair evaluation
    - Took Derek to the doctor's appointment
- Parents must call each and every different entity because they all work in silos
- CCS knows my child and recognizes the importance of his needs; for example, Derek was ready to be discharged from the hospital and the CCS director asked what equipment we needed to get Derek home. I gave the CCS director the list the doctor gave me and all of the equipment was delivered to my house before we got home. You can't get that from a private insurance or Medi-Cal
- I don't know what I would do if I didn't have CCS and the thought of rolling CCS into managed Medi-Cal where you are just another number and not a name scares me. I'm not

saying the managed Medi-Cal plans would not try to do best they could, I just don't think they could do what CCS does

Parent Navigation and Peer-to-Peer Support

- I work at an Family Empowerment Center (FEC)
- As a parent who has this experience, I can help other parents who are new to the system and don't know how the system works and help them learn and navigate
- SB511 requires California to fund FECs; California is supposed to have 32 and we only have 14 FECs that have been started since 2001. For example, up in Northern California, my FEC covers 6 counties, and another FEC covers 3-4 counties, but where do those families go that don't have an FEC in their county?
- I can educate other parents, for examples which waivers are needed and the process to get the appropriate services, equipment and support
- It's very gratifying job, it's an overwhelming job
- Recommendation: We need to get rid of the silos so that they are all working together
- Recommendation: We need to have a lead contact/coordinator who knows the families and can help them navigate the system because families don't know how to do it and they often hear the easiest answer—"No."
- Recommendation: FECs or an entity similar to FECs can help families navigate CCS, Medi-Cal, whatever entity they need for their child.

Follow-up Comments by Dr. Pan: As a primary care physician who took care of children with special needs, I know the hoops I have to go through on my end and I recognize the families have to go through even more hoops. We need to figure out a better way coordinate and to ensure families have the support and tools they need.

Panel 1: Physical/Medical Health Services and Programs

Comments by Dr. Pan: We appreciate your presence and providing an overview of programs and services, particularly we hope to hear how these programs may interface with other silos that we have discussed today and identifying where the funding barriers or opportunities may be to bridge these interfaces.

Presenter: Jennifer Kent, Director, California Department of Health Care Services' California Children's Services

- Over last ten years of the program, we have seen a 61% enrollment growth in children
- To date, DHCS covers approximately 5 million children; 180,000 of those children are in the CCS program

Data Analytics Provided for the 2011 Calendar Year

- $10 billion was spent on children age 0-18 for the calendar year of 2011
- 10 different subpopulations of children that the Department broke down, for example:
    - CCS population
    - Developmentally disabled population
    - Foster care population
    - Other disabilities
    - Undocumented
- The developmentally disabled populations and the CCS populations were extremely high in terms of PMPM costs; roughly $1,800.00 PMPM is spent on the developmental disabled population and about $1,400.00 PMPM is spent on the CCS population. When discussing PMPM this is not a capitation payment but rather the expenditures divided by the children
- The average cost is about $240.00 PMPM; so the very small yet complex populations are driving the expenditures in the program
- The very complex population of children make up just 1% of the population yet drive almost a quarter (24%) of the overall costs
- In the foster care population 62% of the spend on that sub-population was in the Short-Doyle system which is for mental health coverage
- Whereas in CCS subpopulation, 25% of spend was for acute hospital costs, only 3% was for Short-Doyle (mental health) and 28% was for pharmaceuticals
- Depending on the population of children you see very different needs and expenditures
- Emergency Department (ED) room rate admissions per 1000 averages 47 visits for CCS populations; ED room rate admissions per 1000 averages 21 visits across all populations of children; and ED room rate admissions per 1000 for the most costly 1% subpopulation averages 65 visits—illustrating a dramatically different ED rate between subpopulations.
- The most common ED admission is upper respiratory
- An interesting discussion of how do we do a better job of care coordination; for example, if we look at a disease like asthma; a child without asthma conditions in the CCS program had about 41 ED visits per 1000, whereas for a CCS child with asthma the ED visits doubled to 82 visits per 1000, and so we have to do a better job here
- The CCS subpopulation is a very complicated, complex population, the inpatient utilization, excluding ED admissions, is 1,876 per 10,000 member months, that's almost 3.5x higher than the developmentally disabled population and 13x higher than any other disabled population and this is driven in-part by the CCS subpopulations extraordinary medical conditions and some cases very rare conditions
- CCS constitutes 2% of enrollment but 51% of all the acute inpatient days
- Social Services and others are having conversations about mental health and the social support side
- CCS are very individual children with very specific needs; we are very proud of the work we do and we always have room to improve and are working hard to implement
- The Department would like to share the 2015 Healthcare Effectiveness Data and Information Set (HEDIS) dashboards; while there is not a HEDIS measure geared toward children with

complex or special care needs, we do have a number of HEDIS measures that are child focused. For example:
    - Vaccine rates
    - In-patient admission
    - Asthma control
    - Weight counseling
    - BMI index
- The Department would like to share that data with the Committee and this will be the marker for how we will be accountable and the plan will be accountable for outcomes

Presenter: Barbara Sheehy, Contra Costa Administrator, California Children's Services (2002-2015)

Overview of CCS Care and Services

- Arrange, coordinate and authorize payment for specialty medical care for our clients, children ranging in age from birth to 21
- Serve a broad range of medical conditions
- CCS enrollment requires that children meet financial, residential and medical eligibility requirements
- Clients are seen at DHCS-certified facilities and special care centers and seen by CCS-approved providers and comprehensive multidisciplinary pediatric teams

Two-Primary Components of the CCS Program

Component 1: Administrative Case Management Program

- Includes physicians, nurses, eligibility workers, clerical staff and in some counties social workers and nutritionists and others; determine eligibility for the program and work with families and providers to coordinate care such as labs, hospital visits, and coordination between providers and durable medical equipment vendors, etc.
- We review child's treatment plan to ensure children will receive care that meets CCS standards –taking into account family's preferences and needs such as the preferred location or language preferences –and authorize the payment
- We do everything in our power to make sure the child has the right care and it's provided at the right place and at the right time
- We work with families to overcome barriers; for example helping to arrange transportation to get to appointments or helping to ensure families have access to meal vouchers while families are staying at the hospitals at bedside
- We refer our families and caregivers to the Family Resource Centers so that they have the support and gain information from families that have gone through similar experiences
- Overseeing and continually reviewing our clients care

Component 2: Medical Therapy Program

- Provide direct outpatient rehabilitation services at public schools throughout the community
- CCS occupational and physical therapists provide evidence based therapy to our clients as part of the child's prescribed treatment plan and to improve a child's function and long-term potential
- For example, we train and work with a family and the child to learn proper use of the equipment
- We have physicians who specialize in working with children with physical disabilities who come and hold clinics, and as a care team including the therapists and family, evaluate the child's needs and progress and plan for upcoming 6-12 months of care

County Variation

- Some counties have more enhanced services, such as a specific transition program to help youth move into adult care
- Contra Costa County and Alameda County arranged to have a nurse onsite at Children's Hospital Oakland to improve the face-to-face engagement with families and help problem solve with providers

Current Challenges and Barriers

- Challenge 1: Children with special needs are straddling these various entities'—primary care, specialty care, developmental disability system, special education, and mental health—and we are arranged in silos and this results in fragmented care. It's children and families who suffer the most and it's an overwhelming burden on families
- Recommendation: California needs a more child and family-centered approach, a whole-child model to assess all the child's need when planning care and implementing and coordinating services
- Challenge 2: Poor reimbursement rates for providers. CCS provider are paid at the Medi-Cal rate and physicians have a 39% bump; it's still extremely low and it has resulted in the loss of local and statewide providers and this trend is a worry in terms of access to care for kids
- Challenge 3: With the discussion to move CCS into managed care and the potential of dismantling the pediatric system of care in California, there is a concern that the outstanding care that children have access to through CCS may be diminished and is a threat to those children in the CCS program and really all children and families in California

Presenter: Dr. Richard Chinnock, Board President, Children's Specialty Care Coalition

- I've called this a tangled web. As an example, if you think of child, a 3-year-old who has autism, and who also has some compulsive behaviors and now has Type 1 Diabetes; I count at least 12 entities that are trying to coordinate care for that child
- I'm here representing the Children's Specialty Care Coalition as the President, but I was a general pediatrician who practiced in a small town, in South Carolina for 3 years, and I run a

patient-centered medical home for children with heart transplants at Loma Linda, I'm the Chair of Pediatrics at Loma Linda University School of Medicina and recently named the Chief Medical Officer of our Children's Hospital

- The Children's Specialty Care Coalition was founded in 1998 to address the growing crisis of availability of access to subspecialty physicians and we represent about 2,000 subspecialty physicians in the state of California and who are at the forefront of providing care for children with special healthcare needs
- We work as part of the multidisciplinary care teams

Speaking from the Subspecialist Point of View

- Pediatric subspecialty care is typically provided at regional tertiary care center hospitals and outpatient centers to ensure sufficient volume of patients. The CCS program is an integral part of this system of care
- CCS set standards that define what is a qualified physician to provide that care, what is a qualified center, and periodically reviews centers providing a lot of collaborative information and advice and guidance
- We work closely with CCS county administrators and nurses to ensure that children receive the right care, at the right time and at the right location and some day, with the right reimbursement
- It works, however we put together the payment mechanisms, it does work, but it's an incredibly complicated process
- Recommendation: To create a system that is more rational and integrated

Challenges and Barriers to Care

- Challenge: Lack of real-time data that can be used to measure health outcomes and be used to drive systems-wide improvements
- CPQCC is a model that could be used to show how this could be done statewide and also to demonstrate the systems' effectiveness
- Recommendation: Could do better if we had a more rational way of assessing data
- Challenge: Transition; when children turn 21 and age out of CSS
- Challenge: Having access to pediatric subspecialists; I'm recruiting from a nationwide pool of subspecialists not just within California so there has to be some sort of parity of reimbursement rates across state lines
- Challenge: Mental health coordination access is a big challenge
- The system providing ideal communication between generalists and subspecialist needs improvement
- Challenge: If CCS children are enrolled into the managed care model— it's important to consider whether those children stay unique or are rolled into the general population and whether there is a tiering system for how they are paid for based on complexity—this will also be an interesting challenge to work through
- Challenge: Supporting and creating medical homes is a real challenge and I'm not sure we have that worked out for children with complex needs

- Recommendation: We need a different payment system and standards for care
- CCS program in the state is working relatively well, most families are very happy with this system. That said, I'm a firm believer in a whole child model and the details for how this should will be done is key; but the transition needs to be managed in a way that doesn't break what is already working well.
- Let's proceed cautiously in a way that allows us to not lose kids in the transition

Comments and Questions by Dr. Pan

Thank you to everyone. Thank you Director Kent for sharing interesting data about Medi-Cal and CCS

Question 1 for Dr. Chinnock: One of the criticisms of CCS is the separation of subspecialty care and primary care, when we talk about whole-child, we recognize there is a need to bring specialty and primary care together. As we try to move forward to integrate the two, what do you recommend as a way to bring the two together within the CCS program?

Answer: I've thought of this and we are trying to decide how to do this within our region with our local health plan and CCS even if we don't get to whole child model; I think it's going to likely be a hybrid solution based on region and willingness of local general pediatricians, there are some who are willing and able with the right support to do this. The American Academy of Pediatrics has surveyed its members and there is widespread support for doing this, but they all say they need support. For example, while the medical decision making might not be that tricky, I have a social worker, and dietician and a case manager in my medical home that can implement that. So I see it as either a regionalized distributed networks of medical homes for children with complex needs that is their home, or a team, such as the one I have that supports me to provide support

Comments by Dr. Pan: Certainly in my experience as a pediatrician I took care a lot of those children as the primary care and we needed those extra supports. North Carolina has a model where they give coordination of care payments for patients that they are seeing and it's been very successful and has shown significance on examples like asthma and so forth. When you have a coordination of care payments where the primary care physician can utilize this funding and they may pool that money for a social worker, care coordinators, etc.

Question 2 for Kent: Is this something that DCHS is looking at?

Answer: There is a provision in the Affordable Care Act (ACA), it's affectionately referred to as Section 2703, that is the Health Homes model included in the ACA and is a way for states [to have] eight full quarters of claiming to get a 90/10 match, so for $0.10 cents the State puts in the Federal government contributes $0.90 cents for care coordination. So we have been going though a long stakeholder process on the Health Homes model and how it should look in California and what populations are eligible and how to create these homes. The money does not pay for services but it does pay for the coordinating of those services and one of the populations that we have identifies in the stakeholder process has been CCS. We are due to release our proposal out for public comment on

Health Homes and then we would file what's known as a State Plan Amendment with the Federal government asking for funds for this purpose and approval; we are actively engaged in that.

Question 3 for Kent: Dr. Schor had talked about this idea of a report card or standards not just applying to Medi-Cal or CCS but more broadly for children with special needs, is that something the Department would be open to help contribute toward such as with technical assistance and data?

Answer: We have the Medi-Cal Children's Health Advisory Panel (MCHAP),[30] and one of the things that advisory group is working with us on with Dr. Linette Scott, who is the Department's Chief Medical Information Officer, is on developing pediatric dashboards. So that is one of the continuing evolutions of the Department -- we have a lot of data, but it's how we analyze it and share it and use it for decision making and we have been talking with a set of stakeholders about how to best develop measures – because some are in existence and some are not—and how you would make sure the measurement is appropriate, especially if it's going to gauge payments or other types of incentives. The Department would like to have a say in any kind of pediatric dashboard or child health report card.

Comments from Dr. Pan: You mentioned the HEDIS report and certainly that is going to be important but one of the limitation of the HEDIS is that HEDIS is going to look at large scale asthma, most common chronic disease in childhood and dental care, but when you start getting to the more rare conditions it's going to be more processed measured because the numbers are just not large enough. We can look at service quality and access and so forth and perhaps collaborate with Lucile Packard Foundation for Children's Health on this.

Question 4 for Sheehy and Kent: Regarding CCS at the county level, where does the funding come from and what portion is coming from the county and what portion from the state and how does that impact the services you are able or not able to provide in your county versus other counties?

Answer from Sheehy: The majority of the kids covered by CCS services are in full scope Medi-Cal, so the other portion (about 15-18% statewide) is not covered by Medi-Cal, and some of the complexities are with children who are undocumented and some are families with insurance but it's limited and CCS picks up part of the care. For those children without full-scope Medi-Cal the funds are split 50/50 between the State and County. The Medical Therapy Program is also split 50/50 between the State and County and there is no financial eligibility requirement for the MTP program. And for those children covered by full-scope Medi-Cal we have Federal and State funds.[iv]

[iv] Post-hearing Ms. Sheehy provided the following clarification: "There are three different funding streams, representing CCS clients' insurance coverage, supporting the CCS Administrative Case Management Program: CCS Only (7% of the CCS population), Full Scope Medi-Cal (81% of the CCS population), and Optional Targeted Low Income Program (12% of the CCS population). Counties contribute approximately 50% of funding for CCS Only clients, and approximately 10% for the remaining CCS client population. The Medical Therapy Program is funded by

Answer from Kent: Yes, that is almost fully accurate. There is the small population of children that were formally known as Healthy Families Kids, counties have 17.5% and the Department contributes and federal funds. MTP is county funds and federal funds so the county provides the match for the non-federal share, the state does not have a share, and we pick up the tab on Medi-Cal with, a 50/50 split and it's complicated. The state doesn't have the share. The Department picks up the share for Medi-Cal.

Question 5 for Kent: Where does Title V the Maternal and Child Health Grant (MCH) come into this?

Answer: The Department of Public Health has the primary responsibility for the distribution of the Maternal and Child Health (MCH) dollars from Title V; the Department get's about $8 million dollars in MCH funds and we distribute it to the counties to fund care coordination but it's only $8 million dollars and it's a small amount when divided up

Question 6 for Kent: Just to clarify, it's $8 million from MCH that goes to counties to fund coordination of care, do you know what proportion of the cost for the care coordination that MCH funding represents?

Answer: This answer would be on our estimate for what we spend on county administration for CCS because we provide funding to the counties for the administration of the program and this is where it also gets complicated, some counties are independent for CCS so they do the financial, the medical and the clinical assessment for children and then in some counties, we, the State, do the financial or medical assessment so it depends on each state's share. I think the overall spend for CCS is over $3 billion a year and local assistance, meaning county funding would be a much smaller piece of that $3 billion; I would have to get back to you to confirm.

Question 7 to Kent: But the $3 billion is the total CCS spend on services?

Answer: Yes, $3 billion is the total for services and then we would break the local assistance down but we wouldn't specify how much is administrative verses how much is care coordination; they determine that on their own. I can certainly provide that to you after.

50% County and 50% State General funds, and Medi-Cal is billed for medical therapy services which offsets 75% State and 25% County program costs. Counties do vary to a limited extent by the level of county funding allocated to leverage State and Federal funds, resulting in some differences in services provided."

Question 8 to Kent: I know we mainly talked about CCS, but CHDP, which often does primary care; so now, does county contribute funding to CHDP?

Answer: I think the answer is no. I think it's a state-federal program. There have been many changes since the expansion of the ACA, and obviously there will be more changes starting next year when we offer full-scope benefits to all children when we offer full-scope benefits to all children under the age of 18 regardless of documentation status. CHDP is a program that is an entryway into some of the EPSDT services and screens, an important doorway that kids can pass through to get into Medi-Cal, CCS, into EPSTD services. I neglected to mention some of the other specialty programs that the Departments runs including the Pediatric Pallative Care Program and we have the Newborn Hearing Screening Program. The Department does a lot of work and sometimes the CHDP door is the way families enter for a number of different services.

Question 9 to Kent: And just to touch about EPSDT;[31] California seems unique in how it handles EPSDT. EPSDT is also a mechanism for funding other care—there is the treatment part, the T part—and so are there opportunities there for California that we are not taking advantage of?

Answer: I would have to get more grounded on the range of what we do and how we do it through EPSDT. Some parts are the mental health component, some parts are the treatment, sometimes the Medi-Cal managed care plans have responsibility for EPSDT and in other cases, especially as it pertains to children, at the Regional Centers the Department will take over where other services hand off. I'm really struck by the silos; I don't think it's practical to say the silos will ever be knocked down but it's up to us as government entities and programs that we do the back-end coordination better so that the family and the providers don't see that. I would have to get more detail on the EPSTD to answer your question and I'm happy to get that to you.

Comments from Dr. Pan: Thank you, I appreciate that. I would like to explore the opportunities, and I agree with you, I think we are never going to get rid of the silos, but ideally what we would like if it all runs in the background for the families so it is seamless

Question 10 for Sheehy: How does the CCS case manager interface with special education and evaluation at developmental centers, can you touch on that?

Answer: It does happen and ideally would always happen. The coordination happens to the greatest extent between the Medical Therapy Program (MTP) and special education because the children enrolled in that program are on school site and we coordinate heavily with the schools; for example our therapists may go into the classrooms to consult with the teachers on a child's needs. In terms of coordination with our medical case management part of the program, that does happen and can happen both at a client and family level and some counties, with the support of the Lucile Packard Foundation for Children's Health, have developed collaborative care coordination bodies in the counties and are looking at system-wide coordination and trying to develop more relationships to

carefully work together, and especially for the most complex cases to work carefully together. Whenever a family invites a CCS nurse or medical therapy staff member, we are set up to go.[v]

Comments from Dr. Pan: Excellent, well hopefully this Committee is going be sparking a statewide conversation which will then hopefully spark a conversation at the county level about how we coordinate across these different silos. Thank you all very much for being here and testifying; this has been very helpful and we will be following up with some of the questions.

Panel 2: Mental Health Services and Programs

Comments by Dr. Pan: Our next panel is on mental health services and programs. I should preface that this is of particular interest because my clinical specialty has been children with behavioral problems and learning disabilities and so I have worked very closely as a school physician on children who have had challenges at school and with behavior. An area of deep interest to myself personally and I appreciate all of you being here.

