



March 23, 2020

Governor Gavin Newsom
1303 10th Street, Suite 1173
Sacramento, CA 95814

Dear Governor Newsom:

Thank you for your significant leadership during this public health emergency. Your office and leadership team across agencies and departments have already issued extensive authority and resources to mitigate further impact of, respond to, and recover from the COVID-19 pandemic. This includes providing broad authority to the Director of the Department of Developmental Services (DDS) to help those they serve who are impacted by COVID-19, imposing a moratorium on evictions, ensuring essential safety net services by delaying eligibility re-determinations for 90 days, and directing the California Department of Education to ensure that students with disabilities continue to receive special education and related services during the school closures. The State Council on Developmental Disabilities (The Council) recognizes this public health emergency is evolving and unfolding.

The Council is comprised of 31 members you appoint, including individuals with intellectual and developmental disabilities, their families, other partners and state agencies. The Council has a headquarters and 12 Regional Offices in California that are creating information tailored to people with developmental disabilities and answering questions for people with developmental disabilities, their families and the professionals who work with them. The Council writes today with additional recommendations for you to consider to protect the health and safety of all Californians, including people with intellectual and developmental disabilities (including both individuals served by the Regional Center system and those served by the generic system) so children and adults can successfully self-isolate, prevent the spread of infection and ensure continuity of care across the service delivery systems. The Council is also working with our national association, the National Association of Councils on Developmental Disabilities, to address concerns within the purview of Congress or the Administration. For example, the Council is hearing concerns from SSI and SSDI recipients about the negative impact a possible stimulus package that provides cash payments could have without it including a hold harmless for both SGA (substantial gainful activity) and asset limits for the payments, as well as possible waivers of the requirements of the Individuals with Disabilities Education Act.



People with developmental disabilities are likely to be disproportionately impacted by this public health emergency because many have underlying medical conditions, rely on others for care, or live in congregate settings such as nursing homes and group homes. The Council encourages you to continue recognizing people with developmental disabilities when providing public information during press conferences. The Council also encourages you to identify one cross-disability point person who reports directly to you who is responsible for advising you on the complexity of needs of people with disabilities and the intersectionality of entities serving those needs. Also, the Council believes that local and state government agencies should have people with disabilities and their families participating in all mitigation, response, and recovery efforts.

Non-Discrimination in Healthcare

Given that testing and treatment resources are scarce, it will be critical for Health and Human Services Agency to ensure that Medi-Cal and other healthcare providers do not discriminate against people with disabilities. Any policies must be based on objective medical criteria that do not intentionally or inadvertently lead to people with disabilities being disproportionately denied testing or treatment. The Council recommends that Health and Human Services Agency proactively inform providers that any policies they develop must be nondiscriminatory. In particular, Health and Human Services Agency must prohibit inclusion of any criterion that explicitly or implicitly makes “quality of life” a consideration in any “triage” policy. “Quality of life” has long been a pretext for denying treatment, including life-sustaining treatment, to people with developmental disabilities. If “quality of life” is adopted, people with developmental disabilities should be excluded.

Direct Workforce / In-Home Supportive Services (IHSS)/Regional Center Services

Many people are dependent on daily in-home care (personal care, home health etc.) from professional caregivers who travel between homes. California already has a significant shortage of caregivers. Almost 600,000 people rely on IHSS and over 330,000 on Regional Center services. The Council is deeply concerned about the healthcare crisis’ impact on this workforce. The Council believes that contingency plans must be created should caregivers become infected or exposed, need to adhere to quarantine requirements, or are hospitalized and the limited pool of caregivers shrinks to untenable levels. The Council believes the direct support workforce and people with chronic conditions should be among those prioritized for COVID-19 testing. As priorities are being set for personal protective equipment, please consider the needs of those caring for people who have medical conditions in home and other settings. Immigrants, whether documented or not, need to be reassured that they can access public services and testing without fear of impact on their immigration status.



Some recipients may have a network of natural supports that can cover daily care needs. However, a significant number of people do not have unpaid supports. In addition, institutional facilities may be at greater risk for outbreaks, face the same workforce shortages, and have limited capacity. The Council recommends that the Health and Human Services Agency ensures that assistance is available when providers are sick or must self-quarantine including creating emergency registries of providers, expediting this registry through systemic approval of emergency IHSS providers, suspending overtime rules, immediately expanding online provider orientations and other training opportunities, and permitting online provider enrollment. The Council also believes that short-term respite options must be increased for family caregivers, particularly older adult caregivers. Also, CalFresh should be eligible for online purchases. The Council is deeply concerned about an increase in abuse and violence as the strain of the pandemic grows. The Council also suggests creating a process of remote check-in with individuals with developmental disabilities and their families who may be in self-isolation or quarantine, particularly older adult caregivers, to ensure caregivers have proper support and rest and that those they are caring for are safe. The Council recommends increased contact with people with developmental disabilities receiving independent living services as they are particularly vulnerable during isolation. Lastly, specific to DDS, the Council is encouraged by the ways DDS is addressing flexibility and increasing services such as respite services, personal assistance, supported living services, and day care. DDS has also been active in ensuring Regional Centers have ongoing proactive and affirmative contact with people with developmental disabilities and families to understand their ongoing wellbeing and needs and to provide information about additional Regional Center services and supports.

Medi-Cal

Many people with disabilities rely on Medi-Cal funded long-term care services to access basic healthcare and services that ensure their functioning, independent living, and well-being. Some of the most critical services that children and adults with disabilities and their families rely on are nursing and personal care services, specialized rehabilitation and other therapies, intensive mental and behavioral health services, prescription medications, employment services, residential services and transportation services. Providers rely on a face-to-face reimbursement model for Medi-Cal. The Council recommends that in addition to halting re-determinations for 90 days that all terminations of Medi-Cal eligibility are halted. Any requirements for in-person meetings should be waived. The Council also recommends that opportunities to apply for waivers are explored including applying for a disaster waiver under Section 1135 and/or appendix K of the section 1915(c) waiver for use by states during emergencies.



Education and Transition Services

Guidance from the U.S Department of Education that the CDE issued includes information that schools moving to on-line learning must continue to meet their obligations to provide a free and appropriate public education (FAPE) for students with disabilities, including special education and related services. The Council believes it is critical that the California CDE offer additional guidance to schools and post-secondary programs regarding how to ensure their online programs are universally designed and accessible to all students using captioning, CART reporting, screen reader technology and options for recording lectures. Special education coordinators should be directed to create tele-education check-ins with students with disabilities to ensure they are continuing to receive FAPE. If schools are to remain closed for the summer, it is important that schools assess the need for extended school year services to maintain FAPE. Lastly, opportunities to provide pre-employment transitions services to students and youth with disabilities should be explored.

Thank you for your leadership. The Council stands ready to work with you during this public health emergency.

Sincerely,

Maria Marquez, Chair

Cc: Mark Ghaly, Secretary California Health and Human Services
Richard Figueroa, Deputy Cabinet Secretary, Office of the Governor
Tam Ma, Deputy Legislative Secretary, Office of the Governor
Marko Mijic, Deputy Secretary, California Health and Human Services
Samar Muzaffar, Assistant Secretary, California Health and Human Services
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