



# A System in Distress: Caring for Californians with Developmental Disabilities

Report #273 | April 2023



Milton Marks Commission on California State  
Government Organization and Economy

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The Little Hoover Commission, formally known as the Milton Marks "Little Hoover" Commission on California State Government Organization and Economy, is an independent state oversight agency.

By statute, the Commission is a bipartisan board composed of five public members appointed by the governor, four public members appointed by the Legislature, two senators and two assemblymembers.

In creating the Commission in 1962, the Legislature declared its purpose:

**...to secure assistance for the Governor and itself in promoting economy, efficiency and improved services in the transaction of the public business in the various departments, agencies and instrumentalities of the executive branch of the state government, and in making the operation of all state departments, agencies and instrumentalities, and all expenditures of public funds, more directly responsive to the wishes of the people as expressed by their elected representatives...**

The Commission fulfills this charge by listening to the public, consulting with the experts and conferring with the wise. In the course of its investigations, the Commission typically empanels advisory committees, conducts public hearings and visits government operations in action.

Its conclusions are submitted to the Governor and the Legislature for their consideration. Recommendations often take the form of legislation, which the Commission supports through the legislative process.

## Contacting the Commission

All correspondence should be addressed to the Commission Office:

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

(916) 445-2125 | [LittleHoover@lhc.ca.gov](mailto:LittleHoover@lhc.ca.gov)

This report is available from the Commission's website at [www.lhc.ca.gov](http://www.lhc.ca.gov).

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# Letter from the Chair

## April 13, 2023

The Honorable Gavin Newsom  
Governor of California

The Honorable Toni Atkins  
Speaker pro Tempore of the Senate  
and members of the Senate

The Honorable Anthony Rendon  
Speaker of the Assembly  
and members of the Assembly

The Honorable Brian Jones  
Senate Minority Leader

The Honorable James Gallagher  
Assembly Minority Leader

### **DEAR GOVERNOR AND MEMBERS OF THE LEGISLATURE:**

No role of state government is more important than serving the most vulnerable Californians. With that conviction in mind, last year the Little Hoover Commission launched a study of the state's system of care for those with intellectual and developmental disabilities. The attached report outlines our conclusions and recommendations for change.

Our hearings were compelling. Hundreds of Californians participated, either by attending our meetings, speaking to our Commission, or submitting written comments. Some were themselves consumers within the system. Others were family members of consumers. Still others were advocates. They told us their personal stories. They shared with us their frustrations, anxieties, and hopes. We heard their anger, and sometimes their tears. We are grateful for their bravery in sharing their stories publicly. Their personal narratives shaped our thinking about the system, and the reforms that are needed.

We found major problems. Consumers face a bewildering bureaucratic maze. Inconsistent processes confuse and frustrate those seeking help either for themselves or their loved ones, sometimes so deeply that they give up without getting the care they need. The services available to those seeking care vary throughout the state, so that where you live often determines what you receive. Perhaps most troubling of all, care varies by race and ethnicity, a finding that has been confirmed by decades of research, and which we found anew. This should be unacceptable to all our state's leaders in 2023.

Substantial changes are needed. We must improve accountability, beginning with enhanced authority for the Department of Developmental Services to oversee and supervise the network of 21 regional centers and standardize operations to make the system work better for those it is designed to serve. Regional center boards need enhanced protections and training to ensure members are well equipped to make decisions on behalf of their communities, without fear of personal consequences or repercussions. This system must be bolstered by modern technology that facilitates both oversight and individualized client care.

The recommendations in this report will help achieve these goals, remedying the inequities and correcting the disparities that have persisted for too long. The Commission respectfully submits this work and stands prepared to help you take on this challenge.

Sincerely,

Pedro Nava, Chair  
Little Hoover Commission

# ■ Executive Summary

California's system for providing services to individuals with intellectual and developmental disabilities needs reform.

The system is coordinated by a network of 21 nonprofit agencies called regional centers, with oversight from the California Department of Developmental Services. The regional center structure was created in 1969 to help individuals and families access available health, public health, and education systems and provide guidance on how to navigate these systems to meet their unique needs.

Decades of research has identified persistent and ongoing disparities in the availability and quality of services among racial and ethnic groups and among geographic localities. The Commission found inconsistencies in data reporting, technologies, vendorization processes, support for regional center governing boards, and availability of client support.

This report includes seven recommendations to reduce geographic and ethnic disparities so that all who are entitled to services receive similar access.

## **RECOMMENDATION 1: INCREASE CONSISTENCY IN CLIENT EXPERIENCES ACROSS REGIONAL CENTERS**

Each of the state's 21 regional centers currently has discretion to establish its own processes to assess individuals for services, to determine the array of services offered, and to craft policies for providing information to those seeking help. This means the level of care can vary significantly for different individuals – even if they have similar needs.

### **Strategies for Change:**

- a. The Department of Developmental Services should create a consistent intake process to be used by all regional centers.
- b. The Department and regional centers should use technology to make it easier for people to find out what services are available.

- c. The Legislature should require the Department to identify a standard set of core services that should be delivered by every regional center by 2025.

