



January 16, 2026

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

RE: SCDD Written Testimony on Systemwide Progress and Ongoing Barriers in Developmental Services

Dear Chairman Nava and Commissioners,

The State Council on Developmental Disabilities (SCDD) recognizes and thanks the Little Hoover Commission for its continued independent oversight and for seeking input on progress toward implementing its recommendations. We appreciate the opportunity to share what we hear from individuals served and their families about access and persistent barriers within the regional center system. We offer these comments in the same spirit as your work: identifying what strengthens the Lanterman Act's promise and what continues to impede it. In that role, SCDD disrupts systems to make them work better – more effective, efficient, agile, and accountable – for Californians with intellectual and developmental disabilities (IDD) and their families.

SCDD has more than 50 years of experience listening to communities, elevating their voices, and reaching through barriers that contribute to disconnection. Recently, over 4,200 Californians in the IDD community told us their priorities and needs. This collective history and feedback informs the following testimony.

While many of the Commission's recommendations are beginning to take shape, most individuals served and their families are not yet experiencing these changes in their daily lives. Systemwide reform takes time. We recognize that the Department of Developmental Services has launched a range of initiatives, with some already underway and others still in development. Taken together, these efforts reflect steady movement and sustained focus. The Department's leadership and efforts give us optimism even as the full effects are still emerging across regions.



With that in mind, SCDD focuses this testimony on several recurring issues that continue to affect access, consistency, and equity. The sections that follow outline these issues, describe their impact, and note how they relate to the goals identified by the Commission.

Direct Advocacy Support for Navigating and Obtaining Services

To address longstanding challenges in navigating the developmental services system, some regional centers have introduced “promotoras” or similar roles to assist individuals served and families. These positions help explain processes, prepare for planning meetings, and support communication with service coordinators. In practice, this assistance often functions as direct advocacy, helping individuals served and families understand their rights, articulate their needs, and follow complex processes that can otherwise be difficult to manage. The presence of promotoras reflects a recognition that many individuals served and families require additional support to fully participate in planning and to access the services identified as necessary.

Historically, families who are new to the system, who speak languages other than English, or who face barriers in navigating government programs have reported difficulty understanding how to request services, how decisions are made, or how to follow up when delays occur. Direct advocacy support can help bridge these gaps by ensuring that individuals served and families have someone who can guide them through planning and communicate clearly with regional center staff.

This relates to the Commission’s emphasis on system navigation and equitable access, as consistent and reliable support can help ensure that participation in planning is meaningful and that individuals served and families can engage fully in the process. Strengthening and standardizing access to this type of assistance would help individuals served and families better understand the system and more effectively pursue the services they need.

Provider Availability and Cultural and Linguistic Fit

Capacity remains a significant barrier across the developmental services system. Even when services are approved, individuals served and families often cannot locate providers who are available, who can staff the required hours, or who have the skills and experience needed for more intensive or complex support needs. This includes challenges finding providers who understand a person’s language, culture, communication style, or behavioral or medical support needs. As a result, many individuals served end up with services listed on paper but not actually delivered,



leaving individuals and families with unmet needs and requiring them to absorb the workload.

This challenge does not affect all regions or communities equally. Families who are Black, Latino, Asian, immigrant, or who speak languages other than English routinely report limited access to providers who can communicate effectively or who understand cultural expectations around care. Families in rural areas similarly report that services go unused simply because no one is available to provide them. This pattern contributes to well-documented inequities in who can access and benefit from the developmental services system, even when funding exists.

This issue is directly connected to the Commission's emphasis on equitable access, consistent experiences across regions, and reducing racial and ethnic disparities. Capacity limitations sit at the intersection of these goals, because inequitable provider availability is one of the primary drivers of uneven access and inconsistent service delivery.

One promising direction comes from the Self-Determination Program. Under SDP, individuals served and families have the freedom and control to identify, choose, and direct the vendors and staff who best match their language, culture, and support needs. This includes the ability to hire community-based providers who may not be part of the traditional vendor pool but who have the capacity and cultural alignment families are looking for. This flexibility has allowed many individuals served to find support that is a better fit than what is available through the standard vendor system. Expanding this principle more broadly, by decentralizing parts of the vendorization process and allowing individuals served and families to select and engage providers who meet their needs within clear statewide guidelines, would help increase capacity, improve cultural and linguistic match, and support greater equity in service access across regions.

