

Darby's Legacy



Best Practices When Serving Families With Infants and Toddlers Who Are Medically Fragile This document detailing recommended practices was prepared with support from WestEd under a contract from the California Department of Developmental Services (DDS). The content does not necessarily reflect the views or policies of DDS, nor does it indicate endorsement of the recommendations by any individual or state agency.

Preface

Darby's Legacy

By Cindy Rubin

Darby Jean was born on a rare and magical lunar eclipse on the morning of August 21, 2017, at 10:15 a.m., exactly on her due date. Although expectations were low for Darby's ability to breathe independently at birth, she surprised us all and breathed for an entire hour before needing intervention. Darby was a warrior from day one.

In the womb, Darby was diagnosed with Trisomy 13, a rare chromosomal condition. She had the most severe form of the condition, and this diagnosis automatically relegated her to "incompatible with life," a label that was a barrier to many life-improving services. We had a child with a diagnosis that we could not change, but resources existed in the medical and social services fields to aid our child in a manner that would have ultimately shaped our experience for the short time she was alive.

Darby stayed in the NICU for 19 very long and strenuous days. Her journey was one of medical complications, many subsequent hospitalizations, and constant reminders of her delicate condition. As her family, we fought to get the support we needed to care for her at home, to allow her the dignity and privacy she deserved, and the opportunity to make memories with the family that loved her so much. We held our little angel constantly, soaking up her coos and smiles. Just when we began to settle into a new home routine with the help of an approved state waiver, obtaining pediatric home nursing care and hospital-grade equipment, Darby was called home to Heaven.

For the short 15 months that we had with Darby, we fought for the support and resources needed to make her life comfortable and allow us as her family to create memories. Our family struggled to get respite, nursing assistance, and breathing equipment, and we had to endure the lengthy process of trying to qualify for a state waiver. My husband had to quit his job to care for Darby. Having to provide her 24-hour care with no family support, living on one income, and having to blindly navigate the state and social service systems to get resources left our family emotionally, financially, and mentally barren.

The system meant to care for children like Darby and their families failed, but I want our family's experience to be the catalyst for change. There were so many missed opportunities for our family to receive the help that we needed. The entire system needs to be improved, and warm handoffs need to be better coordinated so that families — even those with the direst diagnoses — feel supported and receive the resources they need. It is my hope that by hearing Darby's story and working to change the system, we can ensure that families spend their time making memories and cherishing the moments they have with their child. The Interagency Coordinating Council on Early Intervention dedicates this document to Darby Jean and her family.

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Introduction

Supporting Families Is Critical

Early Start—Part C of the Individuals with Disabilities Education Act (IDEA) in California—recognizes that families are the constant in a baby's life. Family strengths, family support, and family-centered care are the backbone of building and maintaining successful partnerships with all families. This is especially true for families whose children have special health care needs regardless of the setting in which they are being served. These supports and approaches are important to implement along with educating, strengthening, collaborating, and enhancing leadership within the family unit.

The California Interagency Coordinating Council on Early Intervention recognizes that the Department of Developmental Services can enhance and strengthen the system that supports and serves families that have infants in the Neonatal Intensive Care Unit (NICU). Families are exhausted from having their resilience tested in this unexpected and unknown environment. Parent-to-parent support is an important service which matches a veteran parent with a family whose child is in the NICU to provide feeling-focused emotional support and information from a parent who has experienced similar circumstances with their own child. Early Start family resource centers have the capacity to offer parent-toparent matches to NICU families.

Families also need support and tools to cope with preparing for discharge from the NICU and entering Early Start and high-risk infant follow-up programs. These may be unfamiliar experiences for which families feel unprepared. This includes accessing waivers, connecting to their Early Start family resource center, and receiving parent-to-parent support. Family strengths, family support, and family-centered care are the foundations of these supports.

Family support has become an established service in the field of <u>intellectual</u> and <u>developmental disabilities</u> and is part of California's mandate and local service systems, carried out by regional centers, family resource centers, and other community-based organizations. Family support services are considered one of the better ways of supporting families and their children, including "building on natural supports" and encouraging the meaningful and purposeful integration of children in the community.



Focus On Family Support

Best Practice: Focus first on the family. Providers working with families shall be guided by the principles of family support, ensuring that the care they provide is family-centered and focused on each family's unique culture, strengths, needs, and priorities.

The Principles of Family Support

- Providers and families work together in relationships based on equity and respect.
- Providers help to enhance the family's capacity to support the growth and development of all family members.
- Providers recognize that families are resources to their own members, to other families, to programs, and to their communities.
- Providers understand the responsibility to affirm and strengthen the family's cultural, racial, and linguistic identities within their communities, which enhances inclusion.
- Providers offer families services and systems that are fair, responsive, and accountable.
- Providers work with families to access natural supports and formal resources to promote family development.
- Providers are flexible and responsive to emerging family concerns and community needs.
- The principles of family support are modeled in all activities, including planning, governance, and administration.

Family-Centered Care

Family-centered care is based on meeting the family where they are and is a meaningful, collaborative relationship between the family and the provider. It honors the dynamics of strength, culture, tradition, and expertise between families and professionals. Family-centered care values the lived experiences families bring to the relationship.



Concepts of Patient- and Family-Centered Care

- Dignity and Respect. Health care providers listen to and honor patient and family perspectives and internal family connections and complexities.
- Information Sharing. Health care providers offer information directly to families and guide families in discovering needed information on their own.
- Participation. Families take an active role in decision-making and the care process.
- Collaboration. Families and providers work together to cocreate the family's lived experience.

Additional information is available via the <u>Institute for Patient- and Family-</u> <u>Centered Care</u>.

Supporting Families Through Cultural Understanding and Humility

Providers strive to continuously engage families with the knowledge, attitudes, and skills of cultural humility, specifically with "an awareness of one's own possible biases and privilege and the willingness to attempt to mitigate the judgments that come along with those biases" (The Dialogue Company).

Tenets of Cultural Humility¹

- Lifelong learning and critical self-reflection
- Recognition and challenging of power imbalances for respectful partnerships
- Institutional accountability

Strengthening Families™ and Application of the Five Protective Factors

Strengthening Families[™] is a research-informed approach to increase family strengths, enhance child development, and enrich parent–child relationships. It is based on engaging families, programs, and communities in building five key protective factors:

- parental resilience
- social connections
- concrete support in times of need
- knowledge of parenting and child development
- social and emotional development in young children

The Strengthening Families[™] approach helps parents to find resources, supports, or coping strategies that allow them to parent effectively, even when under stress.

¹ Tervalon M., Murray-García, J. (1998). <u>Cultural humility</u> versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. Journal of Health Care for the Poor and Underserved, 9(2), 117–125.