## **RECOMMENDATION 2: TARGET AND REDUCE RACIAL AND ETHNIC DISPARITIES**

Numerous research studies, as well as anecdotal evidence gathered through our investigation, show that there are pervasive disparities in the quality and availability of services among different racial and ethnic groups. The Department of Developmental Services could better use data to identify disparities in spending and service access.

### **Strategies for Change:**

- a. Lawmakers should require the Department to create standard categories to measure the racial and ethnic characteristics of clients receiving services.
- b. The Department should conduct robust analyses using existing data to better understand disparities.
- c. The Department should require regional centers to consistently report on additional metrics by various demographic characteristics.

## **RECOMMENDATION 3: STRENGTHEN STATE OVERSIGHT OF THE DEVELOPMENTAL DISABILITIES SYSTEM**

The system's emphasis on local control makes it difficult for the state to provide oversight and address regional disparities. The Department of Developmental Services has an obligation to understand what is and is not working across the 21 regional centers and to step in and address systemwide problems when necessary.

### **Strategies for Change:**

- a. Lawmakers should amend statute to grant the Director of the Department the authority to issue general directives over the system of regional centers.

- b. The Department should issue detailed guidance to assist regional centers and others to understand the regulations regarding service codes and how they may be used.
- c. Lawmakers should conduct an evaluation of the regional center system to identify policy and procedural differences among the 21 regional centers, assess effectiveness in achieving client outcomes, and identify opportunities for additional standardization.

**RECOMMENDATION 4: MODERNIZE TECHNOLOGY**

The current data systems used by the Department of Developmental Services were developed in the 1980s and lack the functionality to provide real-time financial and client data, making it difficult for the department to provide effective oversight of the regional center system. Further, regional centers use six different case management systems, none of which interfaces with the others.

**Strategies for Change:**

- a. Lawmakers should amend statutory language to require all regional centers to also use a single system to track service delivery.
- b. The Department should articulate a project scope, plan, budget, and timeframe for the development of unified accounting and case management systems, as well as describe their intended functionality and how the new systems will solve existing technology problems.

**RECOMMENDATION 5: STANDARDIZE THE VENDORIZATION PROCESS**

The licensing process service providers must undergo to become vendors is inconsistent across regional centers. Challenges for service providers to enter the system can impact the availability of services.

**Strategies for Change:**

- a. Lawmakers should require the Department to standardize the vendorization process to make it easier for service providers to participate in the system.

**RECOMMENDATION 6: STRENGTHEN AND ENHANCE SUPPORT FOR REGIONAL CENTER GOVERNING BOARDS**

Regional governing boards make critical decisions about services provided in their communities. More should be done to ensure board decisions are independent and board members are fully equipped to participate in board decisions.

**Strategies for Change:**

- a. Lawmakers should add Gubernatorial board appointees, restrict regional center executive staff from involvement in board selection, and enhance board protections from retaliatory action.
- b. Lawmakers should require the Department to increase facilitation services to improve consumer participation on boards and enhance board training opportunities.

**RECOMMENDATION 7: IMPROVE SERVICE COORDINATION**

State law includes a requirement for individuals and families to access all “generic” resources before receiving services through the regional center. While some families have access to help to navigate these programs, many do not. Limited resources are available to provide additional needed support.

- a. The Department should convene a taskforce with relevant state and county agencies to streamline the process of accessing generic services.
- b. The Department should develop, and the Legislature should fund, a competitive grant program to enhance navigation services for regional center clients.

# ■ Introduction

More than a half century ago, limited and fragmented government services to support individuals with developmental disabilities meant that many families in need of help were too often advised to place their child in an institution, frequently away from their home and community.<sup>1</sup> At the time, legislative leaders identified important shortcomings that constrained the ability of individuals with developmental disabilities and their families to seek care closer to home, including a lack of a single agency with responsibility to assure services, a lack of funds to purchase services, and a lack of availability of essential services in many parts of the state.<sup>2</sup>

Lawmakers envisioned an alternative that avoided institutional placement by piecing together scattered resources, eliminating duplicated services, and providing services where none had previously existed.<sup>3</sup> This vision was realized through the Lanterman Developmental Disabilities Services Act (Lanterman Act), which established the framework for a statewide system of community-based services and supports, coordinated by a network of regional non-profit agencies called regional centers, with oversight from the state. The goal: to emphasize individual intellectual, economic, social, and physical health, not just protect and maintain custody of individuals with disabilities.<sup>4</sup>

Intentionally, to serve individuals with developmental disabilities and their families in the most direct, efficient, and effective manner possible, lawmakers tasked regional centers –not state agencies – with offering diagnostic counseling services and linking individuals with services available in their communities, among other duties.<sup>5</sup> Regional centers were specifically designed to help individuals and families access available services from other health, public health, and education systems and help fill the gaps between those services to in order to best meet each individual's unique needs.