Internal Review Processes for Regional Center Service Decisions

Internal review processes for purchasing services play a significant role in how regional centers make decisions. State law requires regional centers to maintain an internal process that reviews service requests to ensure they conform to the Lanterman Act, to consider generic resources and timelines, and to incorporate information individuals served and families provide about their needs. In practice, these processes are often not visible to individuals served or families, who may not know when reviews occur, who participates, or what standards are being applied. This lack of transparency can make it difficult for individuals served and families to understand how decisions are



reached and can limit their ability to participate meaningfully in planning, which is a foundational principle of the Lanterman Act.

Historically, these internal processes have developed differently across regional centers. Some review requests promptly, while others convene less frequently, which can delay access even when there is agreement at the planning level about what services are needed. Families report uncertainty about when a decision will be made, what documentation will be required, or why a request is delayed or denied. Because these reviews occur outside the planning conversation, individuals served and families often experience the system as unpredictable or disconnected from the information they provide during planning.

If these internal review processes did not exist in their current form, or if they operated differently, the experience of individuals served and families would likely change in several ways. Without separate layers of internal review, service decisions might be communicated more directly, timelines could be clearer, and planning discussions could more closely align with final service authorizations. Individuals served and families might also have greater clarity about who is making decisions and how their input influences the outcome. At the same time, removing structure entirely could lead to different challenges if decisions were made without consistent statewide standards.

These considerations reinforce the Commission's focus on improving statewide consistency, strengthening oversight, and aligning internal practices. Enhancing the transparency and predictability of these internal processes, while maintaining appropriate safeguards, would support participation, clarity, and confidence without altering the statutory requirement that such internal processes exist.

Lack of IPP Implementation Deadlines

While the Lanterman Act clearly defines the timing of planning meetings, it does not establish a specific, statewide deadline for when services must begin after an Individual Program Plan is agreed upon. The law requires that the IPP describe who will provide each service and when it will start, but there is no statutory requirement ensuring those start dates occur within a defined timeframe. As a result, individuals served and families may experience significant delays between agreement on a service and the point at which it becomes available. This includes delays in arranging providers, delays caused by internal review processes, and delays in securing staffing or vendor capacity. Because there is no clear implementation deadline, the practical



effect is that planning moves forward, but service delivery often does not follow at the pace individuals served or families expect.

The lack of an implementation deadline is not a new issue. Historically, individuals served and families have reported uncertainty about when services will begin, who is responsible for initiating them, and what timelines they should anticipate. Unlike the clear 30-day requirement to schedule an IPP meeting, service implementation can extend for months without a formal point at which families can say the delay violates a statewide standard. This creates unpredictability and makes it difficult for individuals served and families to plan for work, school, caregiving, transportation, or behavioral support needs. When delays occur without clear timelines, families can feel as if they have participated fully in planning but cannot rely on the system to carry out the plan in a meaningful or timely way.

This concern relates directly to the values of participation, clarity, and timely access embedded in the Lanterman Act. Individuals served and families are expected to participate actively in planning because their input is essential to identifying needs and goals. However, when there is no reliable timeframe for implementation, participation becomes less effective, because individuals served cannot anticipate when supports will actually be available. Predictability, transparency, and follow-through are fundamental to a planning process that respects the rights of individuals served and acknowledges the role families play in supporting them.

This issue also aligns with the Commission's themes of statewide consistency, system navigation, and accountability for service delivery. Without a uniform expectation for when services must start, regional centers develop their own internal practices, leading to different experiences depending on where an individual lives. This makes it difficult for families to understand the system and contributes to the perception that similar needs may be addressed differently in different regions. The Commission's focus on improving consistency and strengthening oversight is closely tied to how implementation timelines are communicated and managed.

If a clear implementation deadline existed, whether in statute or by directive, individuals served and families would have a defined expectation for when services must begin. This could lead to more timely communication, help families plan their schedules and responsibilities, and reduce uncertainty about next steps after planning is complete. It would also support stronger alignment between what is written in the IPP and the services that are delivered, reinforcing the intent of the planning process



and the values of timely access and meaningful participation. Greater clarity and consistency in how implementation timelines are defined and communicated would strengthen trust and improve the overall experience of navigating the system.

Compensatory Services

Compensatory services are a concept borrowed from the special education field, where they are used to make up for services a student should have received but did not. A similar issue arises in the developmental services system when there are delays in implementing an Individual Program Plan. Even when a service is agreed upon in planning, individuals served and families may wait weeks or months before the service begins, due to vendor capacity, staffing shortages, internal review processes, or other system-level delays. During this time, the individual served is without the supports that were identified as necessary. Compensatory services would address this by providing additional service hours later to make up for the hours that were missed through no fault of the individual served or their family.