The Strengthening Families™ Framework

- benefits all families
- builds on family strengths, buffers risk, and promotes better outcomes
- builds on and can be integrated into existing programs, strategies, systems, and community opportunities
- can be implemented through small but significant changes in everyday actions by individuals and organizations
- is grounded in research, practice, and implementation knowledge

Adopting the Strengthening Family Approach

We want to accomplish the following:

- increase parental resilience throughout the child's development
- provide opportunities and resources for **social connections**
- help parents find concrete support in times of NEED
- facilitate increasing knowledge of parenting and child development
- support healthy social and emotional development in young children

We will achieve this by providing opportunities to connect to peer support such as Early Start family resources centers and regional center support groups.

Navigating Health Coverage

Best Practices:

- 1. Provide families support to help them know how to navigate their individual health care plans
- 2. If coverage is limited, other resources may exist:
 - Medi-Cal
 - Financial Assistance Resources
 - Legal Assistance Resources
 - Regional Centers
 - Local Educational Agencies (LEAs)

Support Families to Understand and Navigate Their Individual Health Care Plans

This includes

- co-pay, deductible, and/or coinsurance rates;
- benefits, including the types, frequency, caps, and limits of services and prescriptions covered; and
- what to do if a health plan denies, changes, or delays a request for medical services, denies payment for emergency treatment, or refuses to cover services or treatment for a serious medical condition.

Start With the Evidence of Coverage

The Evidence of Coverage (EOC) is a document that describes in detail the health care benefits a health plan will pay for. The EOC explains what the health plan covers and how it works, including how much the family pays (e.g., premiums, deductibles, co-payments, coinsurance). Families can view their EOC by going to their health plan's website or calling the health plan's member services number to ask for a copy. The member services number is listed on their health plan membership card.

In general, a health plan must pay for a health care service that is a *covered benefit*, as included in the EOC and when medically necessary for the child. A definition of what is *medically necessary* can be found in the EOC.

California law requires health plans to cover basic health care services, which include doctor visits, hospital services, inpatient services (i.e., when one must stay overnight in the hospital), and outpatient services (e.g., minor surgery in a surgery center). Other basic services include the following:

- preventive and routine care, such as vaccinations and checkups
- <u>behavioral health care</u>, including treatment for serious emotional disturbances of a child and substance use disorders
- emergency and urgent care
- rehabilitation therapy, such as physical, occupational, and speech therapy

California has many kinds of health coverage: health insurance; health plans like health maintenance organizations, preferred provider organizations, exclusive provider organizations; and public programs like Medicare and Medi-Cal. It is important to understand all the plans and their networks (i.e., how *in-network* and *out-of-network* services work for the family's insurance plan). They each follow their own sets of rules, and different government agencies regulate each one.

While the EOC explains which government agency regulates the family's health coverage, the two primary regulators in California are listed below. These regulators can help when a family has a question or a complaint:

Health Insurance. The California Department of Insurance regulates life and health insurance policies. Visit <u>www.insurance.ca.gov</u> or call 1-800-927-4357 (Help).

Health Plans (e.g., Health Maintenance Organizations, Medi-Cal Managed Care). The California Department of Managed Health Care (DMHC) regulates these types of health coverage. Visit <u>www.HealthHelp.ca.gov</u> or call 1-888-466-2219.

The EOC also explains what to do if a health plan denies, changes, or delays a request for health care services; denies payment for a claim for health care services; or refuses to cover services as not medically necessary, as experimental, or as investigational treatment for a serious medical condition.



If a family needs help, encourage them to first try and work with the health insurance or health plan.

Families can appeal denials of coverage by the health plan by pointing to the need and making clear what the cost/benefit of the coverage is. To do this, they would follow their plan's appeals process. Families can also file a consumer complaint when there are other issues with the health plan. These issues can be billing problems; cancellation of coverage; claim and co-pay disputes; delays in getting an appointment, referral, or authorization; access to translation services; finding an in-network doctor, hospital, or specialist; complaints about a doctor or plan; and continuity of care.

Need Help with a Health Plan?

The California Department of Managed Health Care (DMHC) is a good place to start. Visit <u>www.dmhc.ca.gov</u> or view the <u>YouTube video</u>.

Here, families can learn about the following:

- Selecting a medical health care plan for the child's needs
- When a family has low or no income or are or may become uninsured
- Types of <u>coverage</u> (e.g., group or individual insurance)
- Types of <u>plans</u> (e.g., the difference between an HMO, a PPO, a POS, or an EPO)
- "I'm Insured, Now What?"
- How to get the <u>best care</u> with a plan
- Health Care <u>Rights</u>
- How to <u>file a complaint</u>, including what to do if a health plan denies, changes, or delays a request for medical services; denies payment for emergency treatment; or refuses to cover experimental or investigational treatment for a serious medical condition

If coverage is limited, other options to consider include the following:

- <u>Medi-Cal as a safety net</u>, along with private health coverage
 - Home and community-based waivers that have institutional deeming to waive the parents' income to meet financial eligibility
 - Home and Community-Based Services for the Developmentally Disabled (HCBS-DD)—for individuals who are [Lanterman Act] Regional Center [i.e., Lanterman Act] eligible
 - Home and Community-Based Alternatives (HCBA)—for medically fragile children
 - Some waivers provide the Health Insurance Prepayment Plan (HIPP), where the state reimburses the monthly cost of insurance covered by the employer.
 - All waivers will be discussed in more detail later in this document.
- California Children's Services (CCS)
 - General Program: must have a CCS-eligible condition and meet Medi-Cal's income guidelines. For families that earn more than \$40,000/year, the child may be eligible for CCS if out-of-pocket medical expenses are expected to be more than 20 percent of the family's adjusted gross income.
 - Medical Therapy Program (MTP): Provides medically necessary physical, occupational therapy services and medical therapy conference services to children and young adults under age 21 with CCS MTP eligible conditions.
- Regional Center Services
 - Early Start (federal IDEA Part C) program for children ages 0–3 with or at risk for disabilities or developmental delays
 - Lanterman Act Services (for children ages 3 and older; disability occurs before age 18; list of five eligible conditions causing "substantial disability" with functional impairments in three or more areas in a list of seven categories)

Assistance With Medications

NeedyMeds.org provides guidance on finding prescription assistance programs (PAPs), as well as a list of organizations that can help with the paperwork to apply to a PAP. They also have their own NeedyMeds Drug Discount Card.

- guidance homepage
- <u>NeedyMeds</u> Drug Discount Card application form
- drug pricing calculator for <u>drug prices</u> and pharmacies

Financial Assistance Resources

Regional Centers:

Early Start and Lanterman Act services may be able to assist with co-pays—refer families to their service coordinator.