The Lanterman Act also created a statutory entitlement to services and supports for Californians with a qualifying disability, regardless of other factors such as income.<sup>6</sup> This entitlement was intended to help “meet the needs of each [person with developmental disabilities], regardless of age or degree of handicap, and at each state of his life’s development.”<sup>7</sup> Today, this feature continues to provide a stark contrast to systems in many other states where individuals with intellectual and developmental disabilities face wait lists or caps to the type of services they may receive.

By the end of the 1970s, the state’s developmental disabilities system had grown to include a network of 21 regional centers, one placed for every one million California residents.<sup>8</sup> In population-dense Los Angeles County, seven regional centers were placed to mirror county health districts.<sup>9</sup> In most other parts of the state, a regional center’s geographic boundaries covered two or more counties.<sup>10</sup> Despite California’s significant population growth, the number of regional centers in this system has not changed.<sup>11</sup>

Today, nearly 400,000 Californians with intellectual and developmental disabilities receive various services and supports through the regional centers to help them live as independently as possible.<sup>12</sup> These include children and adults who have been diagnosed with or are at risk of developing various conditions, such as autism, cerebral palsy, epilepsy, or other serious disabilities that originated before they reached 18 years of age. To many individuals and families, the state’s developmental disabilities services system offers a critical lifeline.

But, this system is not without flaws.

Over the past decade, the state has closed all but two of its developmental centers and the system largely has shifted away from institutional care in congregate settings.<sup>13</sup> Yet, across the state many

individuals still receive services in group settings, even as demand for more independent living and individualized programming has increased.

Despite statutory entitlements and legislative intent to make it easier for individuals and families to get the help they need, some say the system set up by the Lanterman Act has morphed into an overly complex, sometimes labyrinthine bureaucracy. Without a core standard of services available to everyone, issues of fairness and equity abound, particularly when variations in experiences at regional centers differ so much that service offerings can and do vary, even across the street.

And perhaps most significantly, decades of research demonstrate that this system has not equally kept its promise to all eligible Californians and has identified persistent and ongoing disparities in the availability and quality of services among racial and ethnic groups and among geographic localities across the state.<sup>14</sup> These inequities persist despite changes in reporting requirements, policies, and spending to try to make it easier for families to access services.

**...decades of research demonstrate that this system has not equally kept its promise to all eligible Californians and has identified persistent and ongoing disparities in the availability and quality of services among racial and ethnic groups and among geographic localities across the state.**

The Commission launched its review to better understand the experiences and challenges facing

individuals with intellectual and developmental disabilities and their families as they navigate this system to obtain help. Input from hundreds of individuals, family members, caregivers, and others interested in the success of the system underscored its importance. But they also echoed its shortcomings: most notably, that for various reasons, the system is not working equally for everyone who needs it.

The seven recommendations within this report are intended to target – and reduce – geographic, racial and ethnic disparities so that all who are entitled to services have a similar opportunity to realize that assistance. Addressing these long-standing systemic barriers will require more consistent policies and procedures across the network of regional centers, increased leadership and guidance from the state, and the establishment of a core set of services offered statewide. Though other important issues arose during the course of our review and are worthy of consideration, they fell outside the scope of this report.

## **Recommendation 1: Increase Consistency in Client Experiences Across Regional Centers**

People with intellectual and developmental disabilities receive different levels of care depending on where they live.<sup>15</sup> Simply put, the services offered in one regional center may be more or less robust than those offered by another. This is wrong.

These differences can frustrate, confuse, and anger parents as they try to piece together appropriate support for their children. Some parents told the Commission they couldn't understand why their child received less services than others who appeared to have similar needs. Some even moved around the system to try to find the best care. For example, one parent described applying for services for her

daughters at three regional centers over a span of 20 years, encountering barriers and denials for services at two before finally relocating to the third where her daughters now receive the services they need.

In a state as large as California, some variation may be unavoidable. Some areas have more service providers or more transportation than others, for example. The developmental disabilities system has long emphasized local control as a core value to allow each regional center flexibility in determining how services are rendered in order to best meet the needs and preferences of its local community. As independent, non-profit entities, each of the state's 21 regional centers has discretion to establish its own processes to assess individuals for services, to determine the array of service it will offer and under what conditions, and to craft policies for how it will share information to individuals and families seeking help. In theory, local control can have benefits. In practice, however, this discretion has resulted in a system where geography matters too much for families trying to seek services. For California's most vulnerable residents, the services they receive often depends on where they live.

Differences begin at the system's front door. The process to apply for services and the time required to do so vary across regional centers, as does the amount and type of information individuals and families must provide to prove their eligibility. These different intake processes not only make it more challenging for families in some regional centers to gain entry to the system, but they also can create barriers for families who wish to move between regional centers.<sup>16</sup>

Swift access to services is critical for these families, as early interventions can reduce the amount of help individuals may need later in life. The Department of Developmental Services has developed a standardized information packet for regional centers to distribute to families with infants and

toddlers considering the Early Start Program. It also is collaborating with the Association of Regional Center Agencies, an organization which represents all 21 regional centers before the Legislature, to standardize the intake process for these families.<sup>17</sup> We applaud these efforts to standardize entry procedures. But they should not be limited to those families with young children. They should be expanded to ensure that all who enter the system have similar experiences.