Presenter: Karen Baylor, Ph.D., Deputy Director, California Department of Health Care Services' Mental Health and Substance Use Disorder Services

A list identifying the coordination efforts under way with agencies was provided by DHCS to the Select Committee on December 3, 2015 (see Appendix D)

- With the implementation of the Affordable Care Act, we were able to expand mental health services for the mild to moderate under the managed care plans.
- I oversee specialty mental health and this will be the focus of the presentation today
- As you know DHCS is the single state agency for Medi-Cal and through the authority of the 1915(b) Freedom of Choice waiver, we contract with all the counties to provide the specialty mental health services

[v] Post-hearing Ms. Sheehy provided the following clarification: "CCS case managers and occupational and physical therapists do interface with Special Education and the Regional Centers. Ideally this would always occur. Staff participate when asked by a family to attend a client's Individualized Education Plan meeting. The greatest level of collaboration happens between the CCS Medical Therapy Program and Special Education. Each county has an interagency agreement between CCS and the Special Education Local Plan Area, defining the roles and responsibilities of each. We coordinate heavily with schools; for example, CCS occupational and physical therapists may go into classrooms to consult with teachers on a specific child's needs. Our therapy staff and medical case management staff also communicate and coordinate regularly with Regional Center case managers. Several counties, with the support of the Lucile Packard Foundation for Children's Health, have developed care coordination collaboratives to assess and improve local care coordination for children with special needs and their families, especially for the most complex or vulnerable clients."

Examples of Mental Health Services:

- Services include:
    - Individual
    - Group
    - Assessment
    - Planned Development
    - Medication support
    - Psychiatric support
    - Crisis intervention
    - Crisis stabilization
    - EPSDT
    - Targeted case management for psychiatric in-patient
- These services are not just office-based services but a number of these services the county provides out in the communities
- EPSDT is available to those with Medi-Cal under the age of 21
- Counties are required to provide a range of services for the provision of the specialty mental health services for those who meet medical necessity criteria

Agency Oversight

- DHCS' role and responsibility is to provide oversight and monitoring of the mental health plans and we do that through an annual, external quality review that goes out and reviews each county plan once a year and we do a triennial where we look at the whole system and we do chart reviews.
- With the recent 1915(b) approval from CMS they granted us for the first time, a 5-year approval and they had requirements, one of which was that we develop dashboards at the state level and also at the county level and we are working on those now. Hopefully in the near future we will be able to have dashboards and people can go onto the website and see what counties are doing.

Funding

- Regarding funding, there are a number of funding streams which all goes into a big pot at the local level and then local decisions are made for the best interest of those communities and how they spend their dollars
- Brief Highlight of Funding Streams:
    - 2011 Realignment established a behavioral health sub-account for EPSDT specialty mental health, drug Medi-Cal, and other substance issue disorder services—so it all goes into one big bucket and on the local level they decide how to spend those dollars
    - The Mental Health Services Act, which was Prop. 63, the 1% tax on millionaires
    - 1999 Realignment which is a percentage of sales tax revenue and vehicle licenses fee which goes into the local account
    - Federal financial participation which is the Federal piece
    - County General Funds

- On the local level, the counties use all those funding streams to make sure they are providing services needed at the local level

Coordination with other agencies:

- Coordinate with sister agency, the Department of Social Services, on a number of issues regarding foster care and the use of psychotropics
- We work with the Oversight and Accountability Commission on their crisis services workgroup
- We are involved with the Child Welfare Council and others on the Priority Access Project which is looking at families for reunification
- We work with the Office of Juvenile Justice and Delinquency prevention and Attorney General's office on the Defending Childhood Initiative
- And I have a whole list of others but these are the highlights

Comments by Dr. Pan: Wonderful, if you could please provide the list to our staff that would be wonderful. Thank you

Presenter: Terry Rooney, Ph.D., Colusa County - Behavioral Health Director and representing the County Behavioral Health Directors Association

- I'm a 30 year advocate for child services and the parent of a child with special needs
- The county contracts with the state to provide county mental health services which includes individual group services, community services, school-based services, medication services, crisis services, etc.; we are the safety net, we provide the services at the local level

Current Challenges and Barriers Impacting Care

- Challenge: In northern part of the state, Medi-Cal managed care entities and their inability to provide provider networks in our area so we continue to be the providers of services even though they have already been paid to provide those services in a capitated system; we in a fee-for-services system continue to provide those services because the providers are simply not there, primarily we provide psychiatric services, but also all the other specialty mental health services
- Threshold for medical necessity is fairly low for children—all the mild to moderates—this means anything from basic socialization to school services and all the way to crises services for children in need of hospitalization
- I can't speak to the entire state, but I belong to a consortium for the northern state superior region of California and in our region we have two entities; we have Anthem Blue Cross and California Health and Wellness, and although I appreciate the challenges associated with designing those provider networks, at this time, mental health services still falls to us
- Challenge: Congregate Care Reform. I've been advocating for group home reform for many years; I'm pleased to see it's happening but I'm concerned about the dependency of that

reform on mental health services. It will create an increased demand for those services, specifically the higher end services—on a local level, on a regional level, on a statewide level—that I don't feel we are currently prepared to offer.

- The County Mental Health Plan's mandate is always the least restrictive environment and we want to engage people in the community and the home for these children who have had traditionally a higher level of care supporting these children is going to be challenging

Presenter: Steward Teal, M.D., Clinical Professor of Child Psychiatry, University of California at Davis, and representing California Academy of Child and Adolescent Psychiatry

- Worked in Community Mental Health Center in Northern Sacramento for 40+ years, and I was in charge of Children's Mental Health Services in Sacramento County in the early 70s, we got all the kids out of the state hospital and tried to get them into facilities that could accommodate their needs, but afraid we didn't do that for all of them
- Child psychiatry provides services other than handing out medication; what a child psychiatrist does at the community mental health center is first a good evaluation—this is crucial—then you work as a team with the child having a therapist, if the child needs medication then the psychiatrist will provide that, if the child needs other services, the psychiatrist will make that happen. For example I had a child who I thought needed an electroencephalography (EEG) for a potential seizure disorder and it took me 6 months tying to get the HMO to provide that EEG based on my referral and reasons I gave. This is not unusual
- Challenge: Coordination between the child psychiatrist at the clinic and the HMO is a big problem
- Challenge: We have had a lot of issues recently with continuum of care, AB3632 was defunded by former Governor Arnold Schwarzenegger; at that time we had a good relationship with the school district. If we had a child that needed out-of-home placement it could be obtained using AB3632 and the IEP process and that is no longer happening from my experience. The schools are no longer responsible for all of the placement of kids in residential facilities though the IEP process; when that doesn't happen, the child has very few options other than to be made a ward of the court or dependent of the court and the parents lose responsibility for their child and that is just wrong
- For example, I've had kids in the hospital and we could not get placement for them in an appropriate place and we had to tell the parents to abandon the child at the receiving home, which many parents did; they were threatened by social services with being arrested but that never happened as far as I know
- AB3632 was legislation for all special education children that mandated that the IEP process would essentially allow for a sharing of responsibilities for children between the community mental health center and the school district; now the responsibility for the mental health needs of children rests entirely with the school district. There was a sharing of money to fund collaboration but this is no longer happening, as far as I know
- Audit for AB3632 happening now

- Recommendation: Need a continuum of care in child mental health; you need it all. One kid is going to go from the crisis clinic to the hospital to the residential facility back home to outpatient treatment; if one of those pieces isn't there, the child will fall through the cracks and the services just won't be helpful to the families or the children
- Challenge: Record keeping; is very important and particularly for foster children. I remember being here at a conference in 1988 saying we needed a mental health record for foster children, it never happened, it still hasn't happened. Maybe now we can do it because it was a technical issue.
- Recommendation: We desperately need to have a mental health passport or mental health record for a child brought by a social service professional to a clinic, otherwise we don't know if a child has been hospitalized previously, we don't know what the previous medications were, we don't know what trauma the child suffered prior to coming into our community mental health clinic.
- Challenge: The social worker should know these things, but often the social worker doesn't accompany the child to a psychological evaluation. The foster parent also doesn't know these things, we have to have a way to make that happen and no reason why it shouldn't happen

Comments by Dr. Pan: Thank you so very much. I have met foster children who come in with new foster parents, and if I'm fortunate I've already taken care of the foster children before and I happen to know their records better than the new foster parent.

Question 1 for Dr. Baylor: State agency does an annual review, oversight, monitoring and developing a dashboard and so forth. When it comes to the dashboard, are you creating specific measures for children and children with special needs, because sometimes children's needs' can be different from the adult populations? I realize you are in the process of doing this, but what kind of measures are you looking at and are there any related to children with special needs?

Answer: We are doing a huge undertaking called the Performance Outcome System for just children and we have a huge group of subject matter experts that has been meeting on a regular basis and they have come up with a huge list of all different measures that they want us to collect and we are trying to figure out which measures we can easily collect and what's going to take more work, so that's an ongoing process. We also do reports on the Performance Outcome System to the legislature and we are happy to provide those to you as well on the implementation of our performance outcome system.

Question 2 for Dr. Baylor: I understand you are undergoing the development of these dashboards; as a subset of this work; would the Department be willing to help out with creating a dashboard or report card for children with special needs for the mental health component, using the work you are already doing to extract a few measures to use in this way?

Answer: Absolutely, at least from the specialty mental health side, and hopefully soon from the substance use disorder side that will be part of our Performance Outcome System and we will be able to have data posted on the website for access

Question 3 for Dr. Rooney and Dr. Teal: At the county level, what is the interface between the county mental health system and schools in special education? I know as a school physician there are a lot of children with behavioral issues that affect their ability to perform in school. Sometimes they may get mental health services through the school—sometimes that is the only way I have been able to get help for some of the kids, usually not on the severe side but the mild to moderate side. I understand challenges trying to get mental health networks through their health insurance and sometimes you go through the school. How does county mental health interface with the school and also how are funding streams allocated to address the mental health component within the IEP—can you please speak from the mental health perspective?

Answer from Dr. Rooney: There is variability among counties and at my county we are the providers so we provide school-based services at all schools campuses. It's primarily funded through EPSDT and through mental health service act funding. We have a program "Schools First," that involves mental health services on the campuses. I'm a big believer in school-based services in regard to the continuum of care; it is sometimes the place that we first engage with someone with behavior problems, etc. In a county like mine, there is a high percentage of Medi-Cal beneficiaries and not necessarily so in another county so they have to find other mechanisms for funding.

Answer from Dr. Teal: There is something called a SELPA, and each county is different, there are 58 counties, and each one is different, and so when we lost AB3632, we lost a unifying force and now each SELPA runs their own show.

Question 4 for Dr. Rooney: In Colusa County it's through the county mental health system and then do you get any funding from the education system for any piece of what you do or is funding all through EPSDT?

Answer: Not currently, I inherited a system that is not a shared funding, but we do have the opportunity through EPSTD to match funding, so there is a possibility for expanding services that yet has been tapped in my county. In many counties where there are provider networks that is the major mechanism; the mental health director will say give me $0.50 cents and I'll make it a dollar in terms of EPSDT funding. Every county has at least one SELPA, but most counties, especially the large counties have multiple SELPAs such as 8,9,10 SELPAs and so its gets rather complicated. Education, in my experience, is a good partner with mental health, especially when we design systems that mutually support one another's goals.

Question 5 to panel: What about interaction with CCS? I'm sure some of these children have significant medical needs and that may lead to significant stresses at home and so forth. How often do you interface with the CCS coordinators?

Answer from Dr. Rooney: In my experience, the larger counties, family therapy is the main component or service for those children and families in that system.

Answer from Dr. Teal: In Sacramento County, I can never recall interfacing with CCS. I did interface with them when I was providing services at Juvenile Hall.

Comments from Dr. Pan: I did make note that Director Kent mentioned that only 3% of expenditures is for mental health services for CCS children; this could be because the physical health is so expensive, but I wonder if this is the right proportion or is there an unmet need.

Answer from Dr. Teal: I think it would be terrific if we could do more.

Answer from Dr. Rooney: As a parent of a special needs child, I would say it's definitely an area of concern and a need.

Comments from Dr. Pan: Yes, I think it would be good to explore this. I want to thank all of you for your presentations and we look forward to following up on what DHSC is doing on your monitoring and dashboards and also trying to figure out these interfaces. When we talk about children with special needs, mental health sometimes gets put to the side; I certainly know working with children with special needs that mental health is a very important component for the child and family needs.

Panel 3: Developmental Disability Services and Programs

Comments from Dr. Pan: Our next panel is on developmental services and programs

Presenter: Brian Winfield, Acting Deputy Director, California Department of Developmental Services

Overview of System

- In California, we have a system of entitlement for individuals with developmental disabilities which means that individuals who qualify for services receive services through the Regional Centers system
- Qualifying disabilities include intellectual disabilities, autism, epilepsy, cerebral palsy and other disabilities that closely resemble an intellectual disability and/or result in the individual requiring similar services to an individual with intellectual disabilities

- To qualify an individual must have a disability that originates prior to age 18, the disability is expected to be lifelong and the disability is a perceived as a substantial handicap for that individual
- If an individual meets the eligibility criteria, as determined by a regional center, the regional center provides case management and other needed services, which continue through the individual's lifetime
- The Department contracts with 21 private nonprofit Regional Centers located throughout the state of California to provide services to individuals with developmental disabilities and their families
- Services include:
    - Intake and assessment
    - Case management
    - Advocacy
    - Assistance with access and referral to other assistance programs
    - Funding services through the Regional Centers themselves
- As of September 2015, Regional Centers were serving approximately 135,000 children and youth
- In collaboration with the families, Regional Center case managers who are assigned to each family assist them in developing the Individual Family Service Plan (IFSP) for children under the age of 3 years old or the Individual Program Plan (IPP) for individuals age 3 and over
- The IFSP or IPP delineates the needs of the individual and family, and how those needs will be met through case management, advocacy, referral and purchase of necessary services for the individual
- For those individuals under age 3, the Regional Centers provide early intervention services. These are intensive services, typically provided within the family home, and aimed at ameliorating the social, mental and physical well-being of the child, as well as assisting the family to care for the individual
- Some of the other services Regional Centers may assist with include coordinating and purchasing are medical social welfare adaptive equipment and whatever the unique needs of the individuals are to help the person remain in the family home
- Once an individual becomes school age, the education system becomes the primary provider of these services
- Regional centers continue to provide case management, coordinate and purchase services, and assist the family, as needed

Funding for Regional Centers

- Approximately 58% is from the State General Fund, and 42% is Federal funds; in current year, this equates to $2.78 billion in State funding and $1.97 billion in Federal funds

- The Federal fund source is Medicaid, which includes the Home & Community-Based Services Waiver and 1915(i) State Plan Amendment, as well as Title XX TANF funds[vi]
- Federal funds require that the State to share in the costs of services using State funds
- Additionally, the Department receives funding through two grants from the Federal government: a Federal education grant to help fund the Early Start program for children under age 3 and the Social Services Block Grant under Title XX of the Social Security Act
- The Department of Developmental Services distributes funding to regional centers based on eligible expenditures. Regional centers use the funding to pay direct service providers for services they provide pursuant to the IFSP or IPP

State and Local Coordination

- At the State level, the Department engages in activities to coordinate with other State departments and agencies that provide services to individuals with developmental disabilities. Examples of these activities include:
    - Interagency Coordinating Council for Early Intervention, which includes representatives from the Department of Health Care Services (DHCS), Department of Social Services and the Department of Education. The Interagency Coordinating Council also includes service providers, family members and other community representatives who provide the Department with a broad perspective and advice on the administration of the program
    - Transition of Behavioral Health Treatment Services for individuals under 21 years old, which is coordinated with DHCS. While regional centers are currently funding this, behavioral health treatment services will become a Medi-Cal benefit and services will transition to DHCS. The goal is to ensure there is a smooth, seamless transition for families and there is no interruption in services
- The most important piece is the local coordination through the Regional Centers with the case managers who help families navigate the system and obtain the services that they need[vii]

[vi] Post-hearing Mr. Winfield provided the following clarification: "Title XX TANF help fund the Purchase of Service expenditures for consumers under 21 years old age who are eligible for Medi-Cal."

[vii] Post-hearing Mr. Winfield provided the following clarification: "Regional Centers have cultivated relationships with their local school districts, health provider networks, county social service agencies and other to coordinate service provisions and benefit the individual they serve. These relationships help regional centers service coordinators assist families in navigating though the various service delivery systems."

Presenter: Rick Rollens, Legislative Advisor, Association of Regional Center Agencies (ARCA)

On behalf of ARCA, Mr. Rollens also provided the Select Committee with written testimony Tuesday, December 1, 2015 (See Appendix E)

- I'm also the father of a 25-year-old son with autism who has been served by the Regional Center system since 1992 and I'm a parent-founder of the Mind Institute at UC Davis as well as working in the legislature for 24 years
- We submitted a 12-page written testimony to you for review to help with this hearing and future hearings on this subject

Overview of Regional Centers:

- California's community-based developmental services system dates back to the late 1960s, at that time families with children with intellectual disabilities and developmental disabilities wanted an option to institutionalized care
- The 21 not-for-profit Regional Centers were formed to meet the needs of individuals with developmental disabilities in the community
- Note: You can have a developmental disability in California but not be eligible for Regional Center services, since we haven't expanded the definition of what is a developmental disability in our state statutes since 1971, there remain many conditions that go uncovered in our system
- The Regional Centers have three primary goals
    - Help infants and toddlers catch up to their peers
    - Help children to stay with their parents at home
    - Help adults with developmental disabilities to be as independent as possible

Function of ARCA

- ARCA represents the 21-Regional Centers and provides support to achieve their mission through legislation, state budget process and coordination of a variety of statewide projects
- Role is to provide communication, education, and training to Regional Centers throughout the state regarding statewide and federal developments
- Regional Centers serve close to 290,000 individuals and their families; this number continues to grow everyday and as an entitlement program, once someone is found eligible for services that individual is entitled under California law for the rest of his or her life
- Regional Centers serve currently 135,000 children; 98% of children live at home with their families at a cost of approximately $650 million annually[viii]

[viii] During testimony Mr. Rollens had said Regional Centers' annual budget for services was at an estimated rate of $500 million annually, however post-hearing Mr. Rollens corrected this figure: "Regional Centers annual budget for services for children between 0-18 years of age was estimated at $650 million annually."

- Regional Centers provide direct services to individual and families through the assessment, evaluation, case management services and planning of services
- It's important to note: under law, Regional Centers are required to seek out generic services first before providing services directly; this is important because we rely heavily on Medi-Cal, CCS and a number of other programs before Regional Centers purchases services
- Challenge: Safety net of these programs, particularly children's programs, which we rely on have also been impacted by budget cuts
- For children programs, services provided primarily include:
    - Behavioral services; mostly Applied Behavioral Analysis (ABA) for children with autism
    - Respite programs
    - Infant programs
- During the Great Recession, it was decided to severely limit eligibility for the Early Start Program but I'm pleased to report that this legislature—and I know Dr. Pan supported this legislation as well—was able to restore the Early Start program, a very critical program for 0-3years-olds.

Challenges and Barriers

- Challenge: The developmental system has been grossly underfunded for decades and worsened under the great recession; the system has sustained over $1 billion in cuts and also trailer bill language adopted to cut programs, such as the example of the Early Start program
- Recommendation: Restore developmental services to a level where it needs to be
- ARCA is proud members of the Lanterman Coalition;[32] we strongly urge the legislature and the Governor to support stabilizing this system with a 10% increase immediately and increasing funding to 5% annually until reform is achieved
- Challenge: Triage problem, so many service providers going out of business, so many programs not being developed for children's programs and other special populations
- Challenge: Autism epidemic
- Great need to take a look at this system and how we provide rates and reform how we provide rates and support to Regional Centers

Comments from Dr. Pan: Thank you so very much. We did try to put a 10% increase in the budget; we have to keep working on it

Question 1 to Winfield and Rollens: I understand that the State basically takes funds and distributes amongst the Regional Centers; how do you decide how much to distribute and what kind of performance standards or other types of oversight after distributing the funds and are there measures being used to look at outcomes?