Assistance With Health Care Bills

If a family needs help with hospital bills, the California Department of Health Care Access and Information (HCAI) site can help find hospital discount policies and application forms for several <u>hospitals across the State</u>

If the family has Kaiser Permanente insurance, Kaiser Permanente's Medical Financial Assistance (MFA) program covers emergency and medically necessary health care services, pharmacy services and products, and medical supplies provided at Kaiser Permanente facilities (e.g., hospitals, medical centers, medical office buildings), at Kaiser Permanente outpatient pharmacies, or by Kaiser Permanente providers. Services that are not considered an emergency or medically necessary as determined by a Kaiser Permanente provider include but are not limited to cosmetic surgery or services, infertility treatments, retail medical supplies, surrogacy services, and services related to third-party liability or workers' compensation cases.

Please note: The <u>MFA program</u> is not a form of health insurance and cannot be used to subsidize premiums.

Fundraising

If families are considering financial assistance via fundraisers (e.g., GoFundMe) or lawsuit settlements/awards to help pay for medical bills, they should consult with an attorney and/or tax specialist to consider financial obligations. The funds received may be considered income with a tax burden.

Legal Assistance

The Health Consumer Alliance (HCA) offers free, confidential legal assistance in all languages over-the-phone or in-person to help families who are struggling to get or keep health coverage and resolve problems with their health plans. The HCA website is <u>www.healthconsumer.org</u>, or call 888-804-3536 (Voice), 877-735-2929 (TDD). The HCA's website also has a helpful Know Your Rights library with consumer health care fact sheets about a variety of subjects.



Connect Families to the Early Start Program, California Children's Services, and Community-Based Mental Health Services

Best Practice: Families with infants or toddlers should be connected to Early Start, California Children's Services, and Community-Based Mental Health Services as early as possible, with a warm handoff from the Neonatal Intensive Care Unit.

California's Early Start Program

The Early Start program is California's early intervention program for infants and toddlers with or at risk for delays and disabilities and their families. Early Start services are available statewide and can support medically fragile children. For more information, go to <u>www.dds.ca.gov/services/early-start</u>

Infants and toddlers from birth to age 36 months may be eligible for early intervention services through Early Start if, through documented evaluation, they meet one of the following criteria:²

- have a developmental delay in one or more areas of cognitive, communication, social or emotional, adaptive, or physical and motor development, including vision and hearing
- have an established risk condition of known etiology, with a high probability of resulting in delayed development
- are considered at high risk of having a substantial developmental disability due to a combination of biomedical risk factors that have been diagnosed by qualified personnel
- 2 For specific <u>eligibility criteria</u>, refer to California Government Code: Section 95014(a).

Biomedical risk factors include but are not limited to the following:

- prematurity of less than 32 weeks' gestation and/or low birth weight of less than 1500 grams
- assisted ventilation for 48 hours or longer during the first 28 days of life
- smallness for gestational age (i.e., below the third percentile on the National Center for Health Statistics growth charts).
- asphyxia neonatorum associated with a 5-minute Apgar score of 0 to 5.

Anyone can make a referral to Early Start. Parents, health care providers, and others can contact their local regional center if they have a concern about a child's development and would like them to be evaluated to possibly receive Early Start services.

Locate the <u>local Early Start program</u> to find a listing by county; or contact <u>earlystart@dds.ca.gov</u> or 1-800-515-BABY.

Early Start services are arranged by regional centers and/or LEAs. Early Start services may include the following:

- assistive technology
- audiology
- family training, counseling, and home visits
- health services
- medical services for diagnostic/ evaluation purposes only
- nursing services
- nutrition services
- occupational therapy
- physical therapy

- psychological services
- service coordination (i.e., case management)
- sign language and cued language services
- social work services
- special instruction
- speech and language services
- transportation and related costs
- vision services

LEAs and regional centers in California are responsible for providing early intervention and education services to eligible infants and toddlers. More information can be found on this website that has frequently asked questions: "<u>Chapter 12: Information on Early Intervention Services—SERR—Special Education</u> <u>Rights and Responsibilities</u>"

Complaint Process

Parents and others may file a complaint against the Department of Developmental Services, the California Department of Education, any regional center, any LEA, or any provider receiving Early Start funds. Information on the <u>Early Start complaint</u> <u>process</u> website.

For more information about your eligibility rights, go to <u>Early Start Eligibility</u>— Effective January 1, 2015.

Lanterman Act Services Through Regional Centers

The Lanterman Developmental Disabilities Services Act (1977), also known as the Lanterman Act, established the system in California that provides services and supports to meet the needs and choices of individuals with developmental disabilities to support their integration into the community. Services and supports are coordinated by and provided through a system of 21 regional centers located throughout California.

An infant or toddler may be in the Early Start program and receive Lanterman Act services simultaneously if they meet the specific eligibility requirements of both programs.

Eligibility for Lanterman Act services is established through diagnosis and assessment performed by regional centers. To be eligible for services, a person must have a disability that began before their 18th birthday, that is expected to continue indefinitely, and that presents a substantial disability.

Qualifying diagnoses include intellectual disability, cerebral palsy, epilepsy, autism, and other disabling conditions that require supports like those required by a person with an intellectual disability.



This excludes conditions that are solely psychiatric/mental health conditions, solely physical in nature, and/or solely learning disorders. For additional information visit <u>eligibility requirements</u>.

Three- and four-year-olds who are found not eligible for Lanterman services through a regional center can be assessed for provisional eligibility. Information on provisional eligibility is available on the Department of Developmental Services website: <u>Enclosure A—Provisional Eligibility for Regional Center Services</u>.

California Children's Services

The CCS Program is administered as a partnership between county health departments and the California Department of Health Care Services (DHCS). It is a state program for children with certain diseases or health conditions. The CCS Program provides diagnostic and treatment services, medical case management, and physical and occupational therapy services to children under age 21 with CCS-eligible medical conditions.

The local county CCS Program office connects families with doctors and trained health care professionals who know how to care for children with complex health care needs. The CCS Program also provides medical therapy services that are delivered at public schools.

Examples of CCS-eligible conditions include, but are not limited to, chronic medical conditions, such as hearing loss, diabetes, cystic fibrosis, hemophilia, cerebral palsy, heart disease, cancer, traumatic injuries, inherited genetic disorders, and infectious diseases producing major sequelae.

Medical Therapy Program

The MTP is a program within CCS that provides physical therapy, occupational therapy, and medical therapy conference services for children who have physically disabling conditions. Examples of CCS MTP-eligible conditions include cerebral palsy, neuromuscular disease (e.g., muscular dystrophy), musculoskeletal diseases (e.g., arthrogryposis), juvenile rheumatoid arthritis, spina bifida, brachial plexus injury, and acquired injury and illnesses such as burns and traumatic brain injuries. The MTP also serves very young children who have been deemed "at risk" of developing one

of these conditions based on specific physical findings in a High-Risk Infant Follow-Up assessment or examination with their physician. Children and young adults from birth to 21 years of age with these qualifying diagnoses are eligible for medically necessary physical and occupational therapy; medical therapy conferences led by a specialty physician; and coverage of medically necessary orthotics, prosthetics, and rehabilitative durable medical equipment.