The variation continues after people are admitted to the system. Currently, there are no consistent or transparent standards to guide how a regional center will decide what services it will authorize and the conditions under which it will make those determinations. Though all regional centers authorize services on a case-by-case basis through the individual planning process, each has developed its own policies and approaches for determining the type and amount of services they will authorize for each individual.<sup>18</sup>

Without consistent standards, some families say that going to a regional center is like walking into a restaurant with a secret menu, or no menu at all. Only some people know what offerings are available, while others have to guess and dig for information that should be accessible to all. This means that once in the system, an individual is not guaranteed to receive a similar array of services across regional centers, and may receive a dissimilar array of services compared to another regional center client, even if their needs and circumstances are similar.

Individuals and families need to know what services are offered on a regional center's "menu" and which providers offer those services. With the help of technology, this information should be accessible, up-to-date, and available in a consistent manner online across the system. There also should be a baseline of core services available at all regional centers, so that individuals across the state – in

urban and rural areas, in affluent communities and poorer communities – have similar access to basic services. Regional centers should maintain discretion to determine which ancillary services would best meet the needs of their communities.

Per-client annual spending also varies widely, another form of inequity. To some degree, variations in spending clearly reflect economies of scale: larger regional centers tend to spend less per client. Such differences can also reflect varying regional costs in a state as large as California. But in other cases, variations in spending are harder to explain, let alone justify. For example, South Central Regional Center spends nearly \$5,000 more than Harbor Regional Center per client per year, even though both are in Los Angeles County and South Central has almost 3,000 more clients. The difference is quite substantial: South Central's annual per-client spending exceeds Harbor's by more than 30 percent. These spending differences are significant enough to warrant additional research to examine how they translate into different levels of service for individuals across the state.<sup>19</sup>

### **STRATEGIES FOR CHANGE:**

- a. The Department of Developmental Services should lead regional centers in creating a consistent intake process throughout the state. Building on efforts to standardize the intake process for those enrolled in the Early Start Program, the department should standardize the intake processes for others who seek entry at a later age. This effort should include standardizing the intake forms and program planning forms used across all regional centers to ensure that families who must move from one location to another are not faced with new barriers to entry.
- b. The Department of Developmental Services and all regional centers should use technology to make it easier for people to find out what services are available. The department should:

- i. Standardize requirements for regional center websites to post information about services offered.

- ii. Develop and disseminate geomapping tools for regional centers to use to visually display information about service providers by zip codes on their websites.

- c. The Legislature should require the Department of Developmental Services to identify a standard set of core services that should be delivered by every regional center by 2025. The department should be required to reassess these core services every five years to determine what should be added or subtracted from the core.

## **Recommendation 2: Target and Reduce Racial and Ethnic Disparities**

The care a client receives may depend on who they are, the language they speak, and the color of their skin. Race and ethnicity matter even when controlling for variations in a client's living arrangements and service needs, according to findings from two reports published in 2022.<sup>20</sup>

Tragically, this inequity has been present in the system for decades. Researchers at the University of California, San Francisco examined regional center expenditures in 2005 and again in 2013, controlling for individual service needs and other factors, and found persistent disparities in access to services and expenditures based on age, gender, race/ethnicity and geography. Authors concluded that people of color were less likely to receive any services than were white populations. Among those individuals who received services, expenditures for people of color were significantly lower than those for whites, even when controlling for need and other factors. Authors noted that these racial and ethnic disparities were consistent with findings from other studies

dating as far back as the early 1990s.<sup>21</sup>

In recent years California has invested \$66 million to reduce disparities within the developmental disabilities system,<sup>22</sup> yet the Commission heard from many parents and advocates that no significant improvements have been made. One African American parent and advocate recalled a 2011 Los Angeles Times exposé on disparities by race and class in the regional center system that raised awareness of the problems<sup>23</sup> and noted that a decade later this system still does not work for Black people, Latinx people, or minoritized populations even though there are some good programs and some exceptions.

**The demographic data regional centers collect is not standardized, making it difficult to understand how the population being served by one regional center compares to another or to the state as a whole.**

For parents, these disparities not only mean differences in the type and number of services their children receive, but also in the amount of time and effort their families must put in to get help. One Latino parent explained, “I found a group of parents, one was White, one was Asian, and we had conversations when our white friend was receiving an abundance of services, everything I was looking for and buying.” She continued, “we compared and communicated, and we realized that ...our White friend got the most. I got more and I fought for it, and our Asian friend got nothing. It shouldn’t be this way. The system is broken.” Another Latino parent told Commissioners, “I asked for the same thing that

I see other groups with similar abilities get, but I get denied. How is it that White and Caucasian families are able to receive support that others are not allowed to get?”

To date, no one has satisfactorily explained the causes of these inequities. Some suggest the unfettered discretion granted to regional centers can create an avenue for biases – unintentional or otherwise – to seep into decision-making and result in disparities in the amount and types of services individuals receive.<sup>24</sup> Regardless of why they occur, these inequities must be addressed. Part of the problem is rooted in a lack of data. California must take immediate action to ensure that accurate data is available, and that existing data is being analyzed to understand racial and ethnic disparities.