Answer from Winfield: The funding is actually in two different buckets; there is the Operational Funding for Regional Centers to hire their staff and to run the operations and then there is the

Purchase of Service Funding used to fund the services Regional Centers provide. We look at the historical trends of Regional Centers funding of services— and the services are an entitlement— so the services will continue on and we look at those trends and we look at new services coming on line to determine what the budget should be for each of the Regional Centers to fund purchase of services. For operations it's pretty complicated and includes a core staffing formula which looks at the number of individuals they are serving, the number of staff they have, and how many case manager they need and there is a formula to come up with the operations budget

Question 2 to Winfield: Are you taking the pot of money for the year and determining how to allocate the funds based on trends or is funding allocated based on an estimated number of services for the year? Trends can be difficult and so how do you go about doing that; is this about guessing how much Regional Centers are providing and then that is what Regional Centers get for the year or is there any sort of back reconciliation for the differences that might have happened in the actual year?

Answer from Winfield: Well it's a pretty complicated methodology for determining what we believe the budget will be for the upcoming year and so we use the trends from the past and look at future services. There are times when funds have to be shifted from one Regional Center to another to account for a lack of purchase of service funds or an increase. So we monitor that throughout the year and we need to live within our budget each year and that is our goal.

Answer from Rollens: So 90% of the budget goes to purchase of service and goes to the thousands of vendors Regional Centers use throughout the State and about 10% goes to the operations budget where primarily the largest amount of funding from this budget goes to case management services and there was a time—a long time ago—when there was more money in the system that was used and the money was reverted back to the State but those days are long long gone and we haven't seen a year like that in many years. One of the other challenges that we have is that the types of folks we are serving today are different from the folks served 20 and 30 years ago in the system. The needs for folks, particularly in the autism world— and I'm a parent of a child with autism— and the needs are different than the needs for others in our system, yes similar in some ways but also different and an expensive group of folks to support and we really need to take a look at reversing a number of the actions that were taken during the great recession, including the new program development freeze; we are unable to develop new programs, at a time when we are desperately in need of new programs for children and adults. The rates that we pay providers are dismal and the caseload ratio for Regional Centers case managers are not compliant—no Regional Center is caseload ratio compliant as agreed upon for federal funding for this system—we are in jeopardy of losing those federal dollars if we don't do something about that case load ratio.

Question 3 to Rollens: So that is the 42% of funding we are talking about from the federal government; we are not meeting those federal case load ratio requirements?

Answer: We are not meeting those requirements and that's very unfortunate. What sets California apart from many other states—all states rely heavily and some states exclusively on federal dollars —California has a large state contribution to the program that makes it extra special for the folks who live in California but we have fallen so far behind in every level. We have talked about California being 50th for health indicators; well we are like that in almost every area in our developmental disability services system.

Question 4 to Winfield: So you made mention that there are federal requirements for the program and funding. In terms of state oversight, are there other standards that the state also looks at or reports on or does California just use the federal standards? Mr. Rollens just indicated we are not in compliance; do you agree or not agree with that statement?

Answer: We have a whole number of ways we monitor and oversee Regional Centers. What Mr. Rollens is referring to is the assurances we have given to the federal government indicating the types of things the State will do to ensure services are provided to individuals with developmental disabilities and according to law, the Regional Centers are supposed to have a caseload ratio of 1:62 for individuals on the HCBS waiver and it's true, that of all the 21 Regional Centers, none are currently meeting that requirement. The Department does have a whole number of ways that we monitor and oversee through fiscal audits, program audits, and other items like that.

Question 5 to Winfield and Rollens: Is the Agency willing to work with this Committee and others to develop dashboards or a report card for children with special needs to help us provide data or technical assistance in developing such measures, particularly related to children who need developmental services?

Answer from Winfield: Absolutely, happy to help.

Answer from Rollens: You have the commitment from ARCA to do just that and more.

Comments from Dr. Pan: Obviously it's very disturbing to hear that our caseloads are out of compliance, although this is not the first time I've heard this, and certainly we are concerned about the outcomes this has on the families that depend on these services.

Question 5 from Dr. Pan: The other question I have is about the interface— you mentioned autism, insurances are required to provide some coverage, Medi-Cal is supplying coverage, we have schools with special education—how do all these come together from your perspective? Do we have a lot of overlap, how are we trying to coordinate between all those and reduce duplication since services that may be covered by multiple sources?

Answer from Rollens: It was a sea-shift in the way we fund ABA programs, when SB946, Senator Darrell Steinberg's bill, was enacted. Clearly the Regional Centers' clients make up a large number of those receiving benefits through health plans and now Medi-Cal in this area. The cost of those programs has been shifted from the state over to those health plans and to Medi-Cal outside the Regional Center system. We still provide behavioral health services and ABA services to clients who don't fall in those two categories. We are concerned that SB946 is due to sunset in 2017, I'm sure there will be legislation before you in the coming year to postpone or remove the sunset all together; it's been an effective program not only for Regional Center clients but the beauty of SB946 is that even if you are not a Regional Center client you could still access ABA services for a child on the autism spectrum. We have strict eligibility requirements at the Regional Centers to get in under the autism diagnosis but we know there are thousands of children and adults with autism spectrum disorder who are now eligible for services through their health plans and through Medi-Cal.

Comments from Dr. Pan: Thank you so much for your testimony. Obviously we have a lot of challenges in this system and certainly these are important services and the benefits, including the Early Start, which are important to continue to work on.

Panel 4: Special Education Services and Programs

Comments from Dr. Pan: Next panel is on Education services and we have made lots of references thus far to this. Some would say one of the main tasks for all children, not just children with special needs is to learn. Thank you all for coming

Presenter: Chris Drouin, Associate Director, California Department of Education Special Education Division

On behalf of CDE, Mr. Drouin also provided the Select Committee with written testimony on Friday, February 5, 2016 (See Appendix F)

Overview of Services:

- Children qualify for special education and related services if an individualized education program team determines that the student has a disability and because of that disability needs special education and related services.
- Generally, this means that their disability affects their ability to access and make progress in general education curriculum.
- It's important to distinguish that education is not a health or mental health treatment program but rather a place to educate children
- In 2014-2015, over 666,000 of California's 6.2 million students in K through 12th were identified as receiving special education; that's about 10.7% of all school age populations
- This percentage has increase from 10.1% to 10.7% since 2010-2011

- Special education services are provided by a large number of agencies; this includes:
    - 133 Special Education Local Plan Areas (SELPAs)
    - 1,700 Local Education Agencies (LEAs)
    - 58 Counties of Offices of Education
    - 2 state schools for Deaf
    - 1 state school for the Blind
- Local Education Agencies contract with private nonprofit public schools and agencies, including mental health agences to provide services and these are certified by the Dept. of Education

Special Educational Services:

- State and federal laws include a number of procedural and service requirements and include:
    - Child find; LEAs are responsible for having procedures to ensure all students with disabilities and who are in need of special education services are identified, located and evaluated
    - Assessment; Students identified as potentially eligible for special education services are entitled to an assessment to determine if they have a disability that negatively impacts their academic progress and to help plan a program to address their needs
    - Individualized Education Program (IEP); students eligible have an IEP developed by their IEP team and the IEP identifies the appropriate education plan, goals for the student to achieve and related services the student is to receive to help support the student toward making progress toward their goals
    - Annual review: Each IEP is reviewed annually to ensure that current placement goals and services are working for the student and if not to make appropriate changes
    - Special Instruction; Students can receive special instruction and this can occur in a number of settings based on the principle of least restricted environment—first and foremost students are taught in regular classrooms and only placed outside of regular classrooms if the nature and severity of the disability is such that they can't be served adequately in a regular classroom. Students are also served in a resource room, in special classes and special centers in non-public schools.
    - Related services: Includes transportation, and a variety of services to assist the student to benefit from their education, such as language and speech therapy, occupational and physical therapy, and a wide variety of group, and individual and parent counseling services, behavioral intervention services and health and nursing type services

Funding Sources:

- California provides approximately $4.46 billion for special education related services; 73% of these funds are from state sources and 27% are from federal sources
- Over last five years, federal funds have decreased and state funds have increased

- General education funding is not included in this, very important to point out that students with disabilities are students first and as a result there is an expectation that a large portion of their program is paid for out of general education funding
- Special education funding is distributed through the Special Education Local Plan Areas (SELPAs)
- Special Education Local Plan Areas (SELPAs) are a single district or a group of districts that are a sufficient size and scope to be able to plan the number of services that students with disabilities may need
- SELPAs receives special education funding based on all their member LEAs
- Funds distributed according to an allocation plan that is developed locally by all the member LEAs in the SELPA
- The California Department of Education (CDE) allocates budgeted funding based on a formula established through Congress for federal funds or by the legislature depending upon if it's a federal or state fund source
- CDE allocates about $3.25 billion in special education funds from the general funds and those go into two funds:
    - Special education funding, also known as AB602; roughly $2.7 billion
    - Educationally related mental health services; roughly $361, 000
- $1.2 billion in the Individuals with Disabilities Act (IDEA) funds through grant awards; these funds are specified by the federal government and based on a three-part formula:
    - Base-Amount: Established in 1999
    - Overall population of the school: Any amount above the base amount allocated by federal government is based on the general population of students
      *Important to note; this has nothing to do with the number of children with disabilities but rather the overall population of the school
    - 15% based on overall population of those students in poverty
- Several different federal grants; all based on same funding formula, for example:
    - School age programs
    - Pre-school programs
    - Pre-school local entitlement
- Family Empowerment Center also derives from federal funds, and is specified in the budget act and in law
- Mental health funds from the IDEA; roughly $69 million
- Instructional materials funding
- Transportation funds for state special schools

<u>Coordination Efforts Under Way with State Departments and Agencies:</u>

- Lastly the needs of students are complex and children often require services provided across service sectors—what today has been all about—and this involves multiple agencies
- School personnel work in collaboration with other agencies to coordinate educational, therapeutic and medical services for their students
- In California, there are two legal sources that guide coordination of services among agencies:

    - IDEA: Requires the Chief Executive Officer of the state to ensure that an interagency agreement or other mechanism for coordination of services is in place between CDE and any other public agencies that are obligated by public law to provide special education related services
    - Interagency Provisions of Chapter 26.5 of the Government Code or 3632 and which was significantly altered by AB114 in 2011
- CDE is actively coordinating with several other state agencies related to special education, including;
    - Department of Developmental Services (DDS); We have a part in the Part C program for the Early Start Program and we collaborate with the DDS, which acts as the lead agency, to provide services to all of the birth to 3 year old students in the state; and primarily we provide services to low incidence disabilities such as children who are blind, deaf and or have sever orthopedic impairments
    - Department of Rehabilitation and DDS; Working toward developing a memorandum of understanding to increase coordination and opportunities for competitive integrated employment for students with significant disabilities 16 years of age and older
    - Department of Health Care Services (DHCS): Contribute staff time in the administration of the LEA Medi-Cal billing option. LEAs are not a mandatory program, but they are active participants and claim to generate approximately $136 million dollars in funds
    - Working with DHCS to also establish a new agreement for Mental Health Services; under AB 3632 –all the specifics regarding referral timeline, who was responsible for the referral and assessment, what should be in the IEP, were originally laid out in law—all have been removed with the passage of AB114 in 2011 and this has been problematic since that time
    - Challenge: Considerable uncertainty locally about who is suppose to do what when and who is the first payer, second payer
    - Working to update agreements with Department of Social Services, Department of State Hospitals and DHCS as they relate to California's Children's Services

Presenter: Becky Bryant, Director III, Sacramento City Unified School District

- This is a great opportunity for agencies and departments to get together to learn what everyone does and work together in the future Thank you for introducing Assembly concurrent resolution regarding people's first language.
- In California, our SELPAs are geographically organized for funding and services; we have both single and multidistrict SELPAs depending on size and scope
- Sacramento City Unified is a single district SELPA
- Provide all our special education services to our eligible students ages 3 to 22 years old
- We do have a contract with the Sacramento County Office of Education to provide services from birth to 3 years old

- Students become eligible for special education services through a through multi-disciplinary assessment process and must meet an eligibility criterion for one of the 13 eligibility categories
- An IEP team meeting is convened to discuss the results of the assessment, eligibility goals and objectives, and develop the scope and complexity of the services the student is to receive
- Parents are active participants in the IEP process throughout

Examples of Services provided:

- Speech and language services
- Specialized academic instruction within a general education setting
- Specialized academic instruction within a small group setting
- Specialized academic instruction in a setting outside of general education for much of the school day
- Related services, such as occupational therapy services, counseling, physical therapy or behavioral support to name a few, assist students to access their education
- Students served are diverse and may have a wide variety range of needs; some students need less intense services such as speech therapy, whereas other students may require great and intensive services such as nursing support to monitor medical functioning so they can access education

Sacramento City Unified School District (SCUSD)

- We serve students as an individual based on their unique needs
- SCUSD is a large, urban school district
- SCUSD special education department serves between 6,300 - 6,600 students with special needs within a given year
- Operate a full continuum of services and full range of related support services
- Services to support students receiving special education are generally more costly than services in general education
- On average will cost at least 2x as much to educate children with special needs and identified as needing special education

Funding

- Funding has not kept up with the actual cost of providing services
- Each district must contribute a substantial and a growing amount of funds in each fiscal year to provide the IEP mandated services to students
- While appropriate for a district to contribute to the share of cost; the needed contributions have grown so much overtime and now significantly impact a district's budget health
- Recommendation: Increases in both state and federal funding is needed to serve students
- In 2011 SELPAs were given the responsibility to provide educationally related mental health services to assist students; initially this shift from contracting with county mental health providers was a challenge, however, over the past 4 years statewide SELPAs have been able

to develop comprehensive support systems and direct service models to provide mental health services to eligible students

- In our district, we have over 350 students currently receiving some sort of mental health service or counseling, guidance, behavioral support services; in relation to when students were served by county mental health, this never went over 100 students
- Although we can bill for LEA Medi-Cal benefits reimbursements, we don't have access to the funds full-scope EPSDT Medi-Cal reimbursement that county mental health does
- Recommendation: Support legislation and action to allow school districts and SELPAs to access EPSDT Medi-Cal funding
- Implementation of Common Core Standards; our district has provided many opportunities for professional learning for teachers, instructional support staff and parents to have a solid foundation about what is different in this teaching and learning of these standards; best outcome has been rich inclusive learning opportunities teaching in general education and teaching in specialized settings
- Universal Design for Learning; still in the development stages and feel this strategy will serve our students with special need and will assist to provide more inclusive setting for students
- Goal: To ensure each student who leaves our system is ready to engage in post-educational setting or career setting

Transitional Services and Support:

- Transition planning starting at least at 16 years of age is very important and provides a roadmap for students throughout the high school years
- We have a Workability Program in our SELPA, and it has helped students greatly develop employment skills while in high school to carry them after they leave our high school
- Relationship between SCUSD, Sacramento City College and Cal State University Sacramento to help create a solid and more seamless transition as they exit high school
- Goal: Always work to refine our relationships with families, including open dialogue that is proactive and transparent

Presenter: Bob Hamilton, President, California Association of Resource Specialists and Special Education Teachers (CARS+)

- We polled our members to collect recommendations and opinions for this hearing and found some common threads
- Challenge: Since we began fully including students in general education there have been some unexpected consequences; for example general education teachers are now more and more responsible for those students and their instruction
- Which means when you are dealing with a student who has specialized medical needs or mental health needs you are pulling them out of a general education class and they are losing instructional time to meet with a counselor or go to physical therapy

- A lot of cases, the general education teacher may not understand why this is happening, particularly with mental health; general education teachers are asking why are you taking this student out of my class all the time
- Challenge: General education teachers and administrators are not always aware of the intricacies of physical health and mental health issues and there is a lack of training and education
- Challenge: For students receiving counseling for mental health; two challenges, the general education teachers were never included in that processes, and we need the counselors, the families, the students and the school staff to all be involved together so we are all one in the same page
- Challenge: High turnover rate of mental health counselors; perhaps county mental health counselors should be paid more because it seems that this is a stepping stone to private practice
- Challenge: Disconnect between schools and agencies; invited to meetings for foster kids and the meeting was at scheduled at 11am; challenge to meet during the school day and they were rarely attended our meetings because they were late in the day (4pm or 5pm)
- Recommendation: Consistent and regular individual counseling with the student, with the families, and with general education teachers, administrators and staff
- Recommendation: Training for the general education school staff beyond what receiving now
- Recommendation: Need adequate funding; not enough speech and language specialists, not enough school physiologists, not enough school nurses, not enough counselors, not enough special education teachers
- Challenge: Lack of special education teachers; we get requests from districts weekly asking for special education teachers. Some instructors are working as interns or without credentials on emergency basis and this is a huge issue

Comments from Dr. Pan: I'm struck by these parallels' between primary care and special care and then general education and special education for children with complex needs. I agree we want to try to get them in the least restrictive setting and at the same time the child has other needs and the challenge is how to make it all work.

Additional comments by Hamilton: I had an example of a student where least restrictive environment for their student was a group home, because that was the environment the student could best flourish in because that was the environment with the least amount of pressures on the student. The least restrictive environment is not always general education; it needs to be individualized

Presenter: Sharon Sinclair, Health Consultant Supervisor Tehama County Department of Education, California School Nurses Organization

- Very small rural county, we cover over 2,900 square miles, have 11,000 students and we only have 7 school nurses
- Since we are rural we often have very limited services available

- We have more students with complex health needs and with those needs they surviving, they are thriving but they are in school from 3years old to 22
- As school nurses we are responsible for meeting all of their healthcare needs during the school day
- School nurses are not required by the districts; no mandate to have us
- We are uniquely qualified because of our education and background to serve as case managers for families and try to coordinate some of that care for them

- Recommendation: School nurses are in need of funding to provide coordinated care at the schools
- School nurses have the unique qualification to implement protocols to allow students to attend schools
- Now with advanced medicine and care, these children survive and are now in school and now we are trying to meet their health needs in school
- Challenge: Districts are not adequately compensated to have these children in their classrooms. In many districts as much as 50% of the budget comes from the local district and that can be devastating to a district, especially in a small, rural area
- Challenge: Some of our parents have difficulty accessing services; some parents don't have cars that can accommodate a wheelchair for their kids using wheelchairs; so getting to appointments can be very difficult; they may not have gas money to get to those appointments; and sometimes they don't have a reliable transportation; and sometimes they cancel the appointments they have waited months for because they just can't get to that appointment
- Challenge: We have a very high Hispanic population in our community and there can be language barriers related to accessing services. For example, I had a family where it took us two visits to find out the student was not getting his anti-seizure medication and the physician was getting ready to airlift him to UC Davis because we couldn't figure out that he hadn't had medication for two months because the mom couldn't communicate to the pharmacist that her son needed his prescription renewed.
- Many of our families are undocumented; I understand how to get these children health care but that combination of being here undocumented and the challenges with language results in poor outcomes and families unable to adequately access those services early enough which results in cost to the state in the long run
- CCS is underfunded; Tehama County is a dependent county, so all of our services have to go through Sacramento to get approved and that can take months. I had a family wait two years for hearing aids; it was a long time ago and I'm hoping that has been rectified
- Some of my families have had to go as far as Fresno to reach dental care because sedation dentistry is not easily and readily available
- Our CCS team meets 4x a year; so only four opportunities in a year to make sure the student has the equipment that they need and we try to anticipated as best we can for the next three months what they will need and that can be very difficult for our challenging
- Challenge: In our county we have a difficult time finding CCS-panel approved physicians; only have one pediatrician in our county and they are not adequately compensated

- We are only able to offer physical therapy 4x a month in Tehama County because we can't find a physical therapist who is willing to work at the fee CCS can provide

Examples of Medical Care School Nurses Provide Care for:

- G-tubes/tracheostomy tubes; trach-care and suctioning
- Ventilator care, breathing treatments, nebulizers, inhalers
- G-tube meds, oral meds
- Diabetes management
- Anaphylaxis prevention and management
- School have to store meds in refrigerators and locked cabinets
- Train personnel to help students with medications

Challenges and Barriers to Providing Care:

- Shortage of child psychiatry; often our students are seen through telemedicine and it can take several months to get an appointment and you only get just a few minutes with that psychiatrist
- Many kids have emotional disturbances, such as autism, and they are often very complex and underserved
- Families are not provided extra supplies for school and often times we have to reuse g-tubes, feeding bags and extension tubes and syringes,
- Feeding pumps and nebulizer machines have to travel back and forth with students because they only get one
- Many family physicians do not complete request for orders in a timely manner for our students to attend schools so that delays their ability to access their education. Some physicians have gone to a system of charging to complete these orders for them and these families just doesn't have the money to pay for those services
- Medical needs are often complex and require many medical orders
- Recommendation: Physicians who are providing care under the Medi-Cal system should have fair compensation for this, as they are underfunded to begin with
- Recommendation: In order for our students to have adequate education we must provide adequate healthcare, in order for them to thrive not just survive, they must have quality health care and to succeed they must have the best healthcare
- Recommendation: Must adequately fund existing programs
- Recommendation: Healthy students learn better and better school attendance results in better educational outcomes
- Health and mental health are often at the top of the list for poor attendance and some of these students have IEPs.

