

BOARD OF SUPERVISORS

February 7, 2025

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(877) 477-3646

Community & Senior Centers:

(800) 689-8514

Disability Information &

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(888) 677-1199

SUBJECT: REPORT BACK ON PROCLAIMING MARCH AS CEREBRAL PALSY AWARENESS MONTH IN LOS ANGELES COUNTY AND BRINGING RESOURCES TO FAMILIES WHO HAVE LOVED ONES WITH

DISABILITIES (ITEM NO. 5, AGENDA OF MARCH 6,

2024)

On March 6, 2024, your Board adopted a motion¹ directing Aging & Disabilities (AD) and the Department of Health Services (DHS) to report back on resources currently available in the County for people with cerebral palsy and similar muscular disabilities and the different age groups for which these resources are available, and to work in collaboration with the Department of Public Health (DPH) and relevant departments to identify opportunities for outreach and awareness of cerebral palsy and similar disabilities.

The attached report addresses the following three (3) directives:

- Collaboration with Department of Public Health (DPH) and Department of Health Services (DHS)
- 2. Cerebral Palsy Awareness Webinar
- Outreach events in which cerebral palsy awareness is highlighted



¹ https://file.lacounty.gov/SDSInter/bos/supdocs/189128.pdf

1. Collaboration with Department of Public Health (DPH) and Department of Health Services (DHS)

AD coordinated with DPH to identify the data currently available regarding the rates of incidence of cerebral palsy and similar disabilities among County residents, outside of the California's Centers for Disease Control and Prevention (state-level data). Attachment 1 provides demographic data regarding age, gender, race/ethnicity, language and Service Planning Area (SPA) of Los Angeles County residents who have a diagnosis of Cerebral Palsy (CP) or a CP-like condition. A detailed list of CP and CP-like conditions are provided in Attachment 2. Please note the data describes residents under the age of 21 who participate in the California Children's Services Medical Therapy Program, as reported by DPH' Children's Medical Services.

AD also collaborated with DPH to identify resources for residents in need of service. Attachment 3 is a preliminary listing of DPH Medical Resources which will be validated through stakeholder input before being finalized. AD is also coordinating with the Department of Health Services regarding resources currently available in the County for people with cerebral palsy and similar muscular disabilities and the different age groups for which these resources are available.

2. Cerebral Palsy Awareness Webinar

On Wednesday, August 14, 2024, AD hosted its first ever webinar on cerebral palsy. The session was designed to shed light on various aspects of cerebral palsy (CP) and discuss the resources now available to our community:

Cerebral Palsy Webinar - 8-14-2024

Webinar speakers were subject matter experts who helped the department raise awareness and increase understanding of CP and the resources available to those affected by it:

- Deaka McClain, Commissioner, Los Angeles County Commission on Disabilities and Co-Founder and Vice President, Public Relations of Divine Victory Ministries, Inc.
- Christine Segar, Occupational Therapy Manager, County of Los Angeles California Children's Services Medical Therapy Program
- David Castaneda, Participant Choice Specialist, Eastern LA Regional Center
- Reena De Asis, Founder, Inclusive Sol
- Christine Economos, Health Educator, Los Angeles County Department of Public Health, Help Me Grow LA

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The webinar began with the announcement that your Board passed a motion on March 6, 2024, to proclaim March as Cerebral Palsy Awareness Month. This was followed by a description of the disability and statistics reflecting its prevalence in Los Angeles County, including demographics. The webinar also provided information on resources available in Los Angeles County to help bridge the inequity gap and continue advocating for families who need resources. It also served as an opportunity to honor our community, family and friends with CP.

This plenary webinar focused on having the speakers address CP from different perspectives. Following welcoming remarks from Carlos Benavides, President of the Los Angeles County Commission on Disabilities (LACCOD), the speakers included a LACCOD Commissioner who has lived with CP her entire life; a parent discussing her experience of raising a child with CP; representatives of Help Me Grow and California Children's Services, which are both overseen locally by DPH; and a Health Educator from the Eastern Los Angeles Regional Center, who focused on self-determination.