These services typically take place within a Medical Therapy Unit, located on a public-school campus through a partnership between the local CCS MTP and local special education. Government code 7582 relieves any financial responsibility on the part of the family or client for these services and establishes that there is no financial qualification for participation in the MTP.

Referrals to the MTP can come from a physician, a nurse, school personnel, or an early intervention team. An application to the program can be found at <u>How To Apply on the DHCS website</u> and must be completed by the parent or guardian to begin services.

High Risk Infant Follow-Up Program

The CCS High Risk Infant Follow-Up (HRIF) Program was established to identify infants who might develop CCS-eligible conditions after discharge from a CCSapproved NICU. CCS Program standards require that each CCS-approved NICU must have an organized program or a written agreement with another CCS-approved HRIF Program to ensure the follow-up of discharged high-risk infants.

The CCS Program's goal of identifying infants who may develop a CCS-eligible medical condition provides for several diagnostic services for children up to 3 years of age.

The following are reimbursable diagnostic services:

- comprehensive history and physical examination with neurologic assessment
- developmental assessment (Bayley Scales of Infant Development [BSID] or an equivalent test)
- family psychosocial assessment

- hearing assessment
- ophthalmologic assessment
- coordinator services (including assisting families in accessing identified, needed interventions, and facilitating linkages to other agencies and services).

<u>Frequently asked questions</u> (FAQs) on the DHCS website provide information about the CCS HRIF Program.

Pediatric Palliative Care Services

Palliative care is treatment of the pain, other symptoms, and stress of a life-limiting or life-threatening illness. Palliative care services are patient- and family-centered; are provided during a child's illness; and are an important source of support for the sick child, their parents, and their siblings.

The DHCS is required to "establish standards and provide technical assistance for Medi-Cal managed care plans to ensure delivery of palliative care services." Managed-care plan members under 21 years of age may be eligible for palliative care and hospice services concurrently with treatment.³

For clients enrolled in the CCS with life-threatening conditions and a life expectancy that is longer than 6 months, certain palliative care services may be provided through CCS when the palliative care is part of the plan of care of a Special Care Center (SCC). Utilizing a multidisciplinary approach and family-centered care principles, the staff at the SCC perform an assessment and develop an integrated plan, combining therapeutic or life-prolonging treatment with palliative care. Pediatric palliative care (PPC) services are provided in coordination with the patient, family, primary care physician, subspecialty provider, and other community-based providers who may provide PPC services, including the managed care plan (MCP). The child's plan of care through the SCC may include services of a Home Health Agency (HHA) to assess the needs of the family and home environment to determine type, length, and frequency of services needed.

Early and Periodic Screening, Diagnostic, and Treatment Benefit

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) is a Medi-Cal benefit for individuals under the age of 21 who have full-scope Medi-Cal eligibility. Medi-Cal offers no-cost health care screening, diagnostic, and treatment services to prevent, identify, or address health and behavioral health problems. This includes those to "correct or ameliorate" defects and physical and mental illness conditions, substance use disorders, dental disease, and other conditions discovered through screening. With EPSDT, infants, children, and youth can have regular check-ups as well as other screenings when needed. For example, providers will screen for concerns with development, dental or oral health, vision, hearing, mental health, trauma, substance use disorder, nutrition, and other issues or problems they might find during their exam. These services help keep children and youth healthy and meet their developmental needs.

³ Senate Bill 1004, Hernandez, Chapter 574, Statutes of 2014; Center for Medicare and Medicaid Services (CMS) Letter #10-018; Policy Letter (PL) 11-004.

Genetically Handicapped Persons Program

The Genetically Handicapped Persons Program (GHPP) is a statewide program that provides health coverage for individuals 21 years of age and older who have specific <u>genetic diseases</u>. Those under 21 years of age may apply only if they are not eligible for CCS. GHPP services include outpatient medical care; pharmaceutical services; surgeries; nutrition products and medical foods; durable medical equipment; home health services, such as skilled nursing services; therapy services, such as physical therapy, occupational therapy, and speech therapy; and more. GHPP provides complete services to its clients. Unlike other programs, the GHPP covers services even if it is not related for the treatment of the GHPP eligible medical condition. The approval of these services is subject to individual review based on medical need. For more information on the GHPP, visit the <u>GHPP page</u>.

Mental Health Services

Infant-family mental health services are ideally provided as early as possible in the life of an infant or young child who is medically fragile. Intervening early during sensitive periods supports the development of the infant-parent relationship. Adult mental health services support parents who are undergoing the stress of having a baby with medical needs.

Providing psychosocial support in the NICU setting is a recommended best practice. In addition to the family support described earlier, psychosocial services in the NICU can include embedded mental health professionals. Psychologists based in NICU settings provide infant-family mental health services at bedside, address parents' own mental health needs, and provide mental health consultation to medical team members to ensure all providers support the mental health needs of the infant and family. There is a growing recognition of the need for mental health professionals to support families during high-risk pregnancies as well.

NICU medical social workers play a key role in providing psychosocial support during the NICU stay and linking families with infant mental health and adult mental health services after discharge.

County mental health plans (MHPs) provide or arrange for the provision of outpatient and inpatient mental health services to Medi-Cal beneficiaries who meet medical necessity criteria consistent with the treatment needs and goals as documented in their client plans. These services include infant-parent dyadic therapy provided by professionals specializing in infant mental health. If a family member or child needs mental health treatment services, individuals may call the County Department of Mental Health/Behavioral Health and ask for an appointment for an initial assessment.

Parents may be assisted in making a referral by another person or organization, including a doctor, a NICU discharge planner, a family member, a guardian, a Medi-Cal managed-care health plan, or other county agencies. The MHP may not deny a request for an initial assessment to determine whether a child meets the criteria to receive services from the MHP.

If someone has trouble accessing services, they may call the DHCS Office of the Ombudsman at (888) 452-8609 or email <u>MMCDOmbudsmanOffice@dhcs.ca.gov</u>.

For families with private insurance, mental health services are a required benefit as part of the Affordable Care Act. Families can request a referral from their child's primary care provider or contact their medical insurance provider for information about behavioral health services.