Question 1 for Drouin: I appreciate all the partnerships you shared which the Department is working with and if you could keep our Committee apprised and our Committee could be helpful in anyway we would appreciate it. I'll ask the same question I asked the other departments, if we were to start to develop a report card or dashboard for students with special needs, would the Department be willing to help us with this by providing technical assistance or maybe suggest data sources?

Answer from Drouin: We are very committed to using data to report to families, to make decisions about services, to identify places where there are needs so yes, we would be able to assist through our special education and longitudinal education and our data systems would be delighted to participate; there are real possibilities.

Question 2 for panel: I realize each county may be different, but what opportunities are there to interface with CCS or Medi-Cal or Developmental Services or Mental Health to help reduce that overlap and make things more seamless for the families?

Answer from Drouin: I'm at the 10,000 foot level, one of the things that was exciting about IDEA Part C in the early days, there were interagency collaboration groups and I think we could use some models at the school age or transition age to look at cross-agency assessments. It could help contribute to a single assessment or a single reporting process and I think there are models for doing that. One challenge is that we were responsible for coordinating the transition of mental health and we brought experts from health to talk about what should happen and that was an exciting time for creativity for how people should work together. And there are models that work very well that use multiple funding sources and we would be happy to identify those to you.

Comments from Dr. Pan: That would be wonderful, and particularly if there are models that are working very well

Comments from Drouin: In about 1/3 of the SELPAs there are really exciting things being down between the health agencies; there is still a lot to be done.

Answer from Bryant: I think for us, one of our most successful partnerships has been with the Regional Center. We have worked county wide between 5 SELPAs for an agreement with the Regional Centers where we share in the care for students particularly with the ABA services in sort of a gradient fashion, where as children become more school age we take on more services; that has changed since the insurance funding has kicked in but it's one example that worked well. Families new that when they came to the IEP table, Alta Regional Center would be there and we would be working together on the program together.

Comments from Dr. Pan: Maybe we need to find a way to loop the plans in now

Question 3 to panel: I guess the other questions, we have more students with disabilities whether on the health or mental health side; are we maximizing our ability to pay for health care services delivered through education through our federal matches with Title IX and Medi-Cal? If we are

having to deliver health care in school, do we need to figure out how to draw down more health care dollars to fund those services?

Answer from Sinclair: A good place to start would be to mandating that districts have school nurses; we do have districts that don't have school nurses and I've talked to parents with children with special needs who come from those districts and it's very hard. So allocating dollars for those school nurses is very important

Question from Dr. Pan: Is there a way to pay for more school nurse time given school nurses are doing healthcare work and we get more money for kids who qualify for Medi-Cal and the school nurses are taking care of them so we are not putting more burden on the school?

Answer Initiated by Individual in the Audience (Inaudible)

Comment from Dr. Pan: For record keeping purposes we need you to come up and speak in the microphone. Please go ahead and answer in public comment.

Answer from Sinclair: School nurses are not funded adequately and I do think there are dollars out there to make this happen, but I'm not sure how this is going to look.

Comments from Dr. Pan: I know you mentioned there is a collaboration with DHCS to look at that so this is good to know.

Question 4 to panel: Regarding the SELPAs, do SELPAs regularly reach out to one another to collaborate or interface? Is there a more systematic way to get SELPAs to collaborate with each other and other agencies such as CCS or the other agencies?

Answer from Bryant: I can only speak for my own SELPA that I am responsible for and we have interagency agreement with CCS and have a medical therapy unit within our district boundaries. We have a strong partnership with our Regional Center and I'm not certain what all the other SELPAs in the State of California do and I think it's built on community need and the populations of students we serve and I believe these are the factors that go into how partnerships are built.

Comments from Dr. Pan: I know that as someone who has been active in school health, one of the ongoing criticisms has been in schools where there is even a school-based health center, there is often very little connection with special education which is actually providing a lot of health care services. I don't expect the school to run a whole health care system on their own that is very expensive but if there is a way to leverage the existing health care system or developmental services or mental health and vice versa, that is what this Committee is trying to do by spurring those ideas and seeing if there are models out there to use.

Comments from Sinclair: We do work very closely with CCS. Unfortunately, they have two part-time nurses in the program and they don't have enough time to meet with us and they rarely are able to attend IEPs because they just don't have the staff time to do that; they are under-funded.

Comments by Dr. Pan: Before we move to public comments, I just want to thank all the presenters. This has been very informative and thank you for everyone committing to how we can develop standards and measures for quality of care of children at large with special needs and where there may be some opportunity to leverage funds and provide more coordination. This is the first of several hearings the Select Committee will have over the next year and I want to thank all the speakers.

Public Comments

Comments by Dr. Pan: Now we will open for public comment with a 2-minute limit for public comment.

Speaker 1: I'm Dr. Linda Coplain. I'm a developmental behavioral pediatrician with four jobs and one with UCSF Fresno pediatric residency program and I have a particular interest in early intervention. For IDEA Part C, there can be cost savings if we look at using mid-level assessments instead of using diagnostic assessments for eligibility. Mid-level assessments such as the "Peds-DM" or the "Developmental Profile 3." For every dollar that gets spent in IDEA Part C on eligibility assessment that is a dollar taken away from Part C intervention; if we shift to mid-level assessment that decreases the waiting list for more formal diagnostic assessments and can get kids in early and intervention started.

Speaker 2: My name is Christina Hilderband and I'm from Voice for Choice; one thing that really surprised me in listening to this hearing was that there was no mention to why our number of special needs children is increasing in this state and across the county and I would ask you to add this to your list of to-dos and to look at why the number of children with autism and ADHD, all of these chronic diseases increasing across the state and across the country and if there is a way to get rid of those underlying symptoms for what is causing that and that will reduce the burden on our school and on our healthcare system. The other thing I wanted to bring up was SB277, which in it has an IEP clause that is not very clear, in the Assembly Hearing you mentioned all students with IEPs would be able to go to school and when SB277 went to the Assembly floor it was clear; that that wasn't the language in there and the language leaves it very open to interpretation and it does say that students with IEPs could get their services at schools however, there are issues there because in many IEPs; it is written very broadly, so an IEP may say something like 70% of time that the child is in recess that child needs to be interacting with other children; does that mean that the child can only go to school for recess? How does SB277 work with an IEP, the challenge is you don't get an IEP when you go to private school and most children don't get an IEP before kindergarten and you have to be fully vaccinated. So how do we look at those children entering the school and how do they get their assessment?

Speaker 3: I'm Karen Fessel, Autism Health Insurance Project; there were a number of issues that came up that intersect with the kind of work our organization does. There is a lot about falling

through the cracks; one of the presenters mentioned that residential treatment centers are not covered through Medi-Cal and that is a problem because the federal Mental Health Parity Act basically requires that this be covered through health plans and now Medi-Cal is subjected to the federal Mental Health Parity Act, it's exempt from our state mental health parity act and it means they are not complying with the federal law and that is something we need to look at. Also other intermediate levels of care such as intensive outpatient and partial hospital also needs to be covered by Medi-Cal for our children. Something we see a lot is the interplay between school and Medi-Cal, we are seeing a lot of issues with children in which they need ABA services in the school for children to access the curriculum and we are seeing that the children are getting a lot of push back; sometimes the school won't let them in, sometimes the schools don't want an outside person in the school environment and sometimes the health plans are not paying and we see this in the private sector and in the Medi-Cal realm. At some point we would like to have a hearing to see how the implementation is going on the Medi-Cal issue and I hope this Committee is able to address this. Sometimes we tell people not to check the box that would allow the school to clock the money from Medi-Cal because we have seen problems with Medi-Cal refusing to cover items like speech therapy if it's covered by the school district, and we don't like to tell them that because we know the school could use that money but we don't know what else to tell them if it's going to be against them for services that they need and are medically necessary

Speaker 4: Hello I'm Maureen Burness and I've just finished being on the newly formed task force, and one of the things we presented to you and the legislature in the spring was a summary of our report that was done after a year and a half of looking at all of these same barriers to services and what we could do. I just want to make sure you are reinforced with this resource, there really is a good body of work already started that we hope you can use and we would be happy to help you with in any way we can.

Comments by Dr. Pan: I appreciate that and I know lots of people have looked at different aspects of what we are looking at and we hope to bring this all together. We will definitely look at the report.

Speaker 5: Hello my name is Linda Olson, I'm a school nurse for Sutter County Superintendent of Schools and I would say that my experience very much reflects what the nurse from Tehema County spoke to. I see small school districts that have a really medically fragile child that needs to come to school and I am the supervising nurse for the LVN that we hired to ride the van that transports this student because he is too medically fragile to be on the school bus and that nurse is with the student all day doing the tube feeding and the nebulizer treatments and doing the assessments. That small school district has a huge financial burden for that student and there are several other school districts that have this challenge. I don't know where the funding is to help them; I hope you can address this in your Committee

Speaker 6: Hello Dr. Pan, I'm Sherry Coplain, I'm president elect for the California Association of Nurses organization; thank you so much for your support of SB276 which did allow billing for non IEP students; we have been in partnership with DHCS but when you look at reimbursement rates DCHS and California schools will split the rate with the feds and it is a 50/50 percent match and so essentially when you are billing assessments it's $40 per hour or when you are billing treatments it's $40 per hour and when you look at the cost of services and the overhead—and that is what California

schools get—the rates are low. Another issue in addition to the lack of nursing services is really capturing the health issues in school systems; for example, how many children are medically fragile, complex children? How many are on ventilators? How many are on trachs? How many do have diabetes? How many life-threatening allergies are there? We can look at the data but in California, we really don't have any idea of that so the need is really unassisted and we don't know. Schools have worked really hard to help health plans with HEDIS measures, when I was practicing in school nursing, we would have students with full scope asthma come to the office and we could do assessments, deliver nebulizer, rather than sending them directly to an ER visit, which actually happens now because the school secretary has no idea how to do this. So when you are looking at cost saving or helping with vaccines or immunizations, we delivered 22,000 doses of influenza vaccines in San Joaquin County and we can directly decrease pediatric hospitalization. Thank you for your support and this opportunity as well.

Comments from Dr. Pan: Certainly, children spend 1/3 of their time in school and if they have a health condition they will need help with during that time. Thank you for attending and participating and I adjourn the Select Committee on Children with Special Needs.

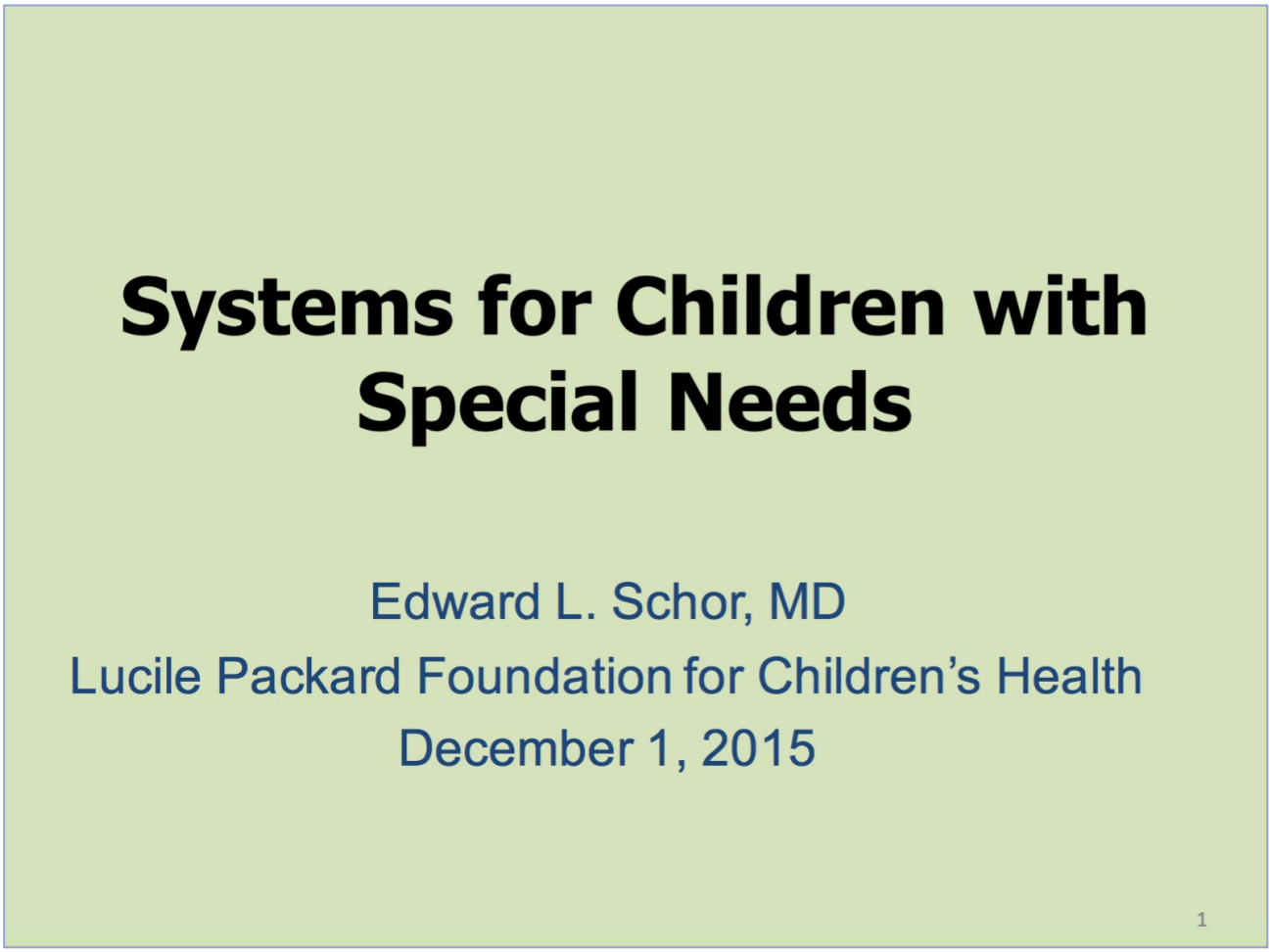
APPENDICES:

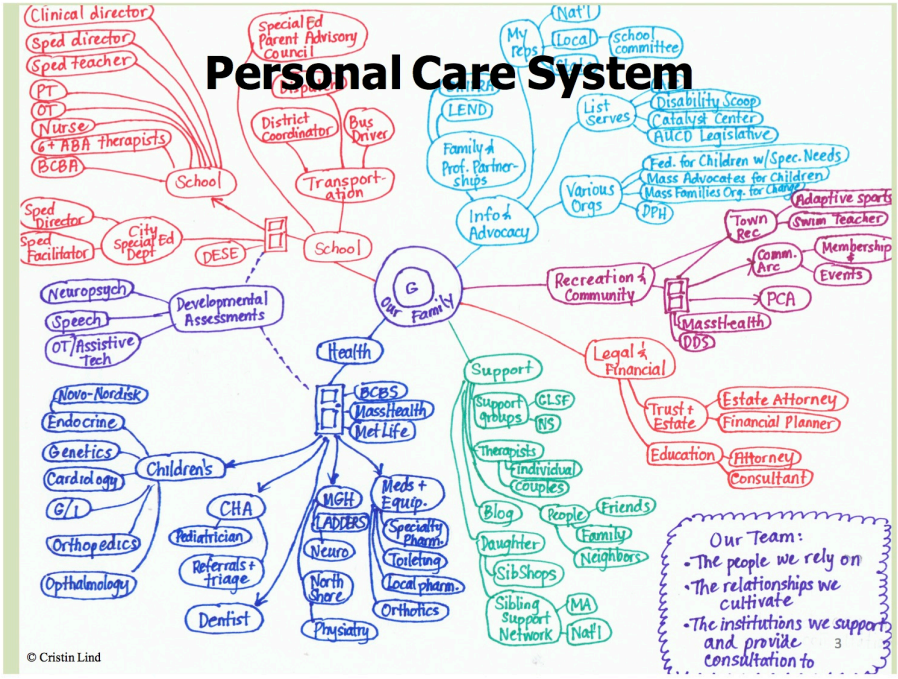
APPENDIX A

Presentation: "Overview Systems of Care: What does the current data show?"

Presenter: Edward Schor, MD, Senior Vice President for Programs and Partnerships, Lucile Packard Foundation for Children's Health

Dr. Schor used power point slides concurrently with the presentation.