The Department of Developmental Services is not maximizing use of existing data to systematically identify disparities in spending and service access. Researchers told Commissioners that a large part of the problem is that the department maintains separate data files for funding, client characteristics, and expenditure/utilization rates and produces distinct reports from each of these files. In order to track and monitor disparities, the department would have to combine and regularly analyze data from these files, controlling for clients’ characteristics, living arrangements, and service needs. Outside researchers have been able to produce this type of analysis, but at times have had to obtain data through a lawsuit or court order in order to do so.<sup>25</sup>

The demographic data regional centers collect is not standardized, making it difficult to understand how the population being served by one regional center compares to another or to the state as a whole. In particular, advocates said that the “Other” racial/ethnic category, a catchall definition used by regional centers in different ways, is especially problematic.<sup>26</sup> Without having a clear, accurate, and consistent way to measure who is (or is not) receiving services,

policymakers, advocates, parents, and others cannot fully understand the extent of disparities.

The current system lacks capacity to track important indicators that would provide insight into where and how disparities in service access occur. For example, regional centers are not required to report the characteristics of individuals who contact them to inquire about services or those who are denied regional center services. There is no way to easily compare across the system which services are actually being used. And, there is no field to track the status of an individuals' pursuit of generic services or to track whether people actually receive the services they need.<sup>27</sup>

### **STRATEGIES FOR CHANGE:**

- a. Lawmakers should require the Department of Developmental Services to create standard categories to track the racial and ethnic characteristics of individuals who receive services from regional centers and require all regional centers to use these categories in their reporting. The department should periodically assess these categories to ensure they accurately reflect California's diverse population.
- b. The Department of Developmental Services should immediately begin to track and monitor disparities using existing data. The department should regularly conduct robust analyses that combine existing data on client characteristics, service needs, and utilization and share findings online.
- c. The Department of Developmental Services should require regional centers to regularly, and consistently, report on additional metrics by varying demographic characteristics, including: individuals who contact a regional center for intake; individuals who are denied regional center services; the use of authorized services; and the status of generic services. This and other relevant data should be made available in machine-readable formats.

## **Recommendation 3: Strengthen State Oversight of the Developmental Disabilities System**

The system's emphasis on local control makes it difficult for the state to provide oversight and address regional disparities.<sup>28</sup> The Legislature should strengthen the ability of the Department of Developmental Services to provide oversight of the regional centers. Furthermore, the Legislature should initiate an evaluation of the entire system. Although our Commission recognizes the advantages of some measure of local control, we also believe it is past time for an analysis of whether the current structure – adopted nearly half a century ago – is best suited to today's challenges.

**State Oversight Authority.** As a steward of the public's money, the Department of Developmental Services has an obligation to understand what is and is not working across the 21 regional centers and to step in and address systemwide problems when necessary. However, the department currently believes it lacks authority to provide this type of broad oversight.

The department is responsible for developing uniform services of accounting, budgeting, and reporting; setting rates and establishing program standards for the services purchased by the regional centers<sup>29</sup>; and funding the regional centers. It has authority to hold regional centers accountable to state law and does so by various means, including conducting audits, reviewing regional center performance contracts, investigating whistleblower complaints, reviewing client appeals, and tracking data. If the department finds that a regional center is not fulfilling its obligations, the department may provide technical assistance, issue a letter of noncompliance, amend a regional center's contract provisions, establish a corrective action plan, or

place a regional center on probation or terminate its contract.<sup>30</sup>

State law currently grants the department director authority to issue directives to the regional centers to protect client rights, health, safety, or welfare, or when necessary to ensure compliance with state and federal laws. This authority is limited to directives that do not conflict with existing statutes or regulations.<sup>31</sup> State law also permits the department director to issue directives for various specific purposes, usually related to implementing a new program such as providing guidance on compliance with the self-determination program or defining the way quality incentive payments will be made to service providers.<sup>32</sup> In either case, it appears this authority is not sufficient to drive systemic change or ensure a level of consistency in experiences for individuals and their families when seeking services. The director of the Department of Developmental Services should have similar oversight authority as the directors of sister agencies, such as the Department of Social Services or the Department of Health Care Services.

**As a steward of the public's money, the Department of Developmental Services has an obligation to understand what is and is not working across the 21 regional centers and to step in and address systemwide problems when necessary. However, the department currently believes it lacks authority to provide this type of broad oversight.**

**Standardizing Service Definitions.** The department has authority to set rates and establish program standards for the services purchased by the regional centers.<sup>33</sup> Through regulations, the department has defined approximately 110 different types of services and assigned each a specific "service code" for regional centers to use when approving vendors to provide various services to individuals with developmental disabilities.<sup>34</sup> The department also has created approximately 50 miscellaneous service codes for regional centers to use to classify vendors that offer something other than what is specifically defined in statute.<sup>35</sup> Together this amounts to approximately 160 codes regional centers can use to categorize the types of services offered. These codes do not include the thousands of subcodes regional centers use for billing and tracking services.<sup>36</sup>

This overly complicated system to track services rendered through regional centers results in a number of challenges. The sheer number of service codes makes it difficult for the department to provide meaningful oversight of the system, compare what is happening across regional centers, or evaluate whether individuals actually receive the services they need. Additionally, regional centers inconsistently use and implement these service codes. These variations can contribute to disparities in the system, where individuals are not guaranteed consistent care for the same type of service. For example, one service provider explained that even when a program is well defined in regulations, such as the supported living program, it does not guarantee that the regional centers will implement that program the same way. One regional center may offer 400 hours of programming a month under this code, while another offers just 20 hours. This creates different experiences for individuals who should be receiving relatively similar services.