Link Families to Home and Community-Based Services and Resources Through Medicaid Waivers

Medicaid is known in California as Medi-Cal. We will use the term Medi-Cal throughout the remainder of this document. A waiver, often referred to as a home and community-based services waiver, is a program throughout the state that expands Medi-Cal eligibility and/or services to children with disabilities or complex medical needs. This is important because if the child is uninsured or the parent's private insurance does not cover the necessary medical and support services, the Medi-Cal waiver can be used to provide those services. The waivers allow the child's eligibility to be based on their own income rather than their parent's income. This enables the family to access important services like private duty nursing care at home and specialized therapies. It also provides access to additional services like respite or home modifications. As of the publication of this document, California has four waivers that apply to children who receive care at home and in the community, which include the HCBS-DD Waiver, HCBA Waiver, self-determination waiver, and HIV/ AIDS waiver. Families can find out information about the waivers and <u>apply online</u> or by email <u>ProFacWAIVER@dhcs.ca.gov</u>.

Best Practices:

- Care-management professionals, such as social workers and medical discharge planners, should understand the Medi-Cal Home and Community-Based Services (HCBS) Waivers, including the Home and Community-Based Alternatives Waiver (HCBA) and Home and Community-Based Services for the Developmental Disabilities (HCBS-DD) Waiver.
- Professionals should link families with information about Medi-Cal and HCBS Waiver programs prior to discharge from neonatal and pediatric intensive care units.

Medi-Cal Eligibility, Application Process, and Benefits

Medi-Cal is a public health insurance program that provides needed health care services to individuals with low incomes; including families with children; older adults; persons with disabilities; children in foster care; pregnant women; and individuals with low income and specific diseases, such as tuberculosis, breast cancer, or HIV/AIDS. Medi-Cal is financed by the state and federal governments.

Eligibility

Medi-Cal eligibility is based primarily on income. Pregnant women, children, and persons who are disabled are allowed to have a higher income level to be eligible. County social services offices make Medi-Cal eligibility determinations. California residency is a basic eligibility requirement. In addition, a California resident must meet other specified criteria (e.g., Social Security Insurance, State Supplementary Payment) and/or have been made eligible for Medi-Cal through institutional deeming (see below).

Medi-Cal is *not* a requirement for regional center services, though many regional center consumers receive Medi-Cal.

Institutional Deeming. "Institutional deeming" is a special Medi-Cal eligibility rule that considers only the personal income and resources of a person under the age of 18 (or a married adult) who is otherwise eligible. This allows a person who meets the other criteria to be determined as eligible for Medi-Cal regardless of their parent's income and resources. This is very helpful because typically a family's health insurance or income will not cover the total cost of these needed services. Through institutional deeming rules, a family may obtain Medi-Cal benefits for needed services regardless of income. This also allows the person to be eligible for all Medi-Cal services. This eligibility applies if the person is enrolled in one of the HCBS Waiver programs, as described below.

Application Process

Medi-Cal applications may be completed

- in person at a local county social security office,
- by mail,
- by phone, or
- online at <u>www.CoveredCA.com</u>.

The process for verifying Medi-Cal eligibility normally takes 45 days. The general process for verification is as follows:

- 1. Apply
- 2. Receive a "Notification of Likely Eligibility" by mail
- 3. Be contacted by a social services office by mail or by phone to request paper verification of income, citizenship, and other criteria that cannot be verified electronically
- 4. Receive "Final Notice of Action" notifying applicant about whether they can receive Medi-Cal
- 5. Receive a Benefits Identification Card

Benefits

Medi-Cal currently provides a core set of health benefits, including doctor visits, hospital care, immunizations, pregnancy-related services, and nursing home care. The Affordable Care Act ensures all Medi-Cal health plans offer what are known as "Essential Health Benefits." These 10 comprehensive services include the following categories:

- outpatient (ambulatory) services
- emergency services
- hospitalization
- maternity and newborn care
- mental health and substance use disorder services
- prescription drugs
- programs such as physical and occupational therapy (known as rehabilitative and habilitative services) and devices
- laboratory services
- preventive and wellness services and chronic disease management
- children's (pediatric) services, including oral and vision care

Medi-Cal 1915(c) Home and Community-Based Services Waivers—Eligibility, Referrals, and Benefits

California has HCBS programs that help people get Medi-Cal-funded services at home. These programs are called "waivers" because certain federal Medicaid rules are waived to provide different or more services than the state offers to other Medicaid (Medi-Cal)-eligible people. To receive waiver program services, there must be a Medi-Cal application for the individual. The Medi-Cal application may occur before or after the request for a waiver. The Medi-Cal application must indicate the need for long-term care services and supports.

There are different kinds of Medi-Cal 1915(c) waivers and individuals may only be on one type of 1915(c) HCBS Waiver at a time. Waivers that may benefit infants and toddlers who are medically fragile include the following:

- HCBA Waiver
- HCBS-DD Waiver

Home and Community-Based Services for Californians with Developmental Disabilities

The HCBS-DD Waiver program recognizes that many individuals at risk of being placed in medical facilities can be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care. This waiver provides home and community-based services to regional center consumers as an alternative to care provided in a facility that meets the federal requirement of an intermediate care facility for individuals with developmental disabilities.

The HCBS-DD Waiver funds certain services that allow persons with developmental disabilities to live at home or in the community. Costs for these services are funded jointly by the federal government's Medicaid program and the State of California.

- Who is eligible for the HCBS-DD Waiver? There are six criteria that the individual must meet for participation in the California HCBS-DD Waiver:
 - meet the Lanterman Act definition of developmental disability: "Developmental disability" means a disability that originates before an individual attains 18 years of age, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual ... (including) intellectual disability, cerebral palsy, epilepsy, and autism ... (and other) disabling conditions found to be closely related to intellectual disability or to require treatment similar to that required for individuals with an intellectual disability [WIC 4512 (a)(1)]
 - be an active regional center consumer
 - have full-scope Medi-Cal benefits (i.e., be eligible to access all services available through Medi-Cal) or meet the requirements for institutional deeming
 - have substantial limitations in adaptive functioning which qualifies the consumer for the level of care provided in an Intermediate Care Facility for the Developmentally Disabled—Habilitation (ICF/DD-H) or Intermediate Care Facility for the Developmentally Disabled-Nursing (ICF/DD-N). Evaluation of each consumer's level of care needs is based on their ability to perform activities of daily living and participate in their community. This qualification is important, not because a person will be admitted to such a facility but because the HCBS-DD Waiver provides funding for services only to individuals who but for the provision of these services would require the level of care provided in an ICF-DD
 - not be concurrently enrolled in another HCBS-DD Waiver
 - choose to participate and receive services through the HCBS-DD Waiver and to reside in a community setting

- Who makes the referral for the HCBS-DD waiver?
 - regional centers
- What are the benefits of the HCBS-DD waiver?
 - Certain federal Medicaid rules are "waived," allowing the state to provide services to people with developmental disabilities or significant health care needs in ways that are not available to other people who are enrolled in Medicaid. Waiver supports or services are different than those available through Medi-Cal.
 - Services may include case management, skilled nursing, home health aide services, respite, accessibility adaptations, transportation, specialized medical equipment and supplies, and family training.
 - For children to receive waiver services, they must meet certain requirements, including having full-scope Medi-Cal eligibility. While Medi-Cal is for individuals who have low income, a process known as institutional deeming (see above) may allow a child who meets other criteria to be determined eligible for Medi-Cal regardless of their parent's income and resources.

