



USC University of
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SYSTEMS OF CARE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

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- The purpose of this webinar is to examine programs and practices (systems) that have evolved to provide services to children and youth with special health care needs and their families

- MCHB: Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson, 1998)
- Nationally, 20% of children have a special need; 21.8% of households with at least one child with special needs
- In CA, about 15% of the child population with special health care needs

- Families are partners in decision making at all levels, and are satisfied with the services they receive
- Receive coordinated, ongoing, comprehensive care within a medical home
- Families have adequate private and/or public insurance to pay for the services they need
- Screened early and continuously for special health care needs
- **Community-based services are organized in ways that so families can use them easily**
- Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence

- Medicaid
 - Health insurance for low income and disabled individuals
 - Title XIX of the Social Security Act, established in 1965
 - Medicaid is a federal and state partnership
 - Federal guidelines define scope of service, extent of coverage and certain administrative requirements
 - States administer their own program, determine income eligibility within federal guidelines, specify services to be covered and payment level and methods
 - Expansion of Medicaid was a focus of the Affordable Care Act

- Medi-Cal
 - California's Medicaid program
 - 29.3% of the CA population is covered by Medi-Cal (11.3 million) (CHIS, 2017)
 - 42.3% of CA's children are covered by Medi-Cal (4.22 million) (CHIS, 2017)
 - Eligibility (CHCF, 2017)
 - Low income parent/caretaker relative and child (45%)
 - Low income adults (ACA expansion) (28%)
 - Low income seniors and persons with disabilities (15%)
 - Former Health Families (CHIP) clients (11%)
 - Children and youth in foster care (1%)
 - Restricted scope Medi-Cal for undocumented individuals (<1%)
 - Special consideration for teens, without consent of parents for STI treatment, pregnancy, family planning, mental health, drug and alcohol treatment
 - In 2016, CA spent \$82.8 billion on Medi-Cal program
 - The federal government matches what we spend on Medi-Cal

– Service delivery

- In 2017, 80% of recipients were in Medi-Cal managed care (CHCF, 2017)
- Some fee for service but becoming less and less

– Services

- Inpatient, outpatient and skilled nursing care
- Equipment and supplies
- Therapies
- Clinic and doctor visits
- Lab tests and x-rays
- Pharmaceuticals
- Medical transportation
- Some services optional for adults, may be reduced during times of budgetary constraint

- Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT)
 - Added to the Medicaid program in 1967
 - Aim is to improve the health of low income children by financing a comprehensive set of benefits and services for children
 - Medically necessary services must be provided to “correct or ameliorate” a condition identified on a screening of any Medicaid beneficiary under age 21 years
 - Services must be provided even if they are not part of the state’s Medicaid plan for the rest of it’s population
 - Examples of services: vision, dental, hearing, mental health

- Child Health and Disability Prevention Program (CHDP)
 - Delivers periodic health assessments to low income children (Medi-Cal recipients up to age 21, or low income individuals, under 200% of poverty, up to age 19); proof of income is not required
 - Assessments provided by individual clinicians, managed care providers, health departments and more
 - Families can be assisted with appointments, transportation and referrals to treatment services, WIC and other programs
 - CHDP providers must be enrolled in the program and provide the assessment as prescribed by the program guidelines, including anticipatory guidance and health education
 - Can be used for required school, sports and camp physicals
 - Periodicity schedule:
<https://www.dhcs.ca.gov/services/chdp/Documents/HealthPeriodicity.pdf>

- Medicaid Waivers
 - States apply to the federal government to waive certain Medicaid rules in order to test new or existing ways deliver and pay for health care services
 - Section 1915(c) waivers (Home and Community Based Services Waivers)- provides long term care services in home or community settings rather than an institution
 - Section 1915 (b) waivers (Freedom of Choice Waivers)- allows states to provide services through managed care delivery systems or otherwise limit choice
 - Section 1115 Research and Demonstration Waiver- allows states to test new approaches to financing and delivering care