Personal Care System
Clinical director
Sped director
Sped teacher
PT
OT
Nurse
G+ ABA therapists
BCBA
School
Special Ed Parent Advisory Council
District Coordinator
Bus Driver
Transport-ation
Sped Director
Sped Facilitator
City Special Ed Dept
DESE
School
Neuropsych
Speech
OT/Assistive Tech
Developmental Assessments
Novo-Nordisk
Endocrine
Genetics
Cardiology
G/I
Orthopedics
Opthalmology
Children's
CHA
Pediatrician
Referrals + triage
Dentist
Health
BCBS
MassHealth
MetLife
MGH
LADDERS
Neuro
North Shore
Physiatry
Meds + Equip.
Specialty Pharm.
Toileting
Local pharm.
Orthotics
G
Our Family
My reps
Nat'l
Local
school committee
LEND
Family & Prof. Partner-ships
Info & Advocacy
List serves
Disability Scoop
Catalyst Center
AUCD Legislative
Various Orgs
Fed. for Children w/Spec. Needs
Mass Advocates for Children
Mass Families Org. for Change
DPH
Adaptive sports
Town Rec
Swim Teacher
Comm. Arc
Membership & Events
PCA
Recreation & Community
MassHealth
DDS
Legal & Financial
Trust + Estate
Estate Attorney
Financial Planner
Education
Attorney
Consultant
Support
Support groups
GLSF
NS
Therapists
Individual
Couples
Blog
People
Friends
Family
Neighbors
Daughter
SibShops
Sibling Support Network
MA
Nat'l
Our Team:
•The people we rely on
•The relationships we cultivate
•The institutions we support and provide consultation to
3
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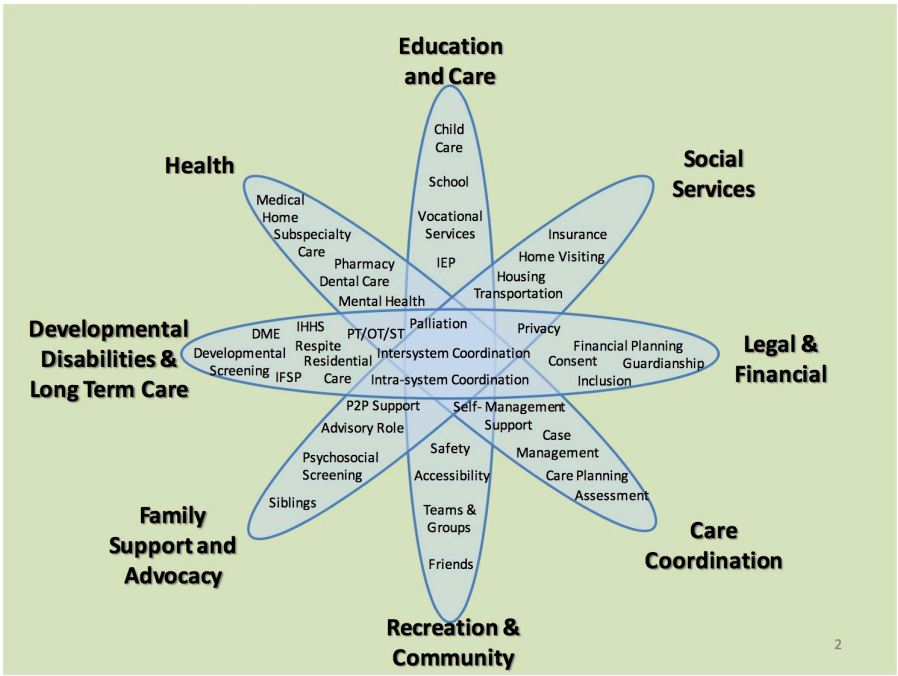
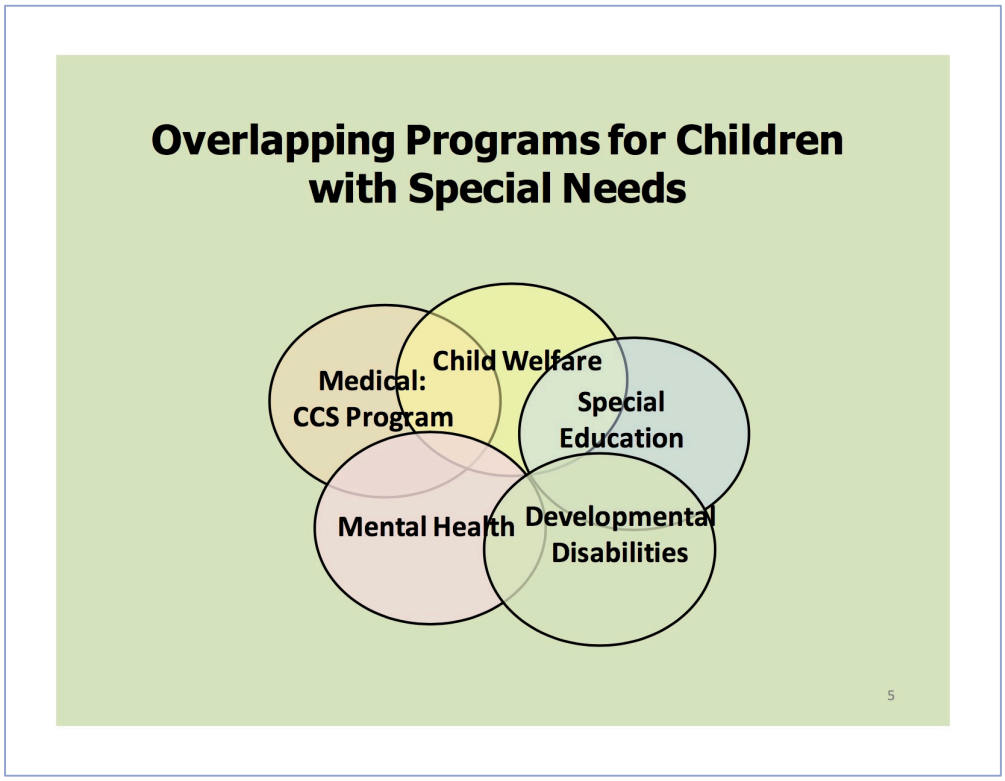

Education and Care
Child Care
School
Vocational Services
IEP
Health
Medical Home
Subspecialty Care
Pharmacy
Dental Care
Mental Health
Social Services
Insurance
Home Visiting
Housing
Transportation
Developmental Disabilities & Long Term Care
DME
IHHS
PT/OT/ST
Palliation
Privacy
Developmental Screening
Respite
Residential Care
IFSP
Intersystem Coordination
Intra-system Coordination
Financial Planning
Consent
Guardianship
Inclusion
Legal & Financial
P2P Support
Advisory Role
Self- Management Support
Case Management
Psychosocial Screening
Safety
Accessibility
Care Planning
Assessment
Siblings
Teams & Groups
Friends
Family Support and Advocacy
Care Coordination
Recreation & Community
2


Overlapping Programs for Children with Special Needs
Medical: CCS Program
Child Welfare
Special Education
Mental Health
Developmental Disabilities
5

California Programs for Children with Special Needs
Child Welfare ~62,000
Medical: CCS Program ~180,000
Special Education ~705,000
Mental Health ~270,000
Developmental Disabilities ~150,000
4

Key Components of a High Performance System for Special Needs Children

1. Whole child, comprehensive coordinated services
2. Integrated service plans and information sharing
3. Meaningful family involvement
4. Adequate number of well-trained professionals
5. Equity of access to good quality services
6. Transparent monitoring to assure quality

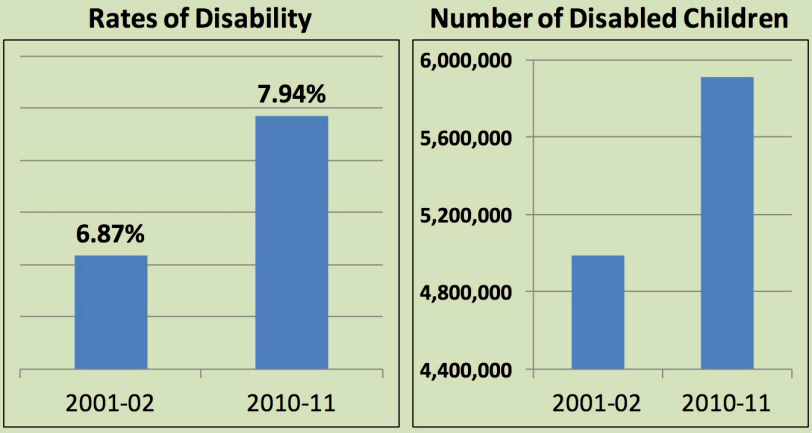
7

Special Needs of Special Needs Children

1. Readily available principle contact
2. Planned, accountable services
3. Multiple system involvement
4. Access to skilled professionals
5. Prevention of progression and comorbidities
6. Special accommodations
7. Family-centered services and supports
8. Readily available and shared records
9. Coordinated or integrated services

6

Changing Trends in Childhood Disability
(2001-2011)



AJ Houtrow et al. Pediatrics 2014; 134(3):530-538

9

Special Needs with Health Components

- **Child Welfare:** Mental illness, substance abuse, post-traumatic stress disorder, chronic illness
- **Special Education:** Prematurity, genetic and congenital disorders, mental illness, chronic illness
- **Developmental Disabilities:** Prematurity, genetic and congenital disorders, neurologic disorders

8

California's Quality of Health Care for CSHCN: National Comparison

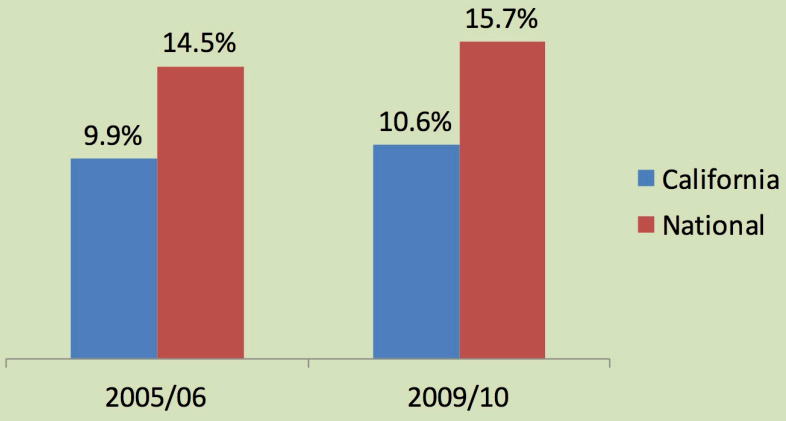
National Ranking

- 50th in having at least one preventive care visit
- 46th for care coordination
- 50th in family-centered care
- 50th in proportion of parents with above average stress
- 45th in developmental screening
- 36th for transition to adult care
- 43rd in receiving needed mental health services

Source: 2009/10 National Survey of Children with Special Health Care Needs

11

Proportion of Children with Special Health Care Needs Ages 0-17



Source: 2005/06 and 2009/10 National Surveys of CSHCN

10

MARCH 2014

Standards for Systems of Care for Children and Youth with Special Health Care Needs

A Product of the National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project

AMCHP ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Lucile Packard Foundation for Children's Health

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Focus of Lucile Packard Foundation for Children's Health

1. Care Planning and Coordination
2. Family Participation and Advocacy
3. Self-Management Support
4. **Disparities in Quality of Care**

12

How State Agencies Can Use System Standards

1. Identify children with special needs as a special population in policy and programs
2. Identify and reference national system standards in system design
3. Monitor adherence to standards
4. Assess and compare performance
5. Guide technical assistance to improve performance
6. Create partnerships among all stakeholders to monitor access and quality

15

Core Domains for System Standards

1. Screening, assessment & referral
2. Eligibility and enrollment
3. Access to care
4. Medical home and care coordination
5. Community-based services
6. Family-professional partnerships
7. Transition to adulthood
8. Information technology
9. Quality assurance & improvement
10. Insurance & financing

14

Edward.Schor@LPFCH.ORG

www.LPFCH.ORG/CSHCN

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APPENDIX B

Presentation: "The Family Perspective"

Presenter: Wendy Longwell, Parent, Family Voices of California

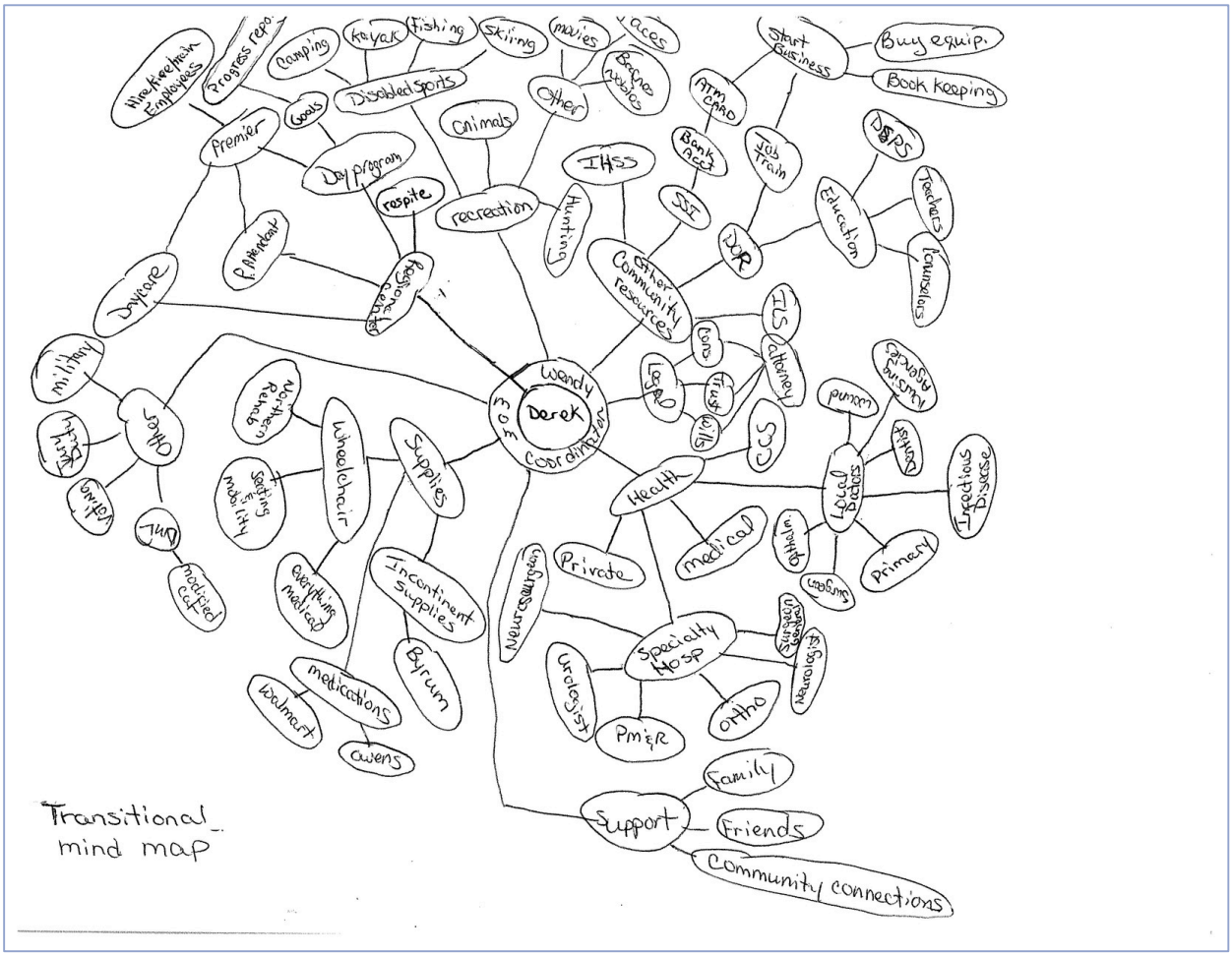
Ms. Longwell shared family photos concurrently with the presentation.

APPENDIX C

Presentation: "The Family Perspective"

Presenter: Wendy Longwell, Parent, Family Voices of California

Ms. Longwell presented a "Care Map" concurrently with the presentation as an example of care coordination.



APPENDIX D

Panel 2: Mental Health Services and Programs

Presenter: Karen Baylor, Ph.D., Deputy Director, California Department of Health Care Services' Mental Health and Substance Use Disorder Services

A list identifying the coordination efforts currently under-way with agencies was provided by the Department of Health Care Services' Mental Health and Substance Use Disorder Services to the Select Committee on December 3, 2015 to accompany presenter Dr. Baylor's testimony.

List of coordination efforts under-way:

- Through the implementation of *Katie A. v. Bonta* settlement, DHCS coordinates with the California Department of Social Services (CDSS) in a Joint Management Structure.
- DHCS is actively working with CDSS on the implementation of the Continuum of Care Reform
- DHCS has been participating with the MHSOAC on the crisis services work group
- DHCS is working with the Child Welfare Council and others on the *Priority Access Project* which is to provide priority to families in reunification
- DHCS is working with the Office of Juvenile Justice and Delinquency Prevention, the Attorney General's Office and others on the Defending Childhood Initiative.
- DHCS continues to work closely with CDSS on the use of psychotropic and antipsychotic medication for foster care youth
- DHCS discusses a wide array of policy and operational issues, including children and youth with special needs, with MCPs through a weekly conference call
- DHCS facilitated the execution of and monitors an MOU between all MCPs and the MHP
- DHCS continues to work with County and State partners to improve coordination of care and timely access to specialty mental health services to foster children placed outside of their counties of origin.

APPENDIX E

Panel 3: Developmental Disability Services and Programs

Presenter: Rick Rollens, Legislative Advisor, Association of Regional Center Agencies (ARCA)

On behalf of ARCA, Mr. Rollens provided the Select Committee with written testimony on Tuesday, December 1, 2015.

915 L Street, Suite 1440, Sacramento, California 95814 • 916.446.7961 • Fax: 916.446.6912 • www.arcanet.org

December 1, 2015

Honorable Richard Pan
Chair, Senate Select Committee on Children With Special Needs
State Capitol, Room 4070
Sacramento, CA 95814

RE: ARCA Testimony December 1, 2015 Senate Select Committee on Children with Special Needs

Honorable Senator Pan:

The Association of Regional Center Agencies (ARCA) represents the network of 21 independent non-profit regional centers that coordinate services for, and advocate on behalf of, over 280,000 Californians with developmental disabilities, which include intellectual disability, autism, cerebral palsy, epilepsy, and conditions closely related to or requiring services similar to intellectual disability.

The developmental services system currently serves individuals in those five categories, but its origins were focused on only intellectual disabilities, what used to be called "mental retardation". In 1969, in response to the grassroots advocacy of parents of individuals with developmental disabilities, the Lanterman Act was signed into law and established that "[the] State of California accepts a responsibility for persons with developmental disabilities and an obligation to them which it must discharge." Today, these twenty-one regional centers work in conjunction with community-based service providers under contract with the state Department of Developmental Services to provide services to individuals with developmental disabilities as an alternative to institutional care. The state's Supreme Court found in 1985 that the Lanterman Act "defines a basic right and a corresponding basic obligation . . . [T]he right which it grants to the developmentally disabled person is to be provided with services that enable him to live a more independent and productive life in the community; the obligation which it imposes on the state is to provide such services." This is the cornerstone of California's community-based developmental services system, what many advocates refer to as "*our* Lanterman Act." This entitlement sets California apart, and once made it a national leader. The state's lack of investment in the service system now leaves it lagging far behind other states and falling further back each year.

The Function of ARCA

The mission of ARCA is to promote, support, and advance regional centers in achieving the intent and mandate of the Lanterman Developmental Disabilities Services Act in providing community-based services that enable individuals with developmental disabilities to achieve their full potential and highest level of self sufficiency. ARCA promotes the continuing entitlement of individuals with developmental disabilities to all services that enable full community inclusion. ARCA is also an active participant in the development of public policy and legislation, and provides communication, education, and training to its regional center members across the State of California.

Page **1** of **12**

Overview of Regional Center Services for Children and Youth

Regional centers are independent, nonprofit agencies that are the official point of entry to the state's service system for people with developmental disabilities and their families. Infants and toddlers (age 0 to 36 months) who are at risk of becoming developmentally disabled or who have a developmental delay may also qualify for intensive intervention services through the state's Early Start Program.
For more than 280,000 Californians with developmental disabilities or in the Early Start Program, their regional center is where service starts. Included in this number are over 130,000 children under the age of eighteen. Businesses called "service providers" contract with centers to provide the many services and supports needed throughout an individual's life. This enables them to lead full, integrated lives in communities of their choosing. Each person's needs, goals, and services are described in an individual program plan (IPP) or individualized family service plan (IFSP). Regional centers' most visible role is to identify, coordinate, and monitor those services, but they also provide:

- Assessment, diagnosis, and referrals;
- Lifelong individualized planning and case management;
- Assistance in finding and accessing community and other resources;
- Payment for services included in the IPP/IFSP for which other funds are not available;
- Advocacy for the protection of legal, civil, and service rights;
- Early intervention services (Early Start) for at-risk infants and their families;
- Supports to help ensure individuals can remain within their family home;
- Planning, placement, and monitoring for 24-hour out-of-home care;
- Training and educational opportunities for individuals and families;
- Community education about developmental disabilities; and,
- Development of new services to better meet individual needs.