While Medi-Cal eligibility is a requirement for participation in waivers, having private insurance does not exclude a child from qualifying for the HCBS-DD waiver.

Families do not have to be on the waiver to receive regional center services. If a family member is eligible for the HCBS-DD Waiver, it is good to enroll in it; however, enrollment is a matter of choice. Unlike other states that restrict services to persons served under the HCBS-DD Waiver, California's regional centers provide the full scope of state-funded services to all eligible persons. Regardless of whether a consumer is eligible for and chooses to enroll in the HCBS-DD Waiver, the consumer will receive person-centered planning, opportunities to choose services and providers, and assurance of the same quality of care. Families should work with their existing case managers (e.g., regional center, waiver agency) to determine if a different waiver would better meet their needs. Those case managers can then facilitate warm handoffs between the waivers to ensure a clean transition in enrollment and services.

Home and Community-Based Alternatives Waiver

The HCBA waiver was formerly known as the Nursing Facility/Acute Hospital (NF/ AH) Waiver. The name was changed in 2017, and it is referred to as California's version of the Katie Beckett waiver. The HCBA Waiver provides Medi-Cal beneficiaries with long-term medical conditions who are determined to need nursing facility or greater level of care with the option of returning to and/or remaining in their homes or home-like community settings instead of being institutionalized. Services are assessed and authorized through HCBA waiver agency (WA) multidisciplinary care teams, comprising a nurse and a social worker.

- Who is eligible for HCBA Waiver?
 - The HCBA Waiver is available to individuals of all ages who are medically fragile or technology dependent and who are assessed to need a nursing facility or greater level of care.
- What are the benefits of the HCBA Waiver?
 - The care management team coordinates waiver and state plan services (e.g., medical, behavioral health, In-Home Supportive Services, etc.) and arranges for other long-term supports and services available in the local community.
 - Services may include private duty nursing, home respite, accessibility adaptations, family/caregiver training, and medical equipment operating expenses.
- How does one apply for an HCBA Waiver?
 - Each HCBA WA has its own version of the waiver application. While DHCS will forward applications to the correct WA, it is faster if applicants send applications directly to the WA responsible for the county/zip code in which they live. To find the WA nearest a family, go to the <u>HCBA website</u> and scroll down to "HCBA Waiver Agencies."

Medi-Cal Complaints and Fair Hearings

Families who have applied for, have received, or are currently receiving benefits/ services from Medi-Cal who have a complaint about how benefits/services are/were handled or whose services have been denied or modified, may take the following courses of action:

- discuss the complaint with a representative of the County Welfare department in the county in which they live (or where they lived when they received the benefits/services)
- file a discrimination complaint; see the information under <u>Non-Discrimination</u> <u>Policy and Language Access</u>
- request a hearing; see the information under How to File a Hearing Request

Families must file their request within 90 days of receiving the Notice of Action (NOA). They may be able to file after 90 days if they have a good reason, like illness or a disability.

Benefits will continue pending review (i.e., Aid Paid Pending) if the hearing is filed within 10 days of receiving the NOA. This process allows for continued services while the case is being reviewed.

Requesting a Hearing

A hearing may be requested by completing the Request for State Hearing on the back of the NOA. Provide all requested information, including the recipient's full name, address, telephone number, the name of the county that took the action against the recipient, the aid program(s) involved, and a detailed reason why a hearing is being sought. If assistance is needed with English, indicate the preferred language (and dialect) and arrangements can be made to have language assistance at the hearing. If an authorized representative has been identified, include that individual's name and address. Write as neatly as possible. If desired, attach a letter to explain why the county's action is not correct. Keep a copy of the hearing request. For more information, please visit the <u>webpage on Your Hearing Rights</u>.

To keep the same benefits while waiting for a hearing, families must ask for a hearing before the date that the benefits are changed or taken away so that they will receive the same benefits until the hearing.

Families may bring a friend, relative, attorney, or anyone else they choose to the hearing. Free legal help may be available through the local legal aid office or welfare rights group.

Families may submit their request in one of the following ways:

- in person at the county welfare department office at the address shown on the NOA
- by mail to the California Department of Social Services: State Hearings Division
 P.O. Box 944243, Mail Station 21-37
 Sacramento, CA 94244-2430
- by fax to the State Hearings Division to 833-281-0905
- online to the California Department of Social Services at the <u>online hearing</u> <u>request page</u>.

Family members can also make a toll-free call to request a state hearing. Please note, due to a high volume of calls, phone lines are very busy.

California Department of Social Services Public Inquiry and Response Phone 800-743-8525 (Voice) 800-952-8349 (TDD)

The State Hearings Division cannot accept requests for a hearing via email.

For additional information, visit <u>State Hearings Requests</u> with the Department of Social Services.

If a family thinks discrimination has affected their benefits or services, they may file a discrimination complaint with the DHCS Office of Civil Rights below:

Office of Civil Rights Department of Health Care Services P. O. Box 997413, MS 0009 Sacramento, CA 95899-7413

Phone: 916-440-7370 Email: <u>CivilRights@dhcs.ca.gov</u>

Families may use the ADA Title VI Discrimination Complaint form to submit their complaint to the DHCS Office of Civil Rights. The form contains additional information about rights. A complaint should be filed as soon as possible or within 180 days of the last act of discrimination. If the complaint involves matters that occurred longer ago than this and a family is requesting a waiver of the time limit, they will be asked to show good cause why they did not file their complaint within the 180-day period.

Discrimination complaints may also be submitted to the United States Department of Health and Human Services, Office of Civil Rights. Additional information on filing discrimination complaints is available on the <u>Non-Discrimination Policy and Language Access webpage</u>.