- [1115\(a\) Waiver - Medi-Cal 2020 Demonstration](#)
- [1915\(b\) Medi-Cal Specialty Mental Health Services Waiver](#)
- 1915(c) Home and Community-Based Services (HCBS) Waivers
 - [AIDS Medi-Cal Waiver Program](#)
 - [Assisted Living Waiver \(ALW\)](#)
 - [Home and Community-Based Alternatives \(HCBA\) Waiver \(formerly NF/AH Waiver\)](#)
 - [Home and Community-Based Services Waiver for the Developmentally Disabled \(HCBS-DD\) Waiver](#)
 - [In-Home Operations \(IHO\)](#)
 - [Multipurpose Senior Services Program \(MSSP\)](#)
 - [Pediatric Palliative Care Waiver \(PPC\)](#)
 - [Self-Determination Program](#)

- Medi-Cal Access Program (MCAP) (formerly Access for Infants and Mothers- AIM)
 - State insurance program for pregnant women without regard to immigration status and their newborns who are over income for Medi-Cal
 - Many pregnant women who are eligible for MCAP may also qualify for Covered California with subsidies, called Advanced Premium Tax Credits, or Cost-Sharing Reductions, but even with subsidies, Covered California can be expensive for low-income women
 - Covers women from 213%-322% of the federal poverty level
 - MCH Access, 2018

- Covered California
 - As a result of the Affordable Care Act, the health care marketplace for CA
 - Allows individuals and small businesses to purchase health insurance at federally subsidized rates
 - Includes ACA expansion of Medi-Cal
 - 4 levels
 - Bronze- health plan pays 60% of covered costs, consumer pays 40%
 - Silver- 70/30
 - Gold- 80/20
 - Platinum- 90/10
 - Plans must cover the 10 essential health benefits of the ACA
 - Provides dental and vision care to children
 - Variety of plans participate, for example, Kaiser, Oscar, Health Net, Blue Cross and more

- California Children's Services (CCS)
 - CA State Title V Program for Children with Special Health Care Needs
 - Arranges, directs and pays for care for children under age 21 who have an eligible condition and whose families are unable to pay for all or part of their care
 - State/County partnership
 - State- establishes and oversees standards statewide, credentials or panels providers and special care centers, manages the program for smaller ("dependent") counties, reimburses providers (39.7% increase over Medi-Cal rates on a FFS basis)
 - Counties- establish eligibility, authorize services, provide care coordination, provides therapy services in MTUs

- CCS pays for doctor and hospital care, PT, OT, lab tests and x-rays, special medical equipment, medication
- Eligibility
 - Under the age of 21
 - Resident of the county in which patient applies- permanent resident of county, does not need to be “documented” but must show intent to reside
 - Financial eligibility- eligible for Medi-Cal, or family income of less than \$40,000 adjusted gross income per year, or expects to pay more than 20% of adjusted gross income in medical expenses
 - Medically eligible diagnosis- generally chronic or catastrophic conditions needing specialty care

- Special Care Centers
 - Centers comprised of professionals who work as a team to provide comprehensive care for children with certain conditions (e.g. cancer, spina bifida, cleft lip and palate)
 - Centers have all specialists needed to care for a child with a particular condition, plus nurses, social workers, therapists, dieticians and provide coordinated care
- Medical Therapy Program (MTP)
 - Therapy services, co-located at public school sites
 - Includes PT, OT and medical therapy conferences (comprehensive evaluations and recommendations)
 - Focuses on children with neurologic or musculoskeletal conditions such as CP, spina bifida, muscular dystrophy and spinal cord injuries
 - Staff may attend IEPs as well
 - No financial eligibility requirement for therapy services, but required for specialized equipment