The webinar was widely promoted on AD's and other County departments and outside agencies' social media platforms and was considered a successful first venture into the realm of CP for the department. Over 100 individuals registered for the event.

The success of the webinar has encouraged the department to continue coordinating CP webinars in the future in honor of Cerebral Palsy Awareness Month, with a focused emphasis on exploring different perspectives when selecting potential speakers. AD will continue to be proactive in seeking out and providing additional resources to those with CP and their caregivers through this platform.

Finally, AD has been making an increased effort to present webinars to the community on various topics directed at its target audience of older adults and people with disabilities (there have been seven in the last year alone). Moving forward, this will continue to be an essential outreach strategy for the department, with a focus on finding ways to enhance how they are presented and reaching out to increase audience engagement.

3. Outreach Events in which Cerebral Palsy Awareness is Highlighted

Outreach has always been a critical component to raising public awareness about AD programs and services. The newly established Disabilities Division is committed to informing and educating the Los Angeles County community about the full spectrum of disabilities and their impact on those who live with them, as well as their caregivers. In response to your Board motion, AD is increasing efforts to emphasize cerebral palsy in its outreach activities.

Deaka McClain is an LACCOD Commissioner and presented on her lifelong experience living with CP at the Cerebral Palsy Awareness webinar. Ms. McClain appeared at the

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annual Abilities Expo on March 15-17, 2024, at the Los Angeles Convention Center, where LACCOD shared a booth with AD. Her participation ensured that the appropriate information and resources, as well as life experiences, would be communicated by someone whom the disability directly impacts. Over the course of the three days the Expo took place, literally thousands of attendees stopped by the AD/LACCOD booth to obtain information about AD programs and services, including CP resources available to the community.

Since the Board Motion was passed, in addition to the Abilities Expo there have been 226 outreach events in which AD has participated that have served as beneficial opportunities to provide information and resources directed at individuals with CP and their caregivers. These events include Resource Fairs (e.g., Santa Clarita Valley Senior Fair – October 10th), Senior Programs (e.g., San Angelo Senior Program – ongoing), theme-specific special events (e.g., World Elder Abuse Awareness Day/Month outreach event – June 4th), large-scale community outdoor festivals (e.g., Taste of Soul – October 19th), and webinars (e.g., Cerebral Palsy Awareness – August 14th).

AD Information & Assistance staff, as well as other division staff assigned to outreach events, many of whom participated in the Cerebral Palsy Awareness Webinar, were provided with appropriate CP resources to provide to the public at these events. In addition, they learned basic information about disability services to answer event participants' questions about it as needed.

Recommendations and Next Steps

In response to the Board Motion, AD has responded to the need to educate the public about cerebral palsy and the CP resources available to the community. The department has accomplished this through its first ever Cerebral Palsy Awareness Webinar on August 14th, as well as an increased level of emphasis on CP at AD's regular outreach events throughout the County. There is still a great deal of work left to be done, especially as ongoing research continues to uncover new information about disability and hope for a cure remains strong.

AD will continue to work with DPH and DHS to finalize a guide highlighting the resources currently available in the County for people with cerebral palsy and similar muscular disabilities and the different age groups for which these resources are available. In addition, as mentioned earlier, the successful Cerebral Palsy Awareness Webinar was the first annual event exploring different aspects of CP through a wide variety of perspectives presented by a vast range of subject matter experts. The department's goal will be to reach an increasing number of participants through a progressively advanced assortment of promotional platforms.

In addition, a greater emphasis will be placed on CP at all appropriate upcoming outreach events with the goals of raising public awareness about the disability, debunking and

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demystifying the long-standing myths and mysteries about it, and educating the community about the wide range of resources available to those with CP and their caregivers. This can only be achieved through active collaborations with other County departments such as DPH and DHS, as well as outside agencies such as those whose representatives presented at the Cerebral Palsy Awareness Webinar.

