



State Council on Developmental Disabilities



STATE OF CALIFORNIA  
Gavin Newsom, Governor

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December 8, 2022

Pedro Nava, Chairman  
Little Hoover Commission  
925 L Street, Suite 805  
Sacramento, CA 95814

Subject: SCDD Comments re California Developmental Disabilities System Study

Chairman Nava and Commissioners,

The State Council on Developmental Disabilities (SCDD) would like to thank the Little Hoover Commission (Commission) for exercising its independent oversight role in studying racial access and disparities in community-based services provided through the Department of Developmental Services (DDS) and regional centers. SCDD appreciates the opportunity to submit these comments and recommendations and serve as a witness at today's hearing.

Established over 50 years ago, SCDD is an independent state department funded by Congress to be a guiding force for positive, life-altering changes for approximately 625,000 Californians with intellectual and developmental disabilities (IDD), whether served by regional centers or not. SCDD's statutory authority is to build the capacity of people with IDD and their families to make changes in their lives, and to join in their advocacy in order to change systems. With a statewide team of 50 employees in 12 offices, our work in 2022 impacted 5 million Californians.

SCDD thanks the Commission for acknowledging the Lanterman Act as groundbreaking legislation. It is a person-centered promise of an entitlement to meet individual needs that still stands unparalleled in the country. At its core, it is a promise of equity. Ambitious, expansive, and far from perfect, the Lanterman Act is more than a statutory structure. It is civil rights document. This is a civil rights conversation.

The Commission has heard passionate perspectives on how the system is not fully delivering the Lanterman Act's promise, and how the system is a "no right door" system. The opaque complexity of regional centers is complicated by their role as the "payer of last resort," sending consumers and families to navigate a labyrinth of multiple systems to secure services. The Commission has heard and documented that who is left out is more likely to be poorer and BIPOC Californians. The more resources a person has the more likely they are to get

*"The Council advocates, promotes & implements policies and practices that achieve self-determination, independence, productivity & inclusion in all aspects of community life for Californians with developmental disabilities and their families."*

resources in a system that rewards those culturally comfortable with advocacy. The Commission has directly experienced frustrations when trying to get answers and determining who is accountable, which is a common experience for individuals and families.

Yet, within the testimony is also a belief in the Lanterman Act itself, its promise of equity, and a collective push to make it succeed for everyone it serves. The Governor and Legislature continue to invest in the state's IDD system, approving over 40 new initiatives in the past two years. At the core of the initiatives is implementing rate reform, a \$1.8 billion adjustment to a long-underfunded system. Also, SCDD and other advocates co-sponsored legislation to end subminimum wage, make Fair Hearings fairer, and provide offramps to conservatorship. All these efforts taken together are intended to fill a gap, provide a new service, or push the system forward. We are in a period of hyper-reform, which often invites additional reforms. SCDD is optimistic that the Commission's own study and recommendations will add to the thinking for success.

To find the path forward from here, we must listen to the community. Listening to people served is at the core of the federal DD Act, Home and Community Based Services (HCBS) waiver, and the Lanterman Act. From our historical position as a statewide independent entity, last year SCDD worked with over 700 community partners, advised 91,000 Californians about their problems, trained 18,000 people, and held 1,200 targeted activities to bridge disparities, including activities in 19 languages. Thank you to the Commission for holding today's session to hear from the public.

These are recommendations based on what SCDD has heard from the public and its own Councilmembers about disparities and accountability.

Listen for needs based on intersectionality, not just identity. A system based on individual needs means listening to the needs of the whole individual, not just one aspect of them, like disability or race. The intersection of a person's experience based on disability, race, gender identity, religion, sexual orientation, or geographic location can tell more meaningful ways to reduce disparities than the typically monolithic methods for discussing racial disparities. Understanding a whole person is the first step in equity.

#### Connect kitchen tables

Reducing disparities is often done through establishing trusting relationships, family by family, person by person. Having a trusted connection is key. The IDD system was founded by families around kitchen tables. That moment of getting a diagnosis feels like being a pioneer, and people can feel lost until they connect with a kitchen table of people with similar experiences. Part of what we do in our work is find those newly formed kitchen tables and connect them to other kitchen tables and to the services they need. Helping unserved people connect to these entitlement services will address another aspect of racial disparities, which is a many regional center's consumer demographics do not reflect the demographics of the catchment area. This means people are not finding their way to a regional center's front door.

### Provide advocacy supports again

You received comments from people with IDD and their families about needing assistance when going up against the system. SCDD hears it too. We can train people on their rights and on services, but in the end, they go through the regional center or school doors on their own. For their IPP with a regional center or IEP with a school, it is still a consumer or student and family vs the regional center or school. As Commission staff identified, it was not always this way. For over 40 years, the State Council used federal dollars from Congress to do this direct, individual advocacy. Congress intended their dollars for DD Councils to be used for systems change, not direct individual advocacy and SCDD had to stop. When we stopped, a hole opened that threads through many of the issues you have heard from the community and you have raised directly. Direct individual advocacy also answers an authority-distance or authority-mistrust dynamic that prevents people from getting what they need from a system that rewards a culture of advocacy. Direct individual advocacy also helps navigate multiple systems.

Additionally, SCDD makes these systemic recommendations.

### Invest in becoming knowledge rich, not just data rich

The state has a decade's worth of information about racial differences in purchase of services expenditures. Year after year it documents racial disparities in expenditures. However, why do racial disparities persist, and does this data set give us insight into it? If not, expand it.

### Focus on the \$12 billion, not just the \$11 million

The Governor and Legislature should be proud of the \$11 million they invest annually in "service access and equity" grants. These are rare dollars, and no other state has put money where their values are in this way. However, a lot of attention goes to the \$11 million, and Georgetown National Center for Cultural Competence will produce an evaluation of these grants in the Spring 2023. These grants should be investing in ideas that transform the \$12 billion system, not just fill gaps. When the \$12 billion functions as it should, the \$11 million is likely not needed.

### Find out the pandemic's impact on racial disparities

COVID exacerbated many existing systemic problems. There were already racial disparities in regional center services, housing, employment, access to and quality of health care, and access to and quality of education. We hear it is worse. We need to know what happened. As a matter of racial equity and justice, the state needs to know the true span of the divide as we work to bridge it.

Thank you for your consideration of these recommendations. People are isolated for many reasons, and we have over 50 years of experience of reaching through the disconnection. SCDD stands ready to work with the Commission and the State in creating a more responsive, inclusive service delivery system that reflects all Californians and changes as California changes.

Pedro Nava, Chairman  
Developmental Disabilities System Study  
December 8, 2022  
Page 4

Sincerely,

A handwritten signature in blue ink, consisting of a large, stylized 'A' followed by a horizontal line and a vertical line that crosses the 'A'.

Aaron Carruthers  
Executive Director  
State Council on Developmental Disabilities