The department currently is taking steps to consolidate and eliminate duplicative service codes. Representatives estimate this effort will standardize

the majority of services delivered through regional centers and will be completed by June 1, 2024.<sup>37</sup> While this streamlining effort is promising, it is unclear whether it will address the discrepancies in the actual services individuals receive unless the department provides additional guidance to clearly define each service code and explain how the regulations should be interpreted. Previously, the department issued a regulatory companion that discussed and offered plain language commentary on each passage in the regulations.<sup>38</sup> Reviving these efforts could help. The department also may need to offer additional training to regional centers and service providers on how to correctly use the service codes and stepping up efforts to enforce consistent application of the regulations across the regional centers.

**System Evaluation.** In addition to measures that would strengthen state oversight, the Legislature should evaluate whether the current structure of independent regional centers is the best option for meeting the needs of Californians with developmental disabilities and determine whether additional opportunities for standardization could ultimately benefit the individuals this system is set up to serve.

To better understand how variations among regional center policies and procedures impact client outcomes, this evaluation should identify differences in the ways regional centers assess client eligibility, approve services for clients, communicate with clients, ensure clients receive services in their plan or identify and address barriers that prevent them from receiving approved services. Additionally, over the course of its review the Commission heard from numerous families critical of the state's developmental disabilities system, but who praised the individuals within the system who often work tirelessly to help them. Given the critical role regional center staff play in assisting individuals and families, this evaluation also should explore how variations

in staffing structure and caseload impact client outcomes, including a review of caseload ratios and workload requirements for regional center service coordinators, and service coordinator salary. Ultimately, this review should assess each regional center to determine its effectiveness in achieving the state's goals, identify underperforming regional centers for targeted improvement, and identify additional opportunities for standardization within the system.

#### **STRATEGIES FOR CHANGE:**

- a. Lawmakers should amend statute to grant the Director of the Department of Developmental Services authority to issue general directives over the system of regional centers.
- b. The Department of Developmental Services should issue detailed guidance to assist regional centers and others understand the regulations regarding the various service codes and how they may be used.
- c. Lawmakers should conduct an evaluation of the regional center system to identify policy and procedural differences among the 21 regional centers, assess effectiveness in achieving client outcomes, and identify opportunities for additional standardization. Findings from this evaluation should be used to inform future policy decisions.

### **Recommendation 4: Modernize Technology**

The Department of Developmental Services' current data systems are so poor that it is impossible to track individual outcomes for those receiving services and are so old it is difficult to find staff with expertise to use them. This antiquated technology lacks the functionality to provide real-time financial and client data and makes it difficult for the department to provide meaningful oversight of the developmental disabilities services system.

All regional centers use the same accounting and budgeting system – a statutory requirement enacted nearly 40 years ago when the system was created.<sup>39</sup> But this antiquated system is difficult to modify and functionally cannot keep pace with regional center needs, such as safeguarding data or tracking multiple service delivery models. Though the department introduced e-billing services in response to legislative direction,<sup>40</sup> data from each regional center is transmitted monthly, limiting the department’s ability to track real-time expenditures.<sup>41</sup>

Regional centers also are required to use a case management system developed in the late 1980s to submit specific client data to the Department of Developmental Services. However, overtime some regional centers developed additional systems to track client data. Today, regional centers use six different case management systems, none of which interface with the others or have the ability to integrate data. These disparate data systems produce poor quality, inconsistent data.<sup>42</sup> Without current data, it is difficult for the department, researchers, and others to track individual and system outcomes and provide meaningful transparency into what is occurring at each regional center.<sup>43</sup> A new case management system could allow for effective program and outcome-based monitoring, while also creating a new avenue for those receiving services from regional centers to access their own case records, track appointments, or review outcomes data, according to department proposals.<sup>44</sup>

The fact that the State of California relies on such antiquated systems is appalling. State government cannot function efficiently or effectively with technology this old. As a step toward modernization, the 2021 Budget included \$6 million funding for the department to develop plans to modernize the case management systems, according to the department. In fiscal year 2023-24, the department requested an additional \$12.7 million from the General Fund for continued planning of the accounting and

case management systems.<sup>45</sup> According to the department, plans for a new case management system will be completed in 2023, with initial implementation beginning in 2025.<sup>46</sup>

Standardization and modernization of these data systems is imperative for the state to ensure that developmental disabilities services are rendered in an equitable and timely manner and that real-time policy and programmatic decisions can be made based on accurate and reliable data. Yet, the traditional way government approaches large technology improvements has too often led to implementation delays and failure to employ cutting-edge technology. These modernization projects must be different. To ensure the planning process is not elongated, the department must be transparent about its process and develop and share a schedule and actionable strategy to realize its ambitious vision.