Funding Structure and Distribution

Regional centers work under contracts with the Department of Developmental Services. Funding for community-based developmental services is divided into two parts that work in tandem to both meet individuals' needs and fulfill state and federal mandates. The Purchase of Service (POS) budget allows regional centers to secure services for individuals from community service providers. The Operations (OPS) budget provides funding for assessment, service coordination, clinical services, quality assurance, programmatic functions, and administrative responsibilities, all of which are required to fulfill federal and state mandates. Funds allocated for POS can only be used for the direct benefit of specific individuals supported by the regional center.

Regional centers use person-centered planning to identify the services and supports needed by individuals and their families to implement each person's IPP, or for children under the age of three, their IFSP. For children and youth, these IPPs and IFSPs are developed by a planning team that includes the individual, the individual's parents, his or her regional center service coordinator, service providers, and others as appropriate or as invited by the individual or the individual's parents. The plan describes the supports and services the individual needs, and identifies who will provide and pay for those services. This process is time-consuming, but allows for the greatest customization of each individual's services to best meet his or her needs, while taking into account his or her preferences, culture, and lifestyle. This type of individualized needs-based determination has been the standard in California for decades and is consistent with recent federal guidance that requires a separation between service planning and service provision functions.

These services are funded through a combination of state and federal money. Approximately 40% of the system's funding comes from federal funding sources, which require the state to assure the federal government that certain requirements are being met related to quality service provision, individual choice, caseload ratios, and the health and safety of the individuals being supported. As the Lanterman Act established an entitlement for developmental services, California provides these valuable services to individuals regardless of family income or eligibility for Medi-Cal. In recent years, however, families have been increasingly expected to participate in the cost of certain services; the amount they contribute is based on their income level. Some families opt to pay for services themselves outright or to not participate in regional center services at all or based on the new requirements the system imposes on service provision. Some developmentally disabled individuals go without needed services because the service does not exist or is at capacity.

Current Challenges and Barriers

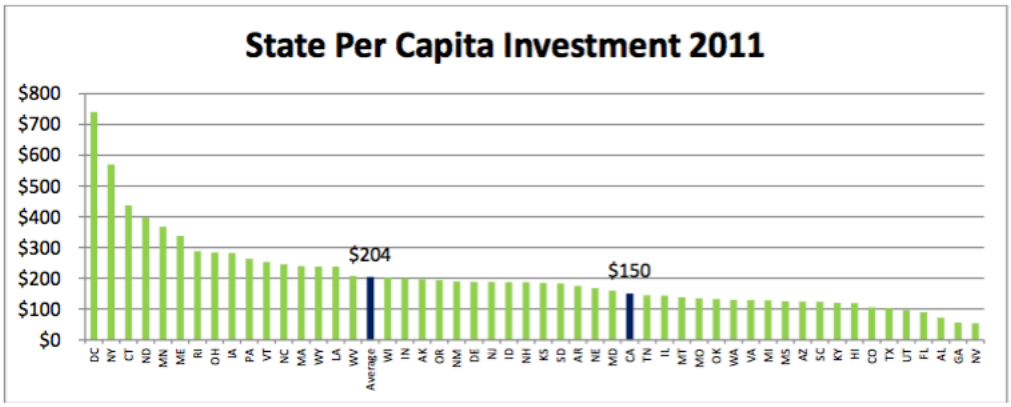
Years – and in some cases decades – of stagnant and reduced funding levels for service provider rates and regional center operations have left regional centers and their community partners all trying to do significantly more with far less. This underfunding is the result of various freezes and cuts that have been made in response to state Budget challenges for several decades. This problem was exacerbated by cuts made since 2008.

During the Great Recession, the community-based developmental services system sustained over $1 billion in cuts, the largest of any health and human services program. In response, difficult choices were made that negatively impacted the service system. Some of these choices, such as limitations on respite care and funding for camp, put additional pressure on families supporting children with developmental disabilities at home – the very group that the Lanterman Act was designed to support. Additionally, from July 2009-January 2015 funded services were eliminated for infants and toddlers with less significant delays, which significantly hampered their ability to catch up to same age peers. Funding for this program has now been restored, but thousands of children missed out on crucial services during this time.

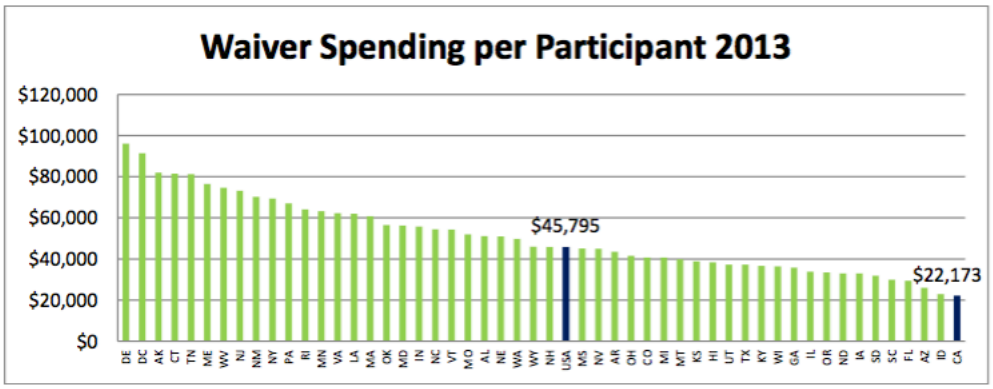
These cuts destabilized the developmental services system and have significantly compromised its ability to meet all of its obligations to individuals served, their families, and the federal government. Service provider rates and regional center operations funding suffer from chronic underfunding that threatens service quality, federal funding, and most importantly, the health and safety of the over 280,000 individuals served by the system today.

State law intends that services "maximize opportunities and choices for living, working, learning, and recreating in the community." However, regional centers cannot always offer the most appropriate service for the individual's needs, only what is available given the current environment.

In 2011, California invested $150 per resident of the state in its developmental services system. In contrast, the average state expended $204 per resident, 36% more than California's investment.



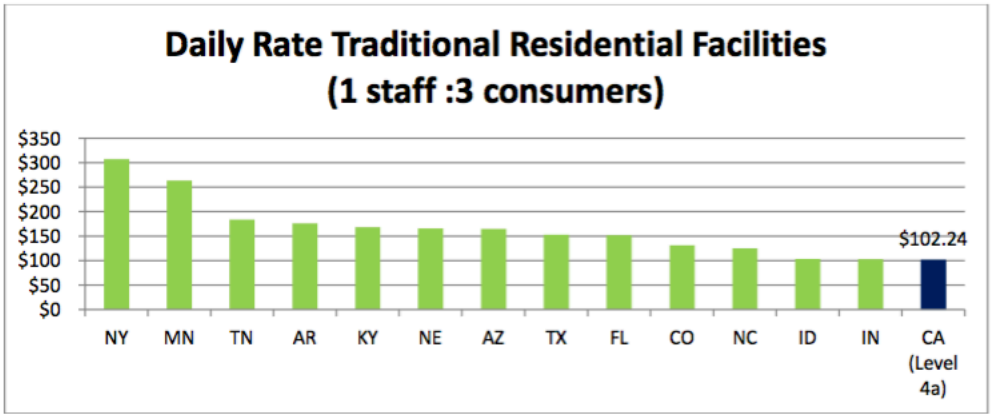
It is clear that California devotes less than average funding for developmental services for each resident of the state. The obvious question is what this means for the support that each individual served by the system receives. The simple answer is that California's financial commitment, even when considering only community services for individuals eligible for the Medicaid Waiver (those with the greatest impact from their disability and eligible for Medi-Cal), is the lowest of any state in the nation. The average investment nationally is *more than double* California's expenditure.



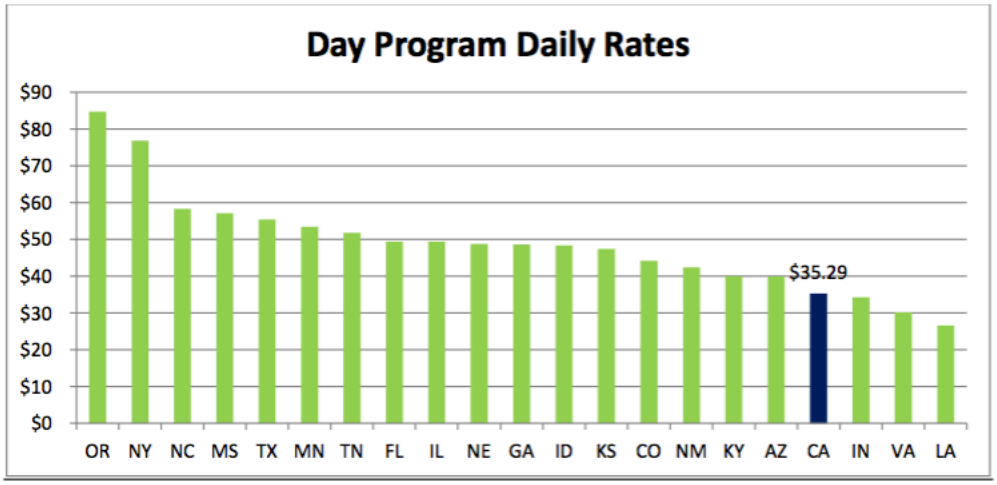
Community Service Provider Rates

ARCA consulted with Norm Davis from Davis Deshaies, a national expert on rate-setting procedures in developmental services. Mr. Davis examined California's community developmental services rates and compared them to rates for similar services in other states taking into account the high cost of living and of doing business in the state. He examined rates for residential facilities, day programs, and supported employment services, as those are core supports that are provided in many other states using largely the same service models as California offers. While day programs and supported employment providers serve only adults and are beyond the purview of this committee, it is important to keep in mind that developmental disabilities are lifelong conditions and that children, youth, and their families need the assurance that a stable adult services system is waiting for them when the time comes.

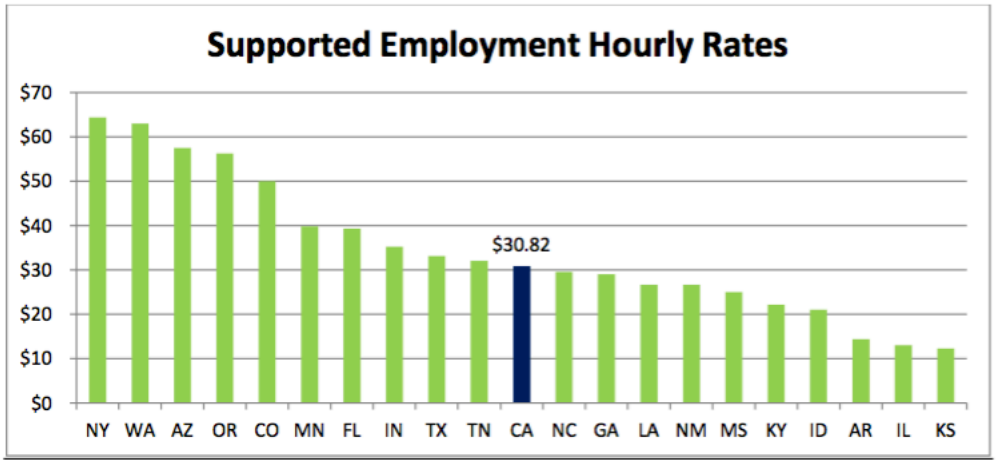
California's residential rates have not kept pace with inflation. Data supplied by Mr. Davis that is displayed graphically below shows that states such as New York and Minnesota now fund similar facilities at rates two and a half to three times the California rate. California's rate for this service is most comparable to rates paid in Indiana and Idaho, which are smaller states with lower costs of living.



California's current rate for Work Activity Programs is $35.29 per day per individual, with rates for some other day programs also less than $37.00 per individual per day. Data from Mr. Davis that appears graphically below illustrates that Oregon and New York have rates that are more than double California's daily rate for these services.

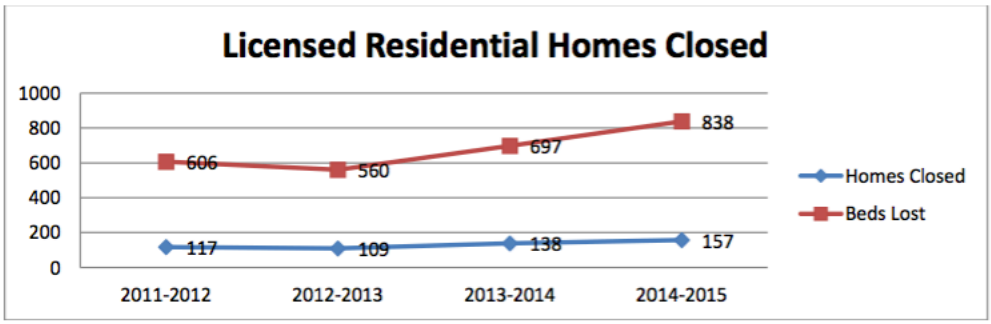


Data supplied by Mr. Davis that is displayed graphically below demonstrates that while California's rate for supported employment is less than $31 per hour, New York, Washington, Arizona, and Oregon all have rates that exceed $56 per hour, which is almost 83% higher than California's rate for this same service.

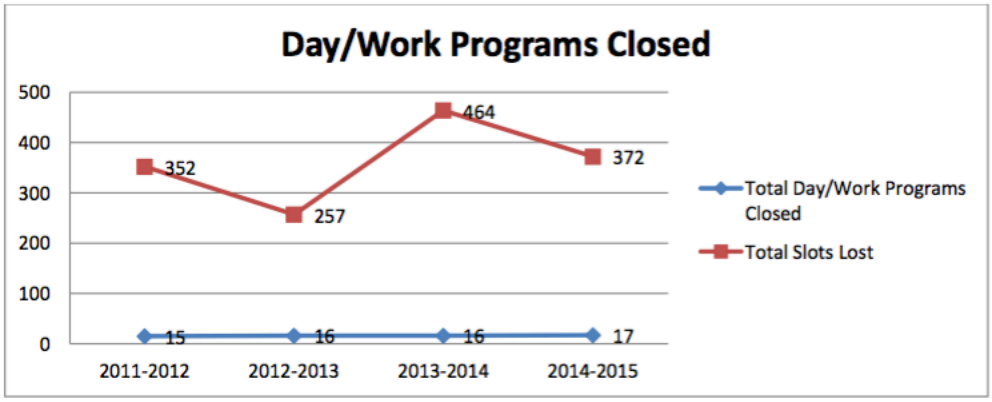


Due to higher real estate and labor costs, including the nation's highest worker's compensation premiums, California is a more expensive state to do business in. Additionally, California's picture is complicated by fifty-eight counties that represent affluence and poverty, densely packed cities and rural agricultural land, and industries ranging from farming to shipping to government to high-tech sectors. Other government programs take these geographic differences into account. For instance, cash aid amounts provided to CalWorks beneficiaries by the Department of Social Services are geographically adjusted with beneficiaries in California's sixteen counties with the highest cost of living receiving approximately 5% greater amounts than those elsewhere in the state.

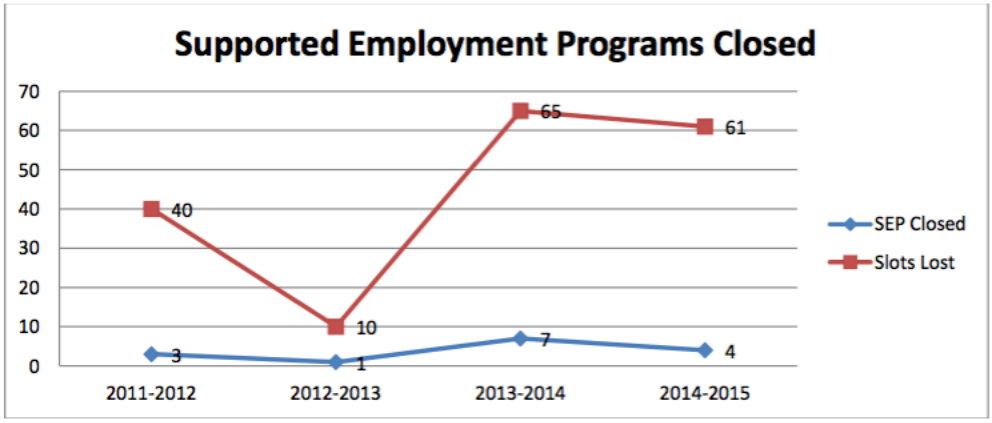
All told, regional centers report the closure of 521 homes since the beginning of Fiscal Year 2011-2012, which represents a loss of over 2,700 available beds. This is the type of loss that limits choice and opportunity for individuals in need of a safe and structured place to live, particularly for children who cannot remain in the family home.



Regional centers report that since the beginning of the 2011-2012 Fiscal Year 64 day and work programs have closed their doors, which is a loss of over 1,400 opportunities for individuals to interact with peers and their communities on a daily basis. These numbers also include many individuals with developmental disabilities that are no longer participating in paid employment opportunities.

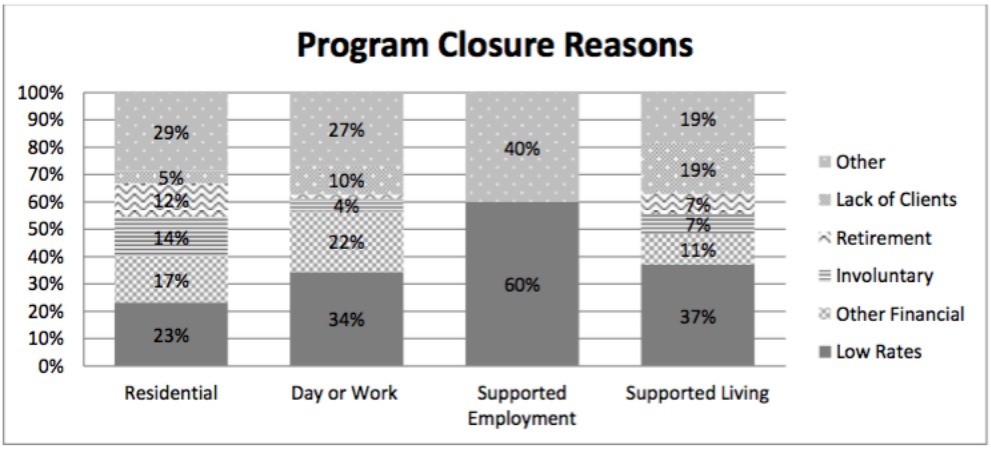


Since the beginning of the 2011-2012 Fiscal Year 15 supported employment programs have stopped providing this service, which is a loss of 176 opportunities for individuals to be supported to work in integrated community settings alongside nondisabled peers.



In a recent survey of regional centers, the reasons given for recent program closures are fairly consistent and are displayed graphically below. The leading identifiable reason for program closure was low rates. A closer examination of the data reveals, however, that the bulk of involuntary program closures due to

service quality can also be traced back to insufficient rates due to factors such as staff turnover and the inability to replace leaving staff members with new staff members of equal qualifications.



Regional Center Operations Funding

A survey conducted by The National Association of State Directors of Developmental Disabilities Services in 2005 indicated that 32 of 37 states responding had caseload ratios of less than 1:59. California was in the 1:60 to 1:99 range with two other states (see the chart below).

Estimated Caseload Ratios – 2005	
Caseload Ratio	Number of States
<1:20	2
1:20 - 1:29	3
1:30 - 1:39	15
1:40 - 1:49	5
1:50 - 1:59	7
1:60 - 1:99	3
>1:100	2

The CityGate study in 1999 found that based on expected client characteristics as for Fiscal Year 1999-2000, the overall caseload ratio needed in California's developmental services system was 1:53. Since then, the number of clients with complex needs have increased dramatically.