California Medi-Cal (Medicaid) Waiver Chart

| Name of Waiver | 1915(c) Home and Community-Based Alternatives (HCBA) (formerly known as the Nursing Facility/Acute Hospital or the "Katie Beckett" Waiver) | 1915(c) Home and Community-Based Services for the Developmentally Disabled (HCBS-DD) | Self-Determination Program (SDP) Waiver for Californians with Developmental Disabilities |
|--|---|--|--|
| What is the primary purpose of this waiver? | To help people with long- term medical conditions get Medi-Cal-funded nursing facility or greater level of care services with the option of returning to and/or remaining in their homes and community | To help people get Medi- Cal-funded services at home and/or in the community | Provides individuals with the control to direct their home and community-based Medi- Cal-funded services, including choosing their providers and managing their services budget |
| What laws and regulations govern the program? | Social Security Act § 1915(c) | Social Security Act § 1915(c) | Social Security Act § 1915(c) |
| Who makes referrals? | NICUs prior to discharge | Regional centers | Regional centers |

| Name of Waiver | 1915(c) Home and Community-Based Alternatives (HCBA) (formerly known as the Nursing Facility/Acute Hospital or the "Katie Beckett" Waiver) | 1915(c) Home and Community-Based Services for the Developmentally Disabled (HCBS-DD) | Self-Determination Program (SDP) Waiver for Californians with Developmental Disabilities |
|---|--|--|--|
| How to enroll? | Online application for the <u>HCBA waiver</u> | Regional center directory | Regional center directory |
| Ages served? | All ages | All ages | All ages |
| Who is eligible? | People who are medically fragile or technology dependent and assessed to need nursing facility or a greater level of care | People who (1) meet the Lanterman Act definition of developmental disability, (2) are active regional center consumers, (3) have full-scope Medi- Cal benefits or meet the requirements for institutional deeming, (4) have substantial limitations in adaptive functioning, (5) are not currently enrolled in another Medi-Cal waiver, and (6) choose to participate and receive services and reside in the community | People who (1) meet the Lanterman Act definition of developmental disability, (2) are active regional center consumers, (3) have full-scope Medi- Cal benefits or meet the requirements for institutional deeming, (4) have substantial limitations in adaptive functioning, (5) are not currently enrolled in another Medi-Cal waiver, and (6) choose to participate and receive services and reside in the community |
| Waiting list? | Yes | No | No |
| What is the enrollment cap on the program? | 8,974 | No limit | No limit |
| What is the level of care requirement? | Nursing facility or a greater level of care | Intermediate Care Facility for the Developmentally Disabled (ICF/DD), ICF/ DD-H (Habilitative), or ICF/DD-N (Nursing) | Intermediate Care Facility for the Developmentally Disabled (ICF/DD), ICF/ DD-H (Habilitative), or ICF/DD-N (Nursing) |

| Name of Waiver | 1915(c) Home and Community-Based Alternatives (HCBA) (formerly known as the Nursing Facility/Acute Hospital or the "Katie Beckett" Waiver) | 1915(c) Home and Community-Based Services for the Developmentally Disabled (HCBS-DD) | Self-Determination Program (SDP) Waiver for Californians with Developmental Disabilities |
|--|--|---|---|
| Includes institutional deeming? | Yes | Yes, enables children who meet certain requirements to be determined eligible for Medi-Cal regardless of their parent's income and resources | Yes, enables children who meet certain requirements to be determined eligible for Medi-Cal regardless of their parent's income and resources |
| What services may be included? | Provides Medi-Cal beneficiaries with long- term medical conditions who are determined to need nursing facility or greater level of care with the option of returning to and/or remaining in their homes or home-like community settings instead of institutionalization; care management team (CMT) coordinates waiver and state plan services and arranges other available long-term supports and service in the community; may include private duty nursing, home respite, accessibility adaptations, family-caregiver training, and medical equipment operating expenses | Behavioral intervention; community living; day service; personal care; employment supports; respite; home health; medical services and supports; speech, hearing, and language services; supports for participant direction; accessibility adaptations; family support and training; nonmedical transportation; housing; and transition supports | Community living; employment supports; personal care; respite; home health; medical services and supports; speech, hearing, and language services; participant direction supports; behavioral intervention; crisis intervention; accessibility adaptations; family support and training; nonmedical transportation; housing; and transition supports |
| Who determines the eligible person's needs? | Person-centered planning process facilitated by a CMT; directed by the beneficiary, their legal representative, and their circle of support | Regional center service coordinator develops an Individualized Program Plan (IPP) utilizing person- centered planning with the participant | Regional center service coordinator develops an IPP utilizing person centered planning with the participant |

| Name of Waiver | 1915(c) Home and Community-Based Alternatives (HCBA) (formerly known as the Nursing Facility/Acute Hospital or the "Katie Beckett" Waiver) | 1915(c) Home and Community-Based Services for the Developmentally Disabled (HCBS-DD) | Self-Determination Program (SDP) Waiver for Californians with Developmental Disabilities |
|--|--|--|---|
| Who selects the service providers? | The beneficiary, their legal representative, and their circle of support, with assistance from the CMT | The participant chooses their service providers from those offered through the regional center. Certain service providers can be chosen by the participant or family for services such as respite, day care, non-medical transportation, nursing, if they choose to | The participant or family determines the service providers |
| Who provides case management? | The CMT, which comprises a registered nurse and a social worker | Regional center service coordinator | The regional center provides limited case management activities (e.g., certifies the participant's budget, reviews progress to achieving IPP objectives, and reports health and safety issues to DDS); the participant develops their spending plan, chooses who will provide their services, and pays for the services out of their budget |
| What state agency administers this program? | Department of Health Care Systems (DHCS) | Department of Developmental Services (DDS) | Department of Developmental Services (DDS) |
| Waiver websites | More information about the <u>HCBA waiver</u> | More information about the <u>HCBS-DD waiver</u> | Access detailed information about the <u>Self-Determination</u> <u>Program waiver</u> |
| State contact | (833) 388-4551 | (833) 421-0061 | (833) 421-0061 |

Resources

Citations

Chávez, V. (2012). Cultural humility: people, principles, and practices.

https://www.youtube.com/watch?v=SaSHLbS1V4w

Tervalon, M., & Murray-García, J. (1998). Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. Journal of Health Care for the Poor and Underserved, 9(2), 117–125.

Definitions

Developmental Disability: <u>https://en.wikipedia.org/wiki/Developmental_disabilities</u> Intellectual Disability: <u>https://en.wikipedia.org/wiki/Intellectual_disability</u>

Links

Department of Developmental Services

https://www.dds.ca.gov

Consumer Rights, Appeals, and Complaints: <u>https://www.dds.ca.gov/general/appeals-complaints-comments/consumer-rights-complaint</u>

Early Start: https://www.dds.ca.gov/services/early-start

Eligibility: https://www.dds.ca.gov/general/eligibility

Home and Community-Based Services Programs: <u>https://www.dds.ca.gov/</u> initiatives/hcbs

Provisional Eligibility for Regional Center Services: <u>https://www.dds.ca.gov/wp-</u> <u>content/uploads/2021/10/DDS_TBL_Letter_Enclosure_A_Provisional_Eligibility_for_</u> <u>Regional_Center_Services.pdf</u>

Regional Center Early Start Intake and Family Resource Centers: <u>https://www.dds.</u> <u>ca.gov/services/early-start/family-resource-center/regional-center-early-start-</u> <u>intake-and-family-resource-centers</u>