#### **STRATEGIES FOR CHANGE:**

- a. Lawmakers should amend statutory language to require all regional centers to also use a single system to track service delivery to people with intellectual and developmental disabilities.
- b. To ensure meaningful and timely progress, the Department of Developmental Services should articulate a project scope, plan, budget, and timeframe for the development of these systems, as well as describe their intended functionality and how the new systems will solve existing technology problems. The department should be required to regularly present status reports to the Legislature.

### **Recommendation 5: Standardize the Vendorization Process**

Basic functions of the state’s 21 regional centers, including the process to license vendors to provide services to those with developmental disabilities, are

not consistent across the system. This means that 21 regional centers can and often have 21 different policies driving their processes for service providers to gain entry, resulting in confusion and delays for vendors and clients alike.

This presents a barrier for small businesses or individuals who wish to offer services but may lack the time or staff resources to complete the process with multiple regional centers. We also heard that these processes could deter existing vendors from expanding services to other, even neighboring, regional centers. For example, one large service provider testified that his organization serves six regional center catchment areas and has to constantly juggle between the regional centers' different approaches to vendorization and other practices. He said more consistency would be extremely helpful, as would the ability to offer the same service across multiple regional centers or even statewide. Others commented that because this system was set up in a time before the internet made remote services available, services remain largely, and in some cases unnecessarily, dependent on geography.<sup>47</sup>

Taken together, these challenges for service providers to enter the system ultimately can impact the availability of services to individuals with developmental disabilities. Numerous individuals and family members spoke passionately about the inequities introduced by a system that offers different services from one regional center to the next, particularly when the disparities occur among neighboring regional centers.

To make it easier for service providers to enter the system and ensure a broader availability of services throughout the state, the vendorization process must be standardized. Today, every individual or organization who wishes to provide and be reimbursed for services through the developmental disabilities system must first go through a "vendorization" process. This process may involve

obtaining licenses or approvals from government agencies and submitting an application and various support materials to a regional center. Service providers must become approved vendors for each type of service they intend to offer regional center clients.<sup>48</sup>

While the state regulates the requirements to become a vendor, each regional center is responsible for verifying that each provider's application meets licensing and other legal requirements and reviewing their application materials to determine which services they may provide. The experiences and types of information required varies between regional centers.

Director Bargmann and a representative from Association of Regional Center Agencies both agreed that change must occur and said they are working together to establish a streamlined vendorization process. They also are considering opportunities to improve courtesy vendorization to allow service providers to operate in multiple regional centers and ways to make it easier for vendors to provide remote services.<sup>49</sup> Lawmakers must ensure these reforms go far enough and are introduced in a timely manner.

Not all individuals and families understand the complications of the vendorization process, nor should they. But many understand that access to service providers can vary across the system. The vendorization process is inefficient and unnecessarily limits the range of providers available to those seeking services. It must be standardized so that individuals and families have access to a vast network of service providers to meet their needs.

### **STRATEGIES FOR CHANGE:**

- a. Lawmakers should require the Department of Developmental Services to standardize the vendorization process to make it easier for service providers to participate in the system, regardless of where they are located. The department should address:

- i. The forms and information regional centers require service providers to submit.
- ii. Establishing a statewide vendorization for providers to apply once to provide services anywhere within the system.
- iii. Creating an approved list of vendors, and making this information publicly accessible, so individuals and families can easily access information about service providers.

## **Recommendation 6: Strengthen and Enhance Support for Regional Center Governing Boards**

Regional centers were created to be independent entities so that people with developmental disabilities and their families could more easily connect and communicate with those making decisions about the services they need and receive.<sup>50</sup> Members of the governing boards – who as volunteers are not compensated for their service – are saddled with tremendous responsibility. Board members review and approve multi-million-dollar expenditures of public money to deliver critical services to people with intellectual and developmental disabilities. They are supposed to connect with and reflect the local community, and ultimately ensure that regional centers meet local needs. Yet family members and advocates told the Commission that in practice, governing board decision-making processes and spending decisions are opaque and may be unduly influenced by regional center staff.

The scope of the Commission’s review did not allow for an audit of regional center board policies and practices. Such an evaluation would be critical to identify opportunities to strengthen board functionality, but also allow policymakers to consider whether this unique governance structure remains the best means to deliver developmental disability

services in California – a question some raised to the Commission. Nevertheless, the concerns raised are sufficient to warrant immediate action to strengthen board oversight by addressing issues related to board selection, composition, protections, and training.