In 2014, service coordinators made up approximately 54% of the regional center workforce, and the Core Staffing Formula sets the position's salary at $34,032 statewide. The current state equivalent salary is $50,340. Individual regional centers must compete with local counties for skilled case management staff. In Contra Costa County the salary for similar positions is $63,401; in Mono County it is $61,716. In addition to higher pay, counties offer a comprehensive benefits package, sometimes even including the

repayment of employees' student loans, that regional centers are unable to match. Had the budgeted annual salary for the service coordinator position kept pace with inflation, it would now be in excess of $61,000 per year. Similarly, the benefit amount assumed in the Core Staffing formula is 23.7% compared to the state's current rate of approximately 48%. The reality of budgeted salaries and benefits for service coordinators falling far below state or county equivalents leaves regional centers no choice but to pay more (the average salary paid by regional centers is $46,121) by hiring fewer service coordinators and other critical employees and using that money for more realistic salary and benefit levels. In both 2014 and 2015, regional centers reported employing over 660 fewer service coordinators statewide than they need to meet required caseload ratios. By 2014 no regional center was able to meet all mandated caseload ratios. Many individuals require intensive case management to seek appropriate services from other agencies such as schools, the Social Security Administration, or programs such as In-Home Supportive Services. It is oftentimes the intensive case management that they receive that prevents them from needing to access more regional center funded services. In direct response to short-sighted underfunding for critical case management support, the need for additional funded services may increase for many individuals.

Changing Populations

Ten years ago a study conducted by Braddock and Hemp concluded that major cost-drivers in California's developmental services system include the transition of services from institutional to community settings and youth aging-out of the school system. These fundamental service needs, in conjunction with increasing rates of autism, must inform today's rate and service development policies. For instance:

- Individuals once served in developmental centers are being successfully supported in community settings at a cost lower than the average for developmental centers, but still higher than the average support cost for an individual in the community. California Health and Human Services Secretary Diana Dooley convened a task force two years ago to address this transition; the group noted the need to stabilize and increase the capacity of the community services system to adequately support all individuals with complex needs.
- With the assistance of individualized services and clinical support, individuals with intensive psychiatric and behavioral support needs are increasingly being served in community-based settings. To come to fruition, these services require not only the development or modification of services to address those specialized concerns, but take a great deal of collaboration and cross-training with agencies whose primary mission is not the service of individuals with developmental disabilities. Additionally, service providers' ability to succeed often hinges on being able to spend time working with families to help them understand and support their family members.
- A number of individuals with developmental disabilities, including youth, find themselves involved in the criminal justice system. These individuals can have co-occurring diagnoses, such as substance addiction, mental illness, or both. Serving these individuals necessitates significant resource development. But it also requires coordination with criminal justice agencies, other treatment and care systems, and regional center service providers to support these individuals to remain within, or return to, the community.
- The cost to support individuals rises sharply as they exit school settings. In the next three years, nearly 25,000 developmentally disabled individuals statewide will leave the educational system, requiring regional centers to provide services previously obtained in school settings, or entirely new services, such as adult day programs or supported employment.

- Individuals with autism oftentimes require customized supports to be successful, which frequently cost more than standard available services. While only 12% of individuals over age 22 served by regional centers are diagnosed with autism, this number jumps to almost 35% for individuals age 18-21, who will be exiting the school system soon.

Innovative models to serve these populations are costly to develop and require rates above artificially-capped limits. Until 2003 regional centers could help providers start programs to address unmet needs through the request for proposal (RFP) process. That option has since been ended for all but the small number of individuals either leaving, or being deflected from entry into, developmental centers or other institutional settings. As a result of long-term rate stagnation, providers do not have the cash reserves or borrowing ability to meet the initial costs of establishing needed programs. In the exceedingly rare cases when they do, they work with the understanding that in many instances the reimbursement rate for the service will not cover their operating expenses, largely as a result of rates being limited beginning in 2008 to the lower of either the regional center or statewide median rate for a service, regardless of the anticipated cost to provide it. Consequently, new and innovative programs are difficult to develop. Many times regional centers issue RFPs for needed services and are unable to locate or interest any qualified applicants to meet identified needs. California prides itself on not having waiting lists for services. Yet individuals and their families have identified needs, with inadequate or no services available to meet them. People are, essentially, waiting for something that is either in short supply or non-existent.

As California's population continues to diversify, the system must serve more individuals in ways that are responsive to and respectful of their language, ethnicity, geography, or family economic situation. Developing new, or augmenting traditional, service models to meet these various needs is essential in order to ensure that individuals of diverse backgrounds can be well-served. Community service providers and regional centers strive to provide services in a variety of languages and settings to accommodate this growing need, but there is no additional funding earmarked to offset the costs associated with customizing service delivery to ethnically diverse and other-language populations . As with other service developments and expansions, identifying providers to serve specific populations is virtually impossible given the existing rate structures.

Priorities for Advancing the System

California's developmental services system is severely underfunded as a result of years of neglecting to make needed investments to sustain it. Steps need to be taken to put the system back on track and ensure the health and safety of the persons served. Three areas that need to be of immediate focus are:

- *Stabilize System Funding* - The service delivery system, including service provider agencies and regional centers, is currently unable to provide services and supports needed to protect the health and safety of individuals and support their integration into the mainstream life of the community. The Lanterman Coalition, of which ARCA is a member, represents various groups touched by developmental disabilities in California (self-advocates, families, service providers, and advocates). The Coalition agrees that service provider rates and regional center operations should receive an immediate 10% increase, and 5% annual increases to provide a measure of system stability until sustainable rates and regional center operating funding formulas can be established, to ensure that needed supports continue to be available to Californians with developmental disabilities for years to come.
- *Commit to Fully Funding New Mandates* - The system must be agile in its response to changing expectations arising from a variety of sources, including shifting service populations and evolving federal, state, and local mandates. State and local changes to minimum wage, sick time

mandates, as well as new service requirements stemming from federal regulations, lead to considerable new costs. In order to meet increased expectations, there must be an explicit commitment to fully fund the impact of these changes for service providers and regional centers alike.

- *Reverse Failed Policies* - In response to state budget shortfalls in the past few years, DDS had to identify strategies to achieve targeted savings amounts. Several of the approaches identified have not achieved the anticipated savings levels and have actually increased fiscal pressures on service providers and regional centers. Fiscal strategies with no benefit added should be reversed. These failed policies that target families with minor children include:
    - Annual Family Program Fee – This program requires families of children not on Medi-Cal to pay an annual fee to DDS. The cost of administering the program likely exceeds the proceeds that it generates. Described by some advocates as a "disability tax," the program acts as a significant artificial barrier between children and needed services.
    - Family support services – Regional centers are prohibited from purchasing services that support families to stay together, such as camp and social recreation services, and are limited in the amount of respite hours that can be provided. Those services support families who choose to maintain an individual with developmental disabilities in the family home – respecting personal choice and avoiding the need for a more expensive residential facility placement. These reductions have put tremendous additional strain on families who strive to maintain loved ones at home, rather than doing the right thing by supporting them to make a decision that best reflects their personal or cultural preferences. These changes have made it harder for families to maintain individuals at home.

Additional information about the challenges facing service providers can be found in the ARCA publication *Inadequate Rates for Service Provision in California*. A similar ARCA publication titled *Funding the Work of California's Regional Centers* provides comparable information about the challenges facing the regional center operations budget. Service provider rates and regional center operations funding suffer from chronic underfunding that threatens service quality, federal funding, and most importantly, the health and safety of the more than 280,000 individuals served by the system today. In order to carry out California's ongoing commitment to individuals with developmental disabilities, significant ongoing investment must be made in the service system now.

Sincerely,

/s/Eileen Richey

Executive Director

Cc: Members, Senate Select Committee on Children with Special Needs
Cristina Jade Peña, Health Policy Analyst & Consultant
Darin Walsh, Deputy Chief of Staff, Office of Senator Richard Pan M.D.
Mark Newton, Deputy Legislative Analyst, Legislative Analyst's Office
Meredith Wurden, Senior Fiscal and Policy Analyst , Legislative Analyst's Office
Carla Castaneda, Principal Program Budget Analyst, Department of Finance
Teresa Calvert, Assistant Program Budget Manager, Department of Finance
Taryn Smith, Consultant, Senate Human Services Committee

Myesha Jackson, Chief Consultant, Assembly Human Services Committee
Michelle Baass, Consultant, Senate Budget Subcommittee #3
Jazmin Hicks, Consultant, Assembly Budget Subcommittee #1
Julie Souliere, Consultant, Assembly Republican Fiscal Office
Mary Bellamy, Consultant on Human Services, Assembly Republican Caucus
Chantele Denny, Human Services Consultant, Senate Republican Fiscal Office
Kirk Feely, Health Consultant, Senate Republican Fiscal Office
Joe Parra, Principal Consultant on Human Services, Senate Republican Caucus
John Doyle, Deputy Director, Department of Developmental Services
Mike Wilkening, Undersecretary, Health and Human Services Agency
Diana Dooley, Secretary, Health and Human Services Agency
Donna Campbell, Governor's Advisor, Health and Human Services

APPENDIX F

Panel 4: Special Education Services and Programs

Presenter: Chris Drouin, Associate Director, California Department of Education Special Education Division

On behalf of CDE, Mr. Drouin also provided the Select Committee with written testimony on Friday, February 5, 2016

Senate Select Committee on Children and Youth with Special Needs
Information Hearing 12/1/2015
Item VIII. Education Services
California Department of Education, Special Education Division
Chris Drouin, Associate Director

1. **Overview of services and care provided for children and youth with special needs, including but not limited to physical, developmental and mental health**

Students with disabilities qualify for special education and related services if an Individualized Educational Program (IEP) team determines that they have a disability and that because of that disability have a need for special education or related services. Generally, this means that their disability affects their ability to access, and make progress in, the school curriculum. Some students with disabilities do not qualify for special education because their disability does not affect their academic access and progress. Under state and federal law there are thirteen categories of disabilities. They are listed in the table below.

Student counts by Disability for Students Aged 3-22		
Disability	Frequency	Percent
Autism	90,734	12.7%
Deaf Blindness	97	0.0%
Deafness	3,244	0.5%
Emotional Disturbance	24,214	3.4%
Established Medical Disability	478	0.1%
Hard of Hearing	8,837	1.2%
Intellectual Disability	43,284	6.1%
Multiple Disability	6,176	0.9%
Orthopedic Impairment	11,791	1.7%
Other Health Impairment	74,811	10.5%
Specific Learning Disability	284,191	39.9%
Speech or Language Impairment	158,778	22.3%
Traumatic Brain Injury	1,734	0.2%
Visual Impairment	3,603	0.5%
Total	711,972	100.0%

SOURCE: December 2014
CASEMIS

In 2014-15, 666,574 of California's 6,235,520 K-12 students are identified as receiving special education (10.7%).

1

Number and Percent of Students Served 2010 - 2015				
Year	General Education (K-12)	Special Education age 3-22	Special Education age 5-22	Special Education age 5-22 percent*
2014-15	6,235,520	711,972	666,574	10.7%
2013-14	6,236,672	699,617	654,711	10.5%
2012-13	6,226,989	688,982	644,115	10.3%
2011-12	6,220,993	679,889	635,970	10.2%
2010-11	6,217,002	672,710	629,457	10.1%
* Percent of students receiving special education. Percent is based on 5-22 as there is no general education data for all preschool age students				

SOURCE: General Education from Dataquest; Special Education from CASEMIS December 2014

This percentage has increased from 10.1% to 10.7% since 2010-11. Among the seven largest states, this compares to a high of 17.8% in New York and a low of 8.7% in Texas.

New York	17.18%
Pennsylvania	15.40%
Ohio	14.77%
Illinois	14.00%
Florida	12.95%
Texas	8.70%

Child Find. LEAs are responsible for having procedures to ensure that all students with disabilities who are in need of special education and related services are identified, located and evaluated. (20 USC §1412(a)(3))

Assessment. Students identified as potentially eligible for special education are entitled to an assessment to determine whether they have a disability negatively impacting their academic progress, and to identify how the disability is impacting their progress. Each student with an IEP must be re-assessed at least once every three years, unless the

parent and other members of the IEP team determine that the re-assessment is not needed. (20 USC § 1414)

Individualized Educational Program (IEP). Based on the results of the assessment, students eligible for special education have an Individual Education Plan (IEP) developed for them by their IEP Team, which consists of the parent or guardian and a team of school staff and other individuals involved in the student's education. The IEP Team identifies the appropriate educational placement for the student, the related services the student is to receive, and goals for the student to achieve during the term of the IEP. IEP-based related services are designed to support the student in making progress toward the IEP goals. Each IEP is to be reviewed annually to ensure that current placement, goals and services are working for the student, and if not, to make appropriate changes. (20 USC § 1414(d))

Free Appropriate Public Education (FAPE). Under state and federal law, Local Educational Agencies (LEAs) are responsible for making a free appropriate public education available to all students with disabilities, 3 to 21 years of age. "Appropriate" is generally defined as suited to meet the student's specific needs, and reasonably planned to result in an educational benefit. (20 USC §1401(9))

Services provided to Students with Disabilities (SWD) ages 3-22		
Service	Count	Percent of SWD
Language and speech	343,440	48.24%
Occupational therapy	66,678	9.37%
Adapted physical education	41,901	5.89%
Individual counseling	34,810	4.89%
Behavior intervention services	31,754	4.46%
Counseling and guidance	26,338	3.70%
Psychological services	18,847	2.65%
Physical therapy	8,777	1.23%
Parent counseling	8,405	1.18%
Health and nursing, other services	7,077	0.99%
Audiological services	6,630	0.93%
Health and nursing, specialized physical health care services	5,391	0.76%
Social work services	5,355	0.75%
Orientation and mobility	2,591	0.36%
Interpreter services	1,834	0.26%
Recreation services	946	0.13%
Residential treatment services	539	0.08%

SOURCE: December 2014 CASEMIS

Placement in the Least Restrictive Environment. State and federal law require that students with IEPs are placed in the least restrictive environment possible to effectively address their educational needs. This means that, to the maximum extent appropriate, children with disabilities must be educated with nondisabled children. As a general requirement, special classes, separate schooling, or other removal from the regular educational environment occurs only if the nature or severity of the student's disability is such that education in regular classes (with the use of supplementary aids and services) cannot be achieved satisfactorily. LEAs are required to have a continuum of alternative placements to address the needs of students with disabilities. (20 USC 1412(a)(5))

Related Services. Related services include a variety of services that may be required to assist the student to benefit from special education. These can include transportation and services to address the student's physical needs, academic support that assists the student toward reaching IEP academic goals, and/or mental health services to address social or behavioral needs. The Individuals with Disabilities Education Act (IDEA) includes a list of related services, though the list is not considered exhaustive. The following table depicts the number of students who receive the services that, in California, most closely align to the federal list of related services. (This is not a complete list of related services provided to California students.)

2. **Description of the funding sources and how funding is distributed to pay for services**

California provides special education funding to LEAs from two primary sources: federal funding, and state funding. Within each category are several sources used to support the education of students with disabilities. Overall, federal funds have decreased and state general funds have increased.

SPECIAL EDUCATION
Local Assistance Funding

Year	Federal	State	Total Budgeted Authority
FY2015–16	$1,206,087,000	$3,257,426,000	$4,463,513,000
FY2014–15	$1,210,078,000	$3,286,970,000	$4,497,048,000
FY2013–14	$1,226,194,000	$3,171,317,000	$4,397,511,000
FY2012–13	$1,235,469,000	$3,220,353,000	$4,455,822,000
FY2011–12	$1,229,085,000	$3,117,119,000	$4,346,204,000
FY2010–11	$1,232,218,000	$3,106,681,000	$4,338,899,000

General Education Funding is Applicable to Students with Disabilities. It is important to recognize that students with disabilities are general education students first, and that their attendance in school generates general education funding. Therefore, general

education funding provided for all students appropriately supports some of the cost of educating students with disabilities. While the Local Control Funding Formula (LCFF) and Local Control Accountability Plan (LCAP) include students with disabilities as a target group, students with disabilities do not generate an LCFF allocation. The special education funding described below is intended to augment this base education funding to support additional costs incurred in providing special education and related services to which students with disabilities are entitled.

Special Education Funding is distributed through Special Education Local Plan Areas (SELPAs). California law has established an administrative structure for special education that involves Special Education Local Plan Areas (SELPAs). SELPAs serve a single LEA or consortium of LEAs in administering the special education system for their constituents. SELPA administrative units are either school districts or county offices of education. To be approved, SELPAs must demonstrate sufficient size, scope, and resources to successfully ensure the delivery of instruction and related services to all students entitled to receive special education in the SELPA's service area. Each SELPA develops a local plan for coordination and delivery of special education services by member LEAs.

SELPAs receive the special education funding on behalf of all of their member LEAs. Funds are distributed according to an allocation plan agreed upon by all of the member LEAs. SELPAs either 1) distribute funding to their member LEAs for the LEAs to pay for special education and related services, 2) retain the funding and provide the special education and related services directly, or 3) some combination of the two. Major funding mechanisms are described below.

The CDE allocates budgeted funding for each LEA based on a formula established by Congress or the Legislature, depending on the source of funding.

State General Funds

AB 602 (Prop 98). The AB 602 special education funding model was established in 1998-99. The AB 602 funding model provides funding to the SELPAs based on a rate per unit of Average Daily Attendance (ADA). Funds are paid through the Principal Apportionment. Principal Apportionment amounts are calculated three times for each fiscal year. SELPA rate per ADA receives annual adjustments for COLA and for growth (or decline) in SELPA ADA.

Educationally Related Mental Health Services. In addition to funds provided through the AB 602 principal apportionment, SELPAs are allocated funds for mental health services based on an ADA based calculation.

Other state general fund grants. Several grants programs were moved from federal funds to state general funds between 2004-2006. These grant programs include Project

Workability, Infant Discretionary funds. Grant funds are provided to LEAs using a different methodology for each program. (See http://www.cde.ca.gov/sp/se/as/leagrnts.asp for more information).

State General Funds		
Program Name	**Allocation Method**	**2015-16 Amount**
AB 602	ADA	$2,743,893,000
Educationally Related Mental Health	ADA	$361,910,000
Project Workability	Non-Competitive Application Process	$39,738,000
Infant Discretionary	Per infant	$2,324,000
Early Intervention Infants*	To Be Determined	$30,000,000

*New Funding for FY 2015-16

Federal IDEA Funds

The federal IDEA requires the CDE to allocate a minimum amount of California's IDEA Section 611 (age 3 to 21) and IDEA Section 619 (Preschool) to funds to flow through to LEAs. The CDE allocates the IDEA funds to LEAs/SELPAs through a grant award. These grant awards are based on a three-part formula required by the IDEA: a base amount, a percentage of population, and a percentage of poverty. The base amount is the amount federal funds provided in 1999. Of the funds allocated in excess of the base amount, 85 percent are allocated on the basis of the relative number of children enrolled in public and private elementary and secondary schools within each SELPA's jurisdiction, and 15 percent on the basis of the relative number of children living in poverty using free and reduced price meal participation as the indicator of poverty. Federal IDEA grants include:

Federal IDEA Funds		
Program Name	**Allocation Method**	**2015-16 Amount**
IDEA 611 LEA Agency Entitlement	Federal Funding Formula	$1,019,045,607
IDEA 611 Preschool Local Entitlement	Federal Funding Formula	$65,528,395
IDEA 611 Other State Agencies	Federal Funding Formula	$1,643,998
IDEA 619 Preschool	Federal Funding Formula	$31,510,000
Family Empowerment Centers	Base of $150,000, an additional amount based on their region's total school enrollment.	$2,794,000
IDEA Mental Health	ADA	$69,000,000
Accessible Instructional Materials	Non-Competitive Application process	$3,861,000

State Special Schools Transportation	Student Transportation Allowances	$3,894,000

The LEA Medi-Cal Billing Option

Strictly speaking, this is not a special education funding source. It is however, a significant source of funds for services for students with disabilities. The LEA Medi-Cal Billing Option Program provides the federal share of reimbursement for health assessment and treatment for Medi-Cal eligible children and family members within the school environment. A LEA provider (generally a school district or county office of education) employs or contracts with qualified medical practitioners to render certain eligible health services. This is a voluntary program and not all LEAs elect to participate. Approximately $136,143,337 in federal funds were claimed in 2013-14.