Special Care Center Type	Directory Listing (Chapter 7)
Amputee Centers	7.07
Bone Marrow Transplant Centers	7.19
Burn Centers (See Miscellaneous Centers)	7.20
Cardiac Centers	7.02
Cleft Palate Centers	7.04
Cochlear Implant Centers	7.36
Communication Disorder Center (Type A)	7.33
Communication Disorder Center (Type B)	7.34
Communication Disorder Center (Type C)	7.35
Craniofacial Centers	7.03
Cystic Fibrosis and Pulmonary Disease Centers	7.11
Extracorporeal Membrane Oxygenation Centers, Neonatal (ECMO)	7.29
Gastrointestinal Centers	7.23
Heart and Lung Transplant Centers	7.31
Heart Transplant Centers	7.27
Hematology/Oncology Centers	7.16
Hemophilia Centers	7.15
High Risk Infant Follow-Up (Community)	7.38
High Risk Infant Follow-Up (Regional)	7.37
Infectious Disease and Immunologic Disorders (IDID) Centers	7.26
Liver Transplant Centers	7.28
Metabolic and Endocrine Centers	7.09
Miscellaneous Centers	7.20
Neonatal Intensive Care Unit (Community)	7.13
Neonatal Intensive Care Unit (Intermediate)	7.14
Neonatal Intensive Care Unit (Regional)	7.12
Pediatric Intensive Care Unit	7.25
Prosthetics/Orthotics Centers	7.21
Rehabilitation Centers	7.05
Renal Dialysis and Transplant Centers	7.10
Rheumatology Disease Centers (See Miscellaneous Centers)	7.20
Selective Posterior Rhizotomy (SPR) Centers	7.30
Sickle Cell Disease Centers	7.17
Specified Inherited Neurological Diseases Centers	7.24
Spina Bifida Centers	7.08

- Genetically Handicapped Persons Program
 - Health care program for adults with certain genetic conditions
 - GHPP Special Care Centers provide coordinated care using multidisciplinary and multispecialty teams, typically located at tertiary medical centers
 - Includes hospital and outpatient care, medications and infusions, medical foods and formulas, surgeries, durable medical equipment
 - Examples of conditions include hemophilia, cystic fibrosis, sickle cell disease, muscular dystrophy, PKU disease and more

- Mental Health

- For those children with Medi-Cal and a serious emotional disorder, specialty mental health services for children and youth are provided by the county level departments of mental health (as a carve out) directly, or through contracted agencies
 - Services can include: individual therapy, dyadic therapy, group therapy, family therapy, parenting programs, therapeutic behavioral services, day treatment, rehabilitation (OT, PT, feeding therapy), education support, in home, school and hospital based services and case management
- For those children with mild to moderate levels of impairment, services are provided through the child's Medi-Cal managed care plan

- Special Education
 - Instruction individually designed to meet the unique needs of children with disabilities
 - Provides for a free, appropriate, public education (FAPE) in the least restrictive environment as guaranteed by the Individuals with Disabilities Education Act (IDEA)
 - Individualized Education Program defines the services for each child
 - Children ages 3-18 (and in some cases 22) who have an eligible condition, including such things as autism, hearing impairment, speech delays, intellectual impairment, traumatic brain injury, other health impairment
 - Services can be provided in a regular classroom, special day classes, non public schools and residential facilities
 - The IEP team includes the parent, general and special education teachers, an administrator who can make decisions, someone who can explain test results, others with knowledge of the child, and anyone the parent wishes to invite

- Many procedural safeguards in the IEP process
 - Notifications
 - Timelines
 - After the written request is received, the district has 15 days to develop an assessment plan
 - The assessment plan is developed and sent to the parents who have up to 15 days to consent to the assessment
 - When the district receives consent, they have 50 calendar days to complete the assessment and schedule the IEP
 - Location
 - Parent/guardian participation
 - Transition planning begins at age 14
- Services can include therapies, educational supports, adapted PE, aides, counseling, health services, transportation and more

- Regional Centers (Department of Developmental Services)
 - Early Start and Lanterman Act services

– Early Start

- CA's early intervention program for infants and toddlers with or at risk for developmental disabilities
- Part of the Individuals with Disabilities Education Act (IDEA), Part C (Regional Center serves as the "lead agency" for early intervention services)
- For children with "low incidence disorders" (blind, deaf, orthopedically handicapped) the lead agency for early intervention is the school system
- Services include therapies, infant development programs, medical services, parent support, respite, assistive technology and service coordination
- Generic resources must be used if available, health insurance, CCS

- Lanterman Act services- for those from 3 throughout life span
 - Basis for developmental services in CA
 - Provides services for those with developmental disabilities- defined as a disability that occurs before the age of 18, can be expected to continue indefinitely, and constitutes a substantial disability for that individual
 - Includes mental retardation (now intellectual disability), cerebral palsy, epilepsy and autism and “5th category”, those that are closely related to mental retardation

