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Proclaiming March as Cerebral Palsy Awareness Month in Los Angeles County and Bringing Resources to Families Who Have Loved Ones with Disabilities

Cerebral palsy is the most common motor disability in childhood and is associated with lifelong physical challenges and contributed to prematurity of the child’s birth. It is caused by trauma to the child’s brain before or during birth, or within the first few years of life, and is not a hereditary or contagious condition. Motor symptoms can range from mild to severe, and common co-morbidities may include problems speaking, hearing, seeing, thinking, feeding, and controlling the bladder. Additional challenges include pain and poor sleep.

According to the Centers for Disease Control and Prevention (CDC), 1 in 345 children are identified with cerebral palsy annually, which means that approximately 10,000 children born each year will develop cerebral palsy in the United States.¹ This medical condition may lead to challenges in movement, balance and posture. In Los Angeles County (County) specifically, there are approximately 295 babies born each year who are diagnosed with cerebral palsy in the first 3 years of life—most of whom are

¹ [March of Dimes
https://www.marchofdimes.org/peristats/data?reg=99&top=2&stop=1&lev=1&slev=6&obj=8&sreg=06&creg=06037](https://www.marchofdimes.org/peristats/data?reg=99&top=2&stop=1&lev=1&slev=6&obj=8&sreg=06&creg=06037)

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children of color. Families of color are also more likely to experience challenges with health access and early intervention, which is key to positive outcomes for the child.

Despite cerebral palsy being the most common lifelong motor disability, there is inadequate dissemination of information about this disability. In addition, there is a gap between research and clinical practice among medical providers. Many of the symptoms associated with cerebral palsy respond well to intervention in early childhood when brain plasticity is at its greatest. As such, delays in diagnosis and referral for intervention may negatively impact clinical outcomes, thereby limiting opportunities and skills required for future participation in school, workplace, and communities. Delays may also contribute to higher rates of mental health problems.

California Children's Services (CCS), operated by the County's Department of Public Health (DPH), is an important resource for children with cerebral palsy, offering diagnostic and treatment services, medical case management, and therapy services. Within CCS, the Medical Therapy Program (MTP) provides specialized occupational therapy and physical therapy for children with cerebral palsy, teaching important skills like self-feeding, bathing, walking, driving a wheelchair, etc. Sadly, many community-based pediatricians are not aware of CCS as a resource.

The DPH has implemented the national *Help Me Grow* model as a local peer-led program designed to help families navigate early childhood systems and appropriate interventions for Children and Youth with Special Health Care Needs (CYSHCN) when identified. These young people have, or are at an increased risk for, chronic physical, developmental, behavioral, or emotional conditions. These include cerebral palsy and other conditions that may require more extensive and coordinated care compared to typical health care needs. The *Help Me Grow* program is led by "Family Partners" who are parents that have raised CYSHCN and offer both emotional and practical support in navigating the health and social service system. Families with small children who have cerebral palsy face multiple barriers caused by disjointing of the existing support systems. The County faces a gap in targeted treatment options and support for caregivers for children under the age of 16 who suffer from disabilities like cerebral palsy.

Medical care for children and young adults with cerebral palsy is coordinated through the seven Regional Centers in the County that contract with the California Department of Developmental Services (DDS) to provide assessments, determine eligibility for services, and offer case management services for people with developmental disabilities, including cerebral palsy. Despite these services, there are resource gaps, including limited online resources to help direct caregivers and families to community programs such as support groups that provide emotional support, coping strategies, resources, and recommendations.

Transitions of care present an additional access challenge for those aging out of Regional Center services or transitioning from early start programs to school based services. For example, once a child turns 3 years old and transitions out of the Early Start Program, the child's school district of residence becomes responsible for providing special education services under the Individuals with Disabilities Education Act (IDEA). Each school district's accommodations and offerings, however, lack uniformity and will vary depending on the district's resources for instruction and support, physical accessibility, proper training for teachers and school staff, etc.

In addition, school districts have relationships with their local California Children's Services (CCS) centers and Medical Therapy Units (MTU) or other providers that offer physical or occupational therapy (PT or OT). Families are required to utilize their school district's services even if they are understaffed or far from the family's home. As an exception, families with greater financial means can choose to use private insurance or pay out of pocket for therapies for their children, leading to an inequitable distribution of health care services. Moreover, Black children are more likely to have cerebral palsy than white children.² Families of color are more likely to be under-insured or uninsured, so they are less likely to receive care during the crucial time when a child is diagnosed with this disability and in need of timely physical therapy.

County residents with cerebral palsy and similar muscular disabilities that are unable to access care when they need it leads to delayed treatment and impacts effective care and significantly reduce outcome later in life. Roughly 40% of American parents of

²National Library of Medicine - <https://pubmed.ncbi.nlm.nih.gov/22081059/>

children with disabilities will leave the workforce to become a full-time caregiver, which can put families at risk for poverty and housing instability.³

While Cerebral Palsy Awareness Month is already nationally recognized in March, this County's Board of Supervisors (Board) wishes to recognize March as the County's Cerebral Palsy Month and launch more local resources, improve County-level data collection, and connect families with loved ones with disabilities to the best resources. As one of the nation's largest counties, this Board should be at the forefront of spearheading positive change.

I THEREFORE MOVE THAT THE BOARD OF SUPERVISORS:

- 1) Proclaim March as Cerebral Palsy Awareness Month and ask the County of Los Angeles (County) employees to wear a green ribbon on March 6, 2024, in honor individuals living with cerebral palsy and to acknowledge family members and activists that come together each March to advocate for the cerebral palsy community.
- 2) Direct the Director of the Department of Aging and Disabilities to work with the Department of Health Services (DHS) and the Commission on Disabilities to report back in writing within 120 days on the following:
 - a. 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;
 - ~~b. 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). This includes demographic data regarding race, ethnicity, age, and disease rates by service planning area; and~~
 - ~~c. The data needed to conduct a needs assessment in the County to better understand how many children and adults suffer from cerebral palsy and other similar disabilities and the need for services.~~

³ https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021_Final.pdf

3) Direct the Department of Aging and Disability to work in collaboration with the Department of ~~Public Health Services (DHS)~~ and relevant departments to report back in writing within 120 days and identify opportunities for outreach and awareness of cerebral palsy and similar disabilities by:

- a. Evaluating existing resources already available through the California Children’s Services program, operated by the DPH, and to leverage existing relationships with external stakeholders working toward similar goals; ~~and~~
- b. Identifying 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). This includes demographic data regarding race, ethnicity, age, and disease rates by service planning area;
- c. Identifying the data needed to conduct a needs assessment in the County to better understand how many children and adults suffer from cerebral palsy and other similar disabilities and the need for services; and
- d. Creating a resource guide for residents in need of service and host a biannual online meeting with community partners to facilitate sharing information and best practices in serving people diagnosed with cerebral palsy.

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(LS/YV)