1. **What strategy and programs do you have underway to coordinate with other agencies and programs, and if not how would you like to see coordination occur?**

The needs of students with disabilities are complex and students often need services that are provided across service sectors involving multiple agencies. School personnel regularly work with staff of other local agencies to coordinate educational, therapeutic and medical services. In recognition of the importance of coordination, both federal and state policymakers have sought to ensure this coordination at the state and local levels. In California there are two legal sources that guide coordination of services among agencies. The first is derived from the IDEA, which requires the Chief Executive Officer of the state to ensure that an interagency agreement or other mechanism for coordination of services is in place between the CDE and any other public agency that is obligated under state or federal law to provide special education or related services. Second, the CDE has relied on the interagency provisions of Chapter 26.5 of the Government Code, which were significantly altered through AB114 in 2011.

Based on these requirements, the CDE coordinates with several other state agencies on activities related to special education. The CDE currently coordinates with the Department of Developmental Services (DDS) in providing services to children with disabilities from birth to age 3. The CDE is working with the DDS and the Department of Rehabilitation (DOR) on a Memorandum of Understanding to increase coordination and opportunities for competitive integrated employment for students with disabilities who are 16 years of age and older. The CDE also works with the Department of Health Care Services (DHCS) in their administration of the LEA Medi-Cal Billing Option program, which allows for reimbursement to LEAs for the cost of some services for some eligible students. Interagency provisions of the Government code were eliminated under AB 114, leaving considerable uncertainty about first payer responsibilities for mental health services to Medi-Cal eligible students, which had been clear under Chapter 26.5. The CDE been working with the DHCS to create an agreement to address these issues.

FOOTNOTES:

[1] PMPM rates are calculated as the total expenditures for the year divided by the total member months for the year (total annual expenditures/total annual member months = PMPM rate).

Source: California Department of Health Care Services. (Feb. 2012). Research and Analytic Studies Section RASS Month of Service - Utilization Tables - Analytic Notes. Retrieved from: http://www.dhcs.ca.gov/dataandstats/statistics/Documents/A_RASS_MOS_Utilization_Tables%20-%20Analytic%20Notes.pdf

[2] The Short-Doyle/Medi-Cal (SDMC) claim process system allows California's County Mental Health Plans (MHPs) to obtain reimbursement of funds for medically necessary specialty mental health services provided to Medi-Cal-eligible beneficiaries and also to Healthy Families subscribers diagnosed as Seriously Emotionally Disturbed (SED).1 The Department of Health Care Services Mental Health Services Division (DHCS MHSD) oversees the SDMC claim processing system

Source: State of California—Health and Human Services Agency. (Oct. 2013). Department of Health Care Services Mental Health Services Division Medi-Cal Billing Manual. Retrieved from: http://www.dhcs.ca.gov/services/MH/Documents/MedCCC/Library/Mental%20Health%20Medi-Cal%20Billing%20Manual_POSTED_1_28_14doc.pdf

[3] Developed by the National Committee for Quality Assurance, the Healthcare Effectiveness Data and Information Set (HEDIS), is on of the most widely used sets of health care performance measures in the United States and more than 90% of United States health plans use HEDIS to measure performance of care and services. HEDIS measures address a broad range of important health issues including but not limited to; Asthma Medication Use, Controlling High Blood Pressure, Comprehensive Diabetes Care, Breast Cancer Screening, Childhood and Adolescent Immunization Status, and Childhood and Adult Weight/BMI Assessment, among others.

Source: National Committee for Quality Assurance, HEDIS Measures. Retrieved from: http://www.ncqa.org/HEDISQualityMeasurement/HEDISMeasures.aspx

[4] 1915(b) Waivers are one of several options available to states that allow the use of Managed Care in the Medicaid Program. When using 1915(b), states have four different options: 1915(b)(1) - Implement a managed care delivery system that restricts the types of providers that people can use to get Medicaid benefits; 1915(b)(2) – Allow a county or local government to act as a choice counselor or enrollment broker) in order to help people pick a managed care plan; 1915(b)(3) – Use the savings that the state gets from a managed care delivery system to provide additional services; and 1915(b)(4) – Restrict the number or type of providers who can provide specific Medicaid services (such as disease management or transportation.

Source: Medicaid, 1915(b) Managed Care Waivers. Retrieved from: http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/managed-care-1915-b-waivers.html

[5] Regional Centers are nonprofit private corporations that contract with the Department of Developmental Services to provide or coordinate services and supports for individuals with developmental disabilities. Regional Centers provide diagnosis and assessment of eligibility and help plan, access, coordinate and monitor the services

and supports that are needed because of a developmental disability. There is no charge for the diagnosis and eligibility assessment. Once eligible, most services and supports are re free regardless of age or income.

Source: California Department of Developmental Services, Information About Regional Centers. Retrieved from: http://www.dds.ca.gov/rc/Home.cfm

[6] Senate Bill 511, enacted as *Education Code 56400–56414* in 2001, established the Family Empowerment Centers (FECs) funded by the California Department of Education (CDE) through an IDEA state set-aside. The FECs provide services to families with children with dis- abilities who are between the ages of 3 and 22 to ensure that parents, guardians, and families of children and young adults with disabilities have access to accurate information, specialized training, and peer-to-peer support.

Source: California Department of Education. (Sept. 2011). Family Empowerment and Disability Council, California Family Empowerment Centers on Disability. Retrieved from: http://www.efrconline.org/myadmin/files/fedc_facts.pdf

[7] The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is the child health component of Medicaid. It's required in every state and is designed to improve the health of low-income children, by financing appropriate and necessary pediatric services. In California, EPSDT is a Medi-Cal benefit for individuals under the age of 21 who have full-scope Medi-Cal eligibility.

Source: United States Department of Health and Human Services, Health Resources and Services Administration Maternal and Child Health EPSDT & Title V Collaborative to Improve Child Health. Retrieved from: http://mchb.hrsa.gov/epsdt/

Source: California Department of Health Care Services Early and Periodic Screening, Diagnosis, and Treatment (EPSDT). Retrieved from: http://www.dhcs.ca.gov/services/Pages/EPSDT.aspx

[8] Defined by the Elementary and Secondary Education Act (ESEA) of 1965, a Local Educational Agency (LEA) is a public board of education or other public authority legally constituted within a State for either administrative control or direction of, or to perform a service function for, public elementary schools or secondary schools in a city, county, township, school district, or other political subdivision of a State, or for a combination of school districts or counties that is recognized in a State as an administrative agency for its public elementary schools or secondary schools.

Source: United States Department of Education, Definitions. Retrieved from: http://www.ed.gov/race-top/district-competition/definitions

[9] California has organized the delivery of special education regionally through the establishment of Special Education Local Plan Areas (SELPAs) which is best defined as a collaborative consortia of school districts, county offices of education and charter school in proximity. Currently, 133 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. 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.

Source: California Department of Education, California Special Education Local Plan Areas. Retrieved from: http://www.cde.ca.gov/sp/se/as/caselpas.asp

[10] An Individualized Family Service Plan (IFSP)and the Individualized Education Program (IEP) are written records identifying the services that the local educational agency (LEA) or the Regional Center is required to provide to meet a child's early intervention or educational needs throughout K-12.

Source: California Department of Education. (2011). Handbook on Developing Individualized Family Service Plans and Individualized Educational Programs in Early Childhood Special Education. Retrieved from: http://www.cde.ca.gov/sp/se/fp/documents/eciifspiec.pdf

[11] Each public school child who receives special education and related services must have an Individualized Education Program (IEP). Each IEP must be designed for one student and must be a truly *individualized* document. The IEP creates an opportunity for teachers, parents, school administrators, related services personnel, and students (when appropriate) to work together to improve educational results for children with disabilities.

Source: United States Department of Education, My Child's Special Needs: A Guide to the Individualized Education Program. Retrieved from: http://www2.ed.gov/parents/needs/speced/iepguide/index.html

[12] The 13 disability categories in California for individuals (newborn through twenty-two years of age) who received special education services in 2013–14 are as follows: Intellectual disabilities; Speech or language impairment; Visual impairment; Emotional disturbance; Orthopedic impairment; Other health impairment; Specific learning disability; Deafness; Hard of hearing; Deaf-blindness; Multiple disabilities; Autism; Traumatic brain injury.

Source: California Department of Education, Special Education—CalEdFacts. Retrived from: http://www.cde.ca.gov/sp/se/sr/cefspeced.asp

[13] The Affordable Care Act of 2010, Section 2703, created an optional Medicaid State Plan benefit for states to establish Health Homes to coordinate care for people with Medicaid who have chronic conditions by adding Section 1945 of the Social Security Act. CMS expects states health home providers to operate under a "whole-person" philosophy. Health Homes providers will integrate and coordinate all primary, acute, behavioral health, and long-term services and supports to treat the whole person.

Source: Center for Medicaid and CHIP Services (CMCS), Medicaid Health Homes. Retrieved from: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Integrating-Care/Health-Homes/Health-Homes.html

[14] The Title V Maternal and Child Health (MCH) Block Grant is a formula grant awarded to states and jurisdictions upon submission of an acceptable plan that addresses the health services needs within a state for the target population of mothers, infants and children, which includes children with special health care needs (CSHCN), and their families. Through this process, each state and jurisdiction supports and promotes the development and coordination of systems of care for the MCH population, which are family-centered, community-based and culturally appropriate.

Source: US Department of Health and Human Services, Title V Maternal and Child Health Services Block Grant to States Program: Guidance and Forms for the Title V Application/Annual Report Expires 12/31/2017. Retrieved from: http://mchb.hrsa.gov/programs/titlevgrants/blockgrantguidance.pdf

[15] The 2011 Realignment readjusts the California Department of Social Services' (CDSS) funding for Adoption Services, Foster Care, Child Welfare Services, and Adult Protective Services, and programs from the state to local governments and redirects specified tax revenues to fund this effort. Senate Bill 1020 (Chapter 40, Statutes of

2012) established the Behavioral Health Subaccount which funds specialty mental health; drug Medi-Cal; residential perinatal drug services and treatment; drug court operations; and other non-drug Medi-Cal programs.

Source: California Department of Social Services, 2011 Realignment Summary. Retrieved from: http://www.dss.cahwnet.gov/cdssweb/PG2800.htm

Source: California Department of Health Care Services. (Sept. 2033) 2011 Realignment Behavioral Health Services Growth Special Account Stakeholder Meeting Conference Call. Retrieved from: http://www.dhcs.ca.gov/services/MH/Documents/Presentation-BehavioralHealthSubaccountGrowthStakeholderMeeting.pdf

[16] 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. This Act imposes a 1% income tax on personal income in excess of $1 million.

Source: California Department of Health Services, Mental Health Services Act (MHSA). Retrieved from: http://www.dhcs.ca.gov/services/mh/Pages/MH_Prop63.aspx

[17] In 1991, the state enacted a major change in the state and local government relationship, known as realignment. The 1991 realignment transferred programs within mental health and social services from the state to the county level, altered program cost-sharing ratios, and provided counties with dedicated tax revenues from the sales tax and vehicle license fee to pay for these changes.

Source: Legislative Analyst's Office. (Feb. 2001). Realignment Revisited: An Evaluation of the 1991 Experiment in State-County Relations. Retrieved from: http://www.lao.ca.gov/2001/realignment/020601_realignment.html

[18] The 1915(c) Home & Community-Based waivers (HCBS) are one of many options available to states to allow the provision of long term care services in home and community based settings under the Medicaid Program. States can offer a variety of services under an HCBS waiver including a combination of standard medical services and non-medical services. Standard services include but are not limited to: case management (i.e. supports and service coordination), homemaker, home health aide, personal care, adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community.

Source: Center for Medicare and Medicaid Services, Medicaid 1915(c) Home & Community-Based Waivers. Retrieved from: https://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/home-and-community-based-1915-c-waivers.html

[19] The Temporary Assistance for Needy Families (TANF) program is designed to provide states with block grants for the purpose of operating state-administered programs which meet one of the following purposes; i. provide assistance to needy families so that children can be cared for in their own homes; ii. reduce the dependency of needy parents by promoting job preparation, work and marriage; iii. prevent and reduce the incidence of out-of-wedlock pregnancies; and or iv. encourage the formation and maintenance of two-parent families.

Source: United States office of Social Security Office, Title IV—Grants to States for Aid and Services to Needy Families with Children and for Child-Welfare Services. Retrieved from: https://www.ssa.gov/OP_Home/ssact/title04/0400.htm

[20] The Individuals with Disabilities Education Act (IDEA)—Part B provides grants to states to assist them in providing a free appropriate public education in the least restrictive environment for children with disabilities ages 3 through 21 (Part B, Sections 611 and 619). In addition, IDEA—Part C formula grant program, assists states in providing early intervention services for infants and toddlers birth through age two and their families.

Source: United States Department of Education, Funding/ Grants: OSEP Grant Opportunities and Funding. Retrieved from: http://www2.ed.gov/fund/grant/apply/osep/index.html

[21] Title XX of the Social Security Act, also referred to as the Social Services Block Grant, is a capped entitlement program. Block grant funds are given to States to help them achieve a wide range of social policy goals. Funds are allocated to the States on the basis of population. Title XX funds can be used for five specified federal purposes including: promoting economic self-sufficiency, preventing or remedying abuse and neglect, and helping individuals avoid institutional care.

Source: United States Government Publishing Office, Section 10. Title XX Social Services Block Grant Program. Retrieved from: https://www.gpo.gov/fdsys/pkg/GPO-CPRT-105WPRT37945/pdf/GPO-CPRT-105WPRT37945-2-10.pdf

[22] Just over 400,000 American children live in foster care, and some 55,000 reside in group homes, residential treatment facilities, psychiatric institutions and emergency shelters. This type of placement—called "congregate care"—may be beneficial for children who require short-term supervision and structure because their behavior may be dangerous.

Source: National Conference of State Legislation. (March 2014). Congregate Care, Residential Treatment and Group Homes State Legislative Enactments 2009-2013. Retrieved from: http://www.ncsl.org/research/human-services/congregate-care-and-group-home-state-legislative-enactments.aspx

[23] In 1984, Assembly Bill 3632 statutorily required a partnership between school districts and county mental health agencies to deliver mental health services to students with individualized education programs (IEPs). In 2011, the California Legislature passed Assembly Bill 114, which repealed the state mandate on special education and county mental health agencies and eliminated related references to mental health services in California statute. As a result of this new legislation, school districts are solely responsible for ensuring that students with disabilities receive special education and related services to meet their needs according to the Individuals with Disabilities Education Act (IDEA) of 2004.

Source: California Department of Education, Special Education, Mental Health Services FAQ. Retrieved from: http://www.cde.ca.gov/sp/se/ac/mhsfaq.asp

[24] Governor Arnold Schwarzenegger, Republican, held office from November 17, 2003 to January 3, 2011

Source: The Governors Gallery, Arnold Schwarzenegger. Retrieved from: http://governors.library.ca.gov/38-schwarzenegger.html

[25] Welfare and Institutions Code Section 5845(d)(7) provides that the Mental Health Services Oversight and Accountability Commission (MHSOAC); primarily responsible holding public mental health systems accountable by providing oversight, review, training and technical assistance, accountability and evaluation of local and statewide projects supported by MHSA funds. MHSOAC receives funding ($40,310,000 for FY2014-15) and 27 positions to support its statutory oversight and accountability for the MHSA.

Source: Department of Health Care Services, Mental Health Services Act Expenditure Report Fiscal Year 2014-2015. Retrieved from: http://www.dhcs.ca.gov/formsandpubs/Documents/Legislative%20Reports/Mental%20Health/MHSA_Expend_Report-Mar2014.pdf

[26] The California Child Welfare Council was established as a statewide multidisciplinary advisory body by the Child Welfare Leadership and Accountability Act of 2006. It is responsible for improving services to children and families in the child welfare system and those at risk of entering the system, particularly emphasizing collaboration among multiple agencies and the courts.

Source: The California Child Welfare Council. (July 2015). California Child Welfare Council 2015-2015 Annual Report. Retrieved from: http://www.chhs.ca.gov/CWCDOC/CWC%20Annual%20Report%202014-15.pdf

[27] Priority Access to Services and Supports Task Force Examines how parents of foster children who have a reunification plan can receive priority access to services they in order to have their children safely returned home, including services across multiple systems.

Source: The California Child Welfare Council. (July 2015). California Child Welfare Council 2015-2015 Annual Report. Retrieved from: http://www.chhs.ca.gov/CWCDOC/CWC%20Annual%20Report%202014-15.pdf

[28] Established in 1997, the California Perinatal Quality Care Collaborative (CPQCC) includes 136 member hospitals, representing over 90% of all neonates cared for in California NICUs, including all California Children's Services (CCS)-approved Intermediate, Community and Regional level NICUs. The CPQCC Perinatal Data System is an integrated data management system that facilitates the identification of important perinatal improvement targets, and monitors the public health effects of planned interventions such as system changes, medical treatments, and/or care behavior modification.

Source: The California Perinatal Quality Care Collaborative (CPQCC). Retrieved from: http://www.cpqcc.org/about-us

[29] Senate Bill 946 requires that every health care service plan and health insurance policy issued, amended, or renewed after 1/1/2012 which provides hospital, medical or surgical coverage, shall provide coverage for behavioral health treatment for pervasive developmental disorder or autism. Senate Bill 126, introduced by Senator Steinberg, extends provisions related to SB 946 until January 1, 2017.

Source: California Legislative Information, Senate Bill 946. Retrieved from: ftp://www.leginfo.ca.gov/pub/11-12/bill/sen/sb_0901-0950/sb_946_bill_20110914_enrolled.html

[30] In January 1, 2014 the Panel became operative as part of the DHCS, and was collaboratively renamed to the Advisory Panel for Medi-Cal Families. MCHAP will advise DHCS on policy and operational issues that affect children in Medi-Cal. Previously, the Panel served as an advisory body for the former Healthy Families Program (HFP) administered by the Managed Risk Medical Insurance Board (MRMIB). The Panel consists of a 15-member advisory

body whose members are recognized stakeholders/experts in their fields, practicing and/or certified medical professionals, advocates who represent the interest of children's health, as well as parent members who provide feedback on topics that impact children in Medi-Cal

Source: California Department of Health Care Services, Medi-Cal Children's Health Advisory Panel. Retrieved from: http://www.dhcs.ca.gov/services/Pages/Medi-Cal_Childrens_Health_Advisory_Panel.aspx

[31] The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Program is the child health component of Medicaid. It's required in every state and is designed to improve the health of low-income children, by financing appropriate and necessary pediatric services. In California, EPSDT is a Medi-Cal benefit for individuals under the age of 21 who have full-scope Medi-Cal eligibility.

Source 1: United States Department of Health and Human Services, Health Resources and Services Administration Maternal and Child Health, EPSDT & Title V Collaborative to Improve Child Health. Retrieved from: http://mchb.hrsa.gov/epsdt/

Source 2: California Department of Health Care Services, Early and Periodic Screening, Diagnosis, and Treatment (EPSDT). Retrieved from: http://www.dhcs.ca.gov/services/Pages/EPSDT.aspx

[32] The Lanterman Coalition consists of the 19 major stakeholders in California's community based developmental services system who commit to the supporting the following: i. the Preservation of the Lanterman Act and the entitlement[A]; ii. no categorical elimination of services; iii. no enrollment caps or waiting lists; iv. no reductions to services and supports important to people with Intellectual and Developmental Disabilities and their families; and v. full support of the community imperative[B] and the Olmstead decision.

Source: The Lanterman Coalition 2015 Membership. Retrieved from: http://www.lantermancoalition.org/about-us.html