– Regional Centers

- Independent, nonprofit private corporations that contract with DDS
- 21 in CA, 7 in LA County
- Each RC has its own community based board that sets its own policies within DDS guidelines...hence some variability between RC
- Provide or coordinate services for individuals with DD and their families
 - Information and referral
 - Assessment and diagnosis
 - Counseling and lifelong planning and service coordination
 - Purchase of necessary services

- RC uses an Individual Program Plan for each client, and assigns all clients a service coordinator
- RC requires the use of “generic resources” before paying for any services, including school, health insurance, CCS
- No charges to families for most services

- In Home Support Services
 - Services for those over 65, disabled or blind who require assistance to stay in their homes, including children
 - Services can include housecleaning, meal prep, laundry, grocery shopping, personal care services (like bathing), accompaniment to medical appointments and protective supervision for the mentally impaired
 - Must be eligible for Medi-Cal and live at home or a place of the client's choosing
 - A social worker does an assessment and determines how many hours of support is needed and authorized
 - The client hires their own IHSS worker and trains them
 - The IHSS worker may be a parent or other relative
 - The county determines the hourly rate and the state issues the payments

- Supplemental Security Income (SSI)
 - Nationwide program, administered by the Social Security Administration (SSA)
 - Provides monthly cash payments to low income individuals who are blind or disabled, including children
 - Income and resource limits apply
 - Must be a US citizen (with few exceptions)
 - State Disability Determination Services determines eligibility on behalf of the SSA, primarily based on record reviews
 - Also provides linkage to Medi-Cal

- Family Voices of CA
 - Linkage of Family Voices National and the Family Resource Networks of CA
 - Statewide collaborative of 52 parent run centers focusing on advocating for children with special health care needs; many co-located with Regional Centers
 - Resource centers provide education and parent to parent support
 - Builds partnerships between parents and professionals
 - Trains families to serve as advocates
 - FV CA is a federally funded family to family health information center
 - Annual Health Summit brings family members, providers and policymakers together to identify and address health challenges facing children with special health care needs

- Children's Hospitals
 - 8 children's hospitals in CA
 - Additionally other university based children's programs (UCLA, UC Davis, etc.)
 - List of CCS paneled hospitals
 - <https://www.dhcs.ca.gov/services/ccs/scc/Pages/SCCName.aspx>
 - List of special care centers by CCS paneled hospitals
 - <https://www.dhcs.ca.gov/services/ccs/scc/Pages/SCCType.aspx>

- Pediatric Subacute Facilities
 - Intensive, licensed, skilled nursing facilities for medically fragile children
 - May be freestanding or located within an acute care hospital
 - Patient must be under the age of 21 and have a tracheostomy and require oxygen and/or suctioning, total parenteral nutrition, continuous IV therapy, peritoneal dialysis, n/g or gastrostomy tube feedings, other medical technologies, continuous availability of an RN, acute care and daily medical visits no longer needed
 - Must include respiratory, speech, OT, PT and dietician services

- Home Health Agency
 - Is primarily engaged in providing skilled nursing services and other therapeutic services
 - Has policies established by a group of professionals (associated with the agency or organization), including one or more physicians and one or more registered professional nurses, to govern the services which it provides
 - Provides for supervision of above-mentioned services by a physician or registered professional nurse
 - Maintains clinical records on all patients
 - Is licensed pursuant to State or local law, or has approval as meeting the standards established for licensing by the State or locality
 - Has in effect an overall plan and budget for institutional planning
 - Meets the federal requirements in the interest of the health and safety of individuals who are furnished services by the HHA
 - CMS.gov
 - May be responsible for providing shift nursing care, or episodic in home care

- Disability Rights CA
 - Established by federal law to protect and advocate for those with disabilities
 - The protection and advocacy agency for CA
 - Provides advocacy, education, investigation and litigation for people with disabilities
 - Various programs
 - Office of Clients Rights Advocacy- free legal information, advice and representation for RC clients
 - Client Assistance Program- helps people get services from the Department of Rehabilitation
 - CA Office of Patients' Rights- advocate and train in the state hospitals
 - Legal Advocacy Unit- their core legal services
 - Many more...IHSS, special education, housing...

- United Advocates for Children and Families
 - Parent voice for children with mental, emotional and behavioral challenges
 - Statewide training, technical assistance, parent to parent support and public policy advocacy

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