Historically, the developmental services system has not had a consistent mechanism for addressing missed service hours caused by implementation delays. When services begin late, the lost time is simply lost, even if the delay affects skill development, behavior stabilization, caregiver stress, or the individual's ability to participate meaningfully in daily life. Because these delays can be lengthy and unpredictable, the absence of a compensatory approach means that individuals served do not receive the full benefit of the services that were identified as necessary during planning. People report that this disconnect between agreement and delivery can affect home routines, school or work participation, and overall stability.

This issue connects to the Lanterman Act's expectations of meaningful participation, timely access, and reliable follow-through on planning decisions. Individuals served and families invest time and effort into the IPP process with the understanding that services listed in the plan will be provided. When delays occur without any mechanism to restore lost hours, the value of participation is diminished. Compensatory services reinforce the idea that planning must translate into action and that individuals served should not lose needed supports because of delays.

This concern is closely aligned with the Commission's focus on consistency, equity of experience, and system accountability. Without a consistent approach to addressing missed services, individuals served in different regions or circumstances may experience very different outcomes after a delay. Some may eventually receive



services but without the benefit of the hours lost; others may struggle to regain stability after a prolonged lapse in support. A clear approach to making up missed hours, whether through statute or directive, would improve transparency, help individuals served and families understand what to expect when delays occur, and ensure that service delivery aligns more closely with planning decisions.

If compensatory services were available as a standard practice, individuals served could recover the hours of support lost during delays, reinforcing the intent of the planning process and providing some continuity where gaps have occurred. Families would have greater clarity about what happens when implementation is postponed and would be able to rely on a defined process for restoring missed support. This approach would not change the statutory structure of developmental services but would strengthen consistency, reinforce timely access, and provide a more reliable experience for individuals served and families when the system is unable to implement services promptly.

Centralized and Portable Information

Individuals served and families interact with many service systems at once, including regional centers, special education, In-Home Supportive Services, and the Department of Rehabilitation. Each system maintains separate records, assessments, and service histories, resulting in individuals served and families repeatedly providing the same information to different agencies. This creates unnecessary administrative burden and increases the likelihood of inconsistent or incomplete information being used in decision-making. A centralized, confidential data system, similar to an electronic medical record used in healthcare, would allow individuals served and families to securely store all relevant information in one place.

Historically, individuals served and families have had to coordinate records across multiple agencies without a unified platform, leading to gaps in communication and delays in sharing critical information. A portable record system would allow individuals served or their families to decide what information is shared, when it is shared, and with whom. This level of control would support autonomy, reduce duplication, and strengthen coordination across service systems.

The Commission's emphasis on improving system navigation and increasing consistency is closely connected to this idea, as a single portal would make information clearer, more accessible, and easier to manage for individuals served and families.



A centralized and portable data system would also improve transitions between systems, such as from school-based services to adult services, by ensuring that information does not have to be re-created at each stage. Even without major structural changes, improving information-sharing practices and exploring secure technology options would support individuals and families, reduce confusion, and strengthen the overall service experience.

Find Out the Pandemic's Impact on Racial Disparities

As we stated in our written comments to the Commission in December 2022, 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 heard then and continue to hear that it is worse.

There is still the need to know what happened. Available data already show significant gaps, but a full assessment is still needed to understand how these disparities evolved during and after the pandemic to understand its full impact on service patterns and outcomes. 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.

Continued Relevance of SCDD's December 2022 Input

The observations and concerns we shared with the Commission in December 2022 remain relevant today. Many of the systemic issues identified in that testimony, such as delays in service implementation, lack of provider capacity, challenges in system navigation, and inequities in access, continue to affect individuals served and their families across the state. While progress has been made in several areas, the experiences reported to us continue to reflect the same themes. For this reason, we are attaching our December 2022 comments for the Commission's consideration. They provide additional context, illustrate the continuity of these challenges, and offer a useful point of comparison for assessing progress over time.

In closing, thank you for your consideration of these observations. Your continued oversight provides a critical lens through which these issues can be better understood and addressed.

We stand ready to work with the Commission and the State to strengthen a service delivery system that is responsive, inclusive, and reflective of California as it is today, and adaptable to the California we are becoming.



Sincerely,

A handwritten signature in blue ink, consisting of a large, stylized 'A' followed by a horizontal line and a loop.

Aaron Carruthers
Executive Director
State Council on Developmental Disabilities



State Council on Developmental Disabilities



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December 8, 2022

Pedro Nava, Chairman
Little Hoover Commission
925 L Street, Suite 805
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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
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December 8, 2022
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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