AD will continue to seek out further opportunities to communicate the essential messages about cerebral palsy, namely that individuals with the disability can still live fulfilling lives, that there are programs, services and resources available to make their lives more manageable, that there is still hope for a cure, and that people care about them. The department looks forward to taking advantage of these opportunities to make life easier for individuals with CP and their caregivers.

If you have any questions concerning this report, please let us know.

c: Dr. Barbara Ferrer, Director, DPH
Dr. Christina R. Ghaly, Director, DHS
Fesia Davenport, CEO

Attachments

Attachment 1

Table 1. Characteristics of currently active California Children's Services (CCS) clients with cerebral palsy (CP) and CP-like condition, 05/01/2024.

Characteristic	n	%
All Clients	2,752	100.0
Age (as of date of data download)		
Less than 1	173	6.3
1	177	6.4
2	150	5.5
3	121	4.4
4-6	268	9.7
7-9	307	11.2
10-12	348	12.6
13-15	411	14.9
16-18	487	17.7
19-21	310	11.3
Gender		
Female	1,202	43.7
Male	1,549	56.3
Unknown	1	0.0
Race/ethnicity		
Hispanic/Latinx	1,616	58.7
White	260	9.4
Black/African American	256	9.3
Asian	123	4.5
Other race not listed	105	3.8
Pacific Islander	7	0.3
Multi-racial(1)	2	0.1
American Indian/Alaska Native	1	0.0
Unknown(2)	382	13.9
Client spoken language		
English	1,859	67.6
Spanish	752	27.3
Armenian	19	0.7
Mandarin	10	0.4
Russian	9	0.3
Korean	8	0.3
Other language not listed	8	0.3
Vietnamese	7	0.3
Farsi	6	0.2
Cantonese	6	0.2
Cambodian	3	0.1
Tagalog	3	0.1
Arabic	2	0.1
Chinese (other)	2	0.1

Japanese Other sign language Unknown	1 1 56	0.0 0.0 2.0
Service Planning Area		
Antelope Valley	247	9.0
East	420	15.3
Metro	213	7.7
San Fernando	488	17.7
San Gabriel	417	15.2
South	479	17.4
South Bay	400	14.5
West	53	1.9
Unknown(3)	35	1.3

⁽¹⁾ Includes "Ameraasian

⁽²⁾ Unknown race/ethnicity includes "No response"

⁽³⁾ Unknown SPA means client did not have an address that was able to be geocoded

Attachment 2





Health Promotion Bureau | Children's Medical Services | California Children's Services

Cerebral Palsy Board Motion Assignment

Collect and report data (rate of incidence, age, ethnicity, SPA, etc.) for CP and Other Similar Disabilities

- ⊠Step 1: Define CP and identify relevant ICD-10 Diagnosis Codes
- ☐ Step 2: Obtain data from DHS and DPH facilities based on ICD-10 Diagnosis Codes

Definition of cerebral palsy (CP)

"A group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems."

(Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B.A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl. 2007 Feb;109:8-14)

ICD-10 Codes related to CP

Cerebral Palsy & similar diagnoses:

G80 - Cerebral Palsy:

G80.9

G80.0	Spastic quadriplegic CP
G80.1	Spastic diplegic CP
G80.2	Spastic hemiplegic CP
G80.3	Spastic quadriplegic CP
G80.4	Ataxic CP
G80.8	Other CP

G81 - Hemiplegia and hemiparesis:

CP, unspecified

G81.00	Flaccid hemiplegia affecting unspecified side
G81.01	Flaccid hemiplegia affecting right dominant side
G81.02	Flaccid hemiplegia affecting left dominant side
G81.03	Flaccid hemiplegia affecting right nondominant side
G81.04	Flaccid hemiplegia affecting left nondominant side
G81.10	Spastic hemiplegia affecting unspecified side
G81.11	Spastic hemiplegia affecting right dominant side
G81.12	Spastic hemiplegia affecting left dominant side
G81.13	Spastic hemiplegia affecting right nondominant side
G81.14	Spastic hemiplegia affecting left nondominant side

Conditions with similar physical manifestations to CP:

G11.4	Hereditary spastic paraplegia
F84.2	Rett's syndrome
G31.80	Leukodystrophy, unspecified

Certain inborn errors of metabolism

E88.9	Metabolic disorder, unspecified
E72.11	Homocystinuria (untreated can cause hemorrhagic/ischemic stroke)
E71.110	Isovaleric acidemia (untreated causes spastic like CP)
E71.120	Methylmalonic acidemia (untreated causes spastic like CP)
E71.121	Propionic acidemia (untreated causes spastic like CP)
E72.29	Other disorders of urea cycle metabolism
E72.51	Non-ketotic hyperglycinemia
E75.22	Gaucher disease
F75.249	Niemann-Pick disease, unspecified

Non-neonatal diagnoses with risk of CP:

163	Cerebral infarction
169.3	Sequelae of cerebral infarction
163.9	Cerebral infarction, unspecified
169.398	Other sequelae of cerebral infarction
I61	Nontraumatic intracerebral hemorrhage
161.9	Nontraumatic intracerebral hemorrhage, unspecified
S06.2	Diffuse traumatic brain injury
S06.3	Focal traumatic brain injury
G93.1	Anoxic brain damage, not elsewhere classified
T74.12	Child physical abuse, confirmed
T74.4	Shaken infant syndrome

Neonatal diagnoses with risk of CP:

Hydrocephalus:

G91.0	Communicating nydrocephalus
G91.1	Obstructive hydrocephalus
G91.2	(Idiopathic) normal pressure hydrocephalus
G91.3	Post-traumatic hydrocephalus, unspecified
G91.4	Hydrocephalus in diseases classified elsewhere
G91.8	Other hydrocephalus

P91.0 P91.82	Neonatal cerebral ischemia Neonatal cerebral infarction
P91.88 P91.9	Other specified disturbances of cerebral status of newborn Disturbance of cerebral status of newborn, unspecified
P91.81	Neonatal encephalopathy
P52.21 P52.22	Intraventricular (nontraumatic) hemorrhage, grade 3, of newborn Intraventricular (nontraumatic) hemorrhage, grade 4, of newborn
P91.6 P91.62 P91.63	Hypoxic ischemic encephalopathy Moderate HIE Severe HIE
P21.9	Birth asphyxia, unspecified
P91.2	Neonatal cerebral leukomalacia
P35.4	Congenital Zika virus disease
P91.1	Acquired periventricular cysts of newborn
P07.23	Extreme immaturity of newborn (prematurity)
P07.0	Extremely low birth weight newborn





Health Promotion Bureau | Children's Medical Services | California Children's Services

Cerebral Palsy Board Motion Assignment

Create Resource Guide for Individuals with CP and Other Similar Disabilities

☐ Step 1: Gather existing resources
□Step 2: Select and Organize resources
□Step 3: Create draft Resource Guide
Next Steps (time permitting)
□Step 4: Elicit stakeholder input
☐ Step 5: Finalize Resource Guide—include translation into other languages

Medical Resources from Department of Public Health (DPH)

1. California Children's Services (CCS)

a. PROGRAM DESCRIPTION

California Children's Services (CCS) is a joint state and county program providing specialized medical services for infants, children and young adults with cerebral palsy (CP) and other chronic/complex medical conditions. In LA County, CCS is administered as a partnership between the California Department of Health Care Services (DHCS) and the Children's Medical Services (CMS) division of the Los Angeles County Department of Public Health (DPH).