**... governing board decision-making processes and spending decisions are opaque and may be unduly influenced by regional center staff.**

**Board selection.** State law includes conflict of interest policies that direct regional center board members and employees to act “in the best interest of regional center consumers and their families... and be free from conflicts of interest that could adversely influence their judgement, objectivity, or loyalty to the regional center, its consumers, or its mission.”<sup>51</sup> Yet some family members and advocates shared concerns about the lack of clear and definitive prohibitions against executive staff involvement in board recruitment, which is seen by some as a conflict of interest. Such involvement has the potential to cloud a board member’s ability to provide objective, independent oversight, particularly when considering issues where the priorities or preferences of regional center staff and the local community diverge.

The Commission informally surveyed a number of executive directors to learn more about how board members are selected for their regional center. Though practices seem to vary by regional center, many shared that regional center staff were involved in aspects of recruitment, such as advertising or promoting board opportunities or recommending potential board members. Some described an independent nominating committee process for

vetting, interviewing, and ultimately selecting potential board applicants. The Commission could not determine the extent of executive involvement in board selection. Yet additional guidance and consistency regarding the board selection process could help to mitigate potential risks and ensure boards remain accountable to the communities they represent.

**Board composition.** State law includes a number of requirements regarding the composition of regional center governing boards. Specifically, at least 25 percent of members must include people with developmental disabilities, at least half of the members must be either individuals with developmental disabilities or their parents or legal guardians, and the board must include members with various professional experiences and reflect the geographic and ethnic characteristics of the area served.<sup>52</sup> Despite these requirements, board composition varies among regional centers. For example, some regional centers, such as Valley Mountain Regional Center, enhance board membership by including a member selected by the provider community. Amending the composition of regional center governing boards to include additional outside perspectives would be one way to improve board independence. If done with input from the Department of Developmental Services, additional appointees could strengthen oversight and transparency of regional center operations and better position the department to track outcomes and enforce accountability.

**Board protections.** Every regional center has whistleblower protections in place that offer protection if a conflict arises between individual board members and regional center leadership.<sup>53</sup> However, advocates told the Commission these general policies do not offer sufficient protections for board members who might wish to oppose a staff decision or opinion. As a result, they said some board members who fear retaliation in the

form of an unwanted change in their or their family member's services from the regional center may be overly deferential to regional center staff. "Boards of directors say to us, we're afraid to hold the executive director accountable because we're afraid we're going to lose our services or our family member's services," one advocate shared.<sup>54</sup> Board members already bear great responsibilities by serving as leaders of these important organizations and should not also fear a personal loss in services when taking on these responsibilities.

**Board training.** Regional center governing board members, particularly those who also receive regional center services, do not consistently have adequate supports necessary to fully participate in board decisions, according to a number of advocates. Board members may receive training from a number of sources, including regional center staff or hired consultants, the Department of Developmental Services, the State Council on Developmental Disabilities, and outside organizations such as community advocacy groups. Despite these resources, observers said board members tend to rely on regional center staff for their expertise.

To better equip board members to fulfill their oversight responsibilities, some said there should be additional training on the roles and responsibilities of the governing board members and ongoing training to help ensure board members fully understand the items before them and the potential consequences of their decisions. Some of those who receive services from regional centers may also need one-on-one assistance to review materials and prepare for board meetings, and again to facilitate their participation in a board discussion. This type of assistance would need to come from a neutral party who understood their role was to facilitate the board member's participation and not to advise their thinking. To maintain board independence, this training should not come from regional center staff.

## STRATEGIES FOR CHANGE:

- a. To help ensure regional center board decisions are independent, lawmakers should:
  - i. Amend statute to require that two board seats are filled by individuals appointed by the Governor, with input from the Department of Developmental Services.
  - ii. Amend statute to add clarifying language that restricts regional center executive staff from any involvement in selecting board members.
  - iii. Enhance statutory language to protect board members from any retaliatory action stemming from their board service.
- b. To better support board members and ensure that all are equipped to fully participate in board decisions, lawmakers should require the Department of Developmental Services to:
  - i. Increase facilitation services to improve consumer participation on boards.
  - ii. Enhance training curriculum and opportunities for board members so board members are less reliant on support from regional center staff.

## Recommendation 7: Improve Service Coordination

State law includes a requirement for individuals and families to access all “generic” resources before receiving services through the regional center.<sup>55</sup> Generic services refer to programs and resources available to the general public, such as education services, In-Home Supportive Services, Medi-Cal, as well as private insurance. Regional centers are required to notify families of these generic resources – and receive training for their staff about the availability and requirements of generic services.<sup>56</sup>

However, they are not required to assist individuals and families in efforts to access these services. In practice, this leaves individuals and families to navigate a maze of various agencies, often without assistance, in order to either secure the services they need or a denial so they can then apply to the regional center for help. Some refer to this as the “all wrong doors” approach to service delivery.

While some individuals and families are comfortable navigating this system of generic services or have time and resources upon which they can draw to help advocate for better or more services, not all families are equally resourced or comfortable advocating for themselves. The current approach can become overly burdensome for families who lack or have limited access to transportation, who are not able to take leave from work, or who are not fluent in English and must rely on the help of translators to communicate their needs. Communities of color may also encounter structural racism as they navigate through the maze of generic agencies. As a result