Regional Center Eligibility and Services: <u>https://www.dds.ca.gov/general/eligibility</u>

Department of Health Care Services

https://www.dhcs.ca.gov

Affordable Care Act, Concurrent Care for Children Letter: <u>https://www.dhcs.ca.gov/</u> formsandpubs/Documents/MMCDAPLsandPolicyLetters/PL2011/PL11-004.pdf

California Children's Services (CCS): <u>https://www.dhcs.ca.gov/Services/CCS</u>

CCS Application: <u>https://www.dhcs.ca.gov/services/ccs/Pages/apply.aspx</u>

CCS Program Overview: <u>https://www.dhcs.ca.gov/services/ccs/Pages/</u> <u>ProgramOverview.aspx</u>

Early and Periodic Screening, Diagnostic, and Treatment Services: <u>https://www.</u><u>dhcs.ca.gov/services/Pages/EPSDT.aspx</u>

Genetically Handicapped Persons Program: <u>https://www.dhcs.ca.gov/services/ghpp</u>

HCBA Waiver: https://www.dhcs.ca.gov/services/ltc/Documents/2019HCBAApp.pdf

HCBS-DD Waiver: ProFacWAIVER@dhcs.ca.gov

High Risk Infant Follow-up FAQs: <u>https://www.dhcs.ca.gov/services/ccs/</u> Documents/HRIF-FAQs-April-2020.pdf

High Risk Infant Follow-up Program: <u>https://www.dhcs.ca.gov/services/ccs/Pages/</u> <u>HRIF.aspx</u>

Medi-Cal Beneficiaries: <u>https://www.dhcs.ca.gov/services/medi-cal/eligibility/</u> <u>Pages/Beneficiaries.aspx</u>

Medi-Cal Fair Hearing: <u>https://www.dhcs.ca.gov/services/medi-cal/Pages/Medi-CalFairHearing.aspx</u>

Non-Discrimination Policy and Language Access: <u>https://www.dhcs.ca.gov/Pages/</u> Language_Access.aspx

Palliative Care Letter CMS Letter #10-018: <u>https://www.dhcs.ca.gov/formsandpubs/</u> Documents/MMCDAPLsandPolicyLetters/APL2018/APL18-020.pdf

SB 1004 Medi-Cal Palliative Care Policy: <u>https://www.dhcs.ca.gov/provgovpart/</u> Documents/SB1004PalliativeCarePolicyDoc11282017.pdf

Your Hearing Rights: <u>https://www.dhcs.ca.gov/services/medi-cal/Documents/Your_</u> <u>Hearing_Rights.pdf</u>

Department of Healthcare Access and Information

https://syfphr.hcai.ca.gov/FacilityList.aspx

Department of Insurance

http://www.insurance.ca.gov

Department of Managed Health Care

www.dmhc.ca.gov

Behavioral Health Care: <u>https://www.dmhc.ca.gov/HealthCareinCalifornia/</u> <u>GettheBestCare/BehavioralHealthCare.aspx</u>

Emergency and Urgent Care: <u>https://www.dmhc.ca.gov/HealthCareinCalifornia/</u> <u>GettheBestCare/EmergencyandUrgentCare.aspx</u>

Health Plan Dashboard: <u>www.HealthHelp.ca.gov</u>

How to file a complaint: <u>https://www.dmhc.ca.gov/FileaComplaint.aspx</u>

How to get the best care with a plan: <u>https://www.dmhc.ca.gov/</u> <u>HealthCareinCalifornia/GettheBestCare.aspx</u>

I'm insured, Now What?: <u>https://www.dmhc.ca.gov/HealthCareinCalifornia/</u> ImInsured,NowWhat.aspx

Preventive Care: <u>https://www.dmhc.ca.gov/HealthCareinCalifornia/GettheBestCare/</u> <u>PreventiveCare.aspx</u>

Selecting a medical health care plan for the child's needs: <u>https://www.dmhc.</u> <u>ca.gov/HealthCareinCalifornia/ChoosetheRightPlan.aspx</u>

Types of coverage, group or individual insurance: <u>https://www.dmhc.ca.gov/</u> <u>HealthCareinCalifornia/TypesofCoverage.aspx</u>

Types of plans, the difference between an HMO, a PPO, a POS, or an EPO: <u>https://www.dmhc.ca.gov/HealthCareinCalifornia/TypesofPlans.aspx</u>

When a family has low or no income or are or may become uninsured: <u>https://www.dmhc.ca.gov/HealthCareinCalifornia/LoworNo-</u><u>IncomeOptionsandTheUninsured.aspx</u>

Your Health Care Rights: <u>https://www.dmhc.ca.gov/HealthCareinCalifornia/</u> YourHealthCareRights.aspx

Department of Social Services

State Hearing Requests: https://www.cdss.ca.gov/hearing-requests

Disability Rights California

www.disabilityrightsca.org

Early Start Eligibility: <u>https://www.disabilityrightsca.org/system/files?file=file-attachments/F05701.pd</u>f

Information on Early Intervention Services: <u>https://serr.disabilityrightsca.org/serr-manual/chapter-12-information-on-early-intervention-services</u>

Medi-Cal Waivers: <u>https://www.disabilityrightsca.org/publications/the-home-and-community-based-alternatives-hcb-alternatives-waiver#:~:text=Home%20</u> and%20Community%2DBased%20Services%20(HCBS)%20Waivers%20are%20programs,other%20Medi%2DCal%20funded%20institution

Special Education Rights & Responsibilities: <u>https://serr.disabilityrightsca.org/serr-</u> manual/chapter-12-information-on-early-intervention-services

Early Start Eligibility Criteria

https://leginfo.legislature.ca.gov/faces/codes_displayText. xhtml?lawCode=GOV&division=&title=14.&part=&chapter=4.&article=

Free to Grow

http://www.freetogrow.org

Health Consumer Alliance

https://healthconsumer.org

Institute for Patient- and Family-Centered Care

https://www.ipfcc.org

Johnson & Johnson Patient Assistance

https://jjpaf.org/about

Kaiser Permanente Medical Financial Assistance Program

https://about.kaiserpermanente.org/community-health/about-community-health/ medical-financial-assistance-program

Kids' Waivers

https://www.kidswaivers.org

Maternal and Child Health Access Directory

http://www.mchaccess.org/staff.htm

NeedyMeds Drug Discount

Application Form: <u>https://www.needymeds.org/drug-discount-card</u> Drug Pricing Calculator: <u>https://www.needymeds.org/drug-pricing</u> Homepage: <u>https://www.needymeds.org/pap</u>

Strengthening Families™

https://cssp.org/our-work/project/strengthening-families

Handout: <u>https://www.flgov.com/wp-content/uploads/childadvocacy/</u> <u>strengthening_families_protective_factors.pdf</u>

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