There are two major components to CCS: the General Program and the Medical Therapy Program. The General Program provides case management and authorizations of services, including "diagnostic services" (Newborn Hearing Screening Program; High-Risk Infant Follow-Up) and "treatment services" (emergency room care, hospital stays, surgery, medication, and special equipment). The Medical Therapy Program (MTP) provides occupational therapy (OT) and physical therapy (PT) services for children at 23 therapy units housed in public schools throughout LA County. MTP also provides home or school visits to assess the natural environments, participates in Individual Educational Planning (IEP) meetings, and provides Medical Therapy Conferences (MTC) to assess a full and comprehensive care plan for clients.

Currently, CCS offers services for approximately 195,000 children statewide and 47,000 children in Los Angeles County alone. To serve these clients and their families, LA County CCS employs physicians and nurses to coordinate and authorize care for these children. Additionally, CCS employs occupational therapists, physical therapists, social workers, dentists, audiologists, and support

staff to serve its clients. This does not include physicians, nurses, caregivers, social workers, nutritionists, therapists, and other external providers that CCS may authorize to provide medical care for these children.

- b. ADDITIONAL INFORMATION ABOUT CCS:
 - i. <u>CCS Website</u> (<u>www.publichealth.lacounty.gov/cms/</u> CCS.htm)
 - ii. CCS Handbook (English and Spanish) (Attached to PDF)



iii. CCS provides highly specialized occupational therapy (OT) and physical therapy (PT) at 23 Medical Therapy Units (MTUs) throughout Los Angeles: MTU Locator

2. Children's Medical Services (CMS) Family Support Reference Guide

- a. Family-centered care is the partnership between families and professionals. Key principles: Families and professionals work together in the best interest of the child and family. As the child grows, (s)he/they assumes a partnership role. Everyone respects the skills and expertise brought to the relationship, and decisions are made together by the participants.
- b. <u>CMS Family Support Reference Guide</u> (http://www.publichealth.lacounty.gov/cms/docs/FamilySupRefGuide2019.pdf)

Medical Resources from Department of Health Services (DHS)

1. Rancho Los Amigos National Rehabilitation Center

High Risk Infant Follow-Up Clinics

- 1. Cedars-Sinai Medical Center
- 2. Children's Hospital Los Angeles
- 3. Kaiser Permanente Los Angeles Medical Center
- 4. LAC + USC Medical Center
- 5. UCLA Mattel Children's hospital at Ronald Reagan

Community-based children's hospitals in and near Los Angeles

- 1. Children's Hospital Los Angeles
- 2. Children's Hospital of Orange County
- 3. Luskin Orthopaedic Institute for Children
- 4. Miller Children's and Women's Hospital Los Angeles
- 5. Shriner Children's Southern California

6. <u>UCLA Mattel Children's Hospital</u>

Adult medicine clinics

- 1. Rancho Los Amigos National Rehabilitation Center Adult Medicine Clinics
- 2. UCLA Health at Santa Monica Medical Center

University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD)

- 1. UCLA Tarjan Center—adult and pediatric
- 2. <u>USC Center for Excellence in Developmental Disabilities, Children's Hospital, Los Angeles</u>—no adult, pediatric only

Regional Centers

DDS oversees the coordination and delivery of services for Californians with developmental disabilities through a statewide network of community-based, non-profit agencies known as regional centers. Regional Centers provide assessments, determine eligibility for services, and offer case management services across the lifespan. There are 21 regional centers throughout California, 7 of which are in Los Angeles County. Regional centers contract with the State Department of Developmental Services to coordinate services for individuals with developmental disabilities.

This is a breakdown of Regional Centers and the cities they serve, key contact information, and summary of their services: (Attached to PDF)



Listing of Other Resources that have been vetted/approved for CCS clients

CCS Resource Brochure (English and Spanish) last reviewed in 2023. (Attached to PDF)





2. Early Identification and Intervention for Infants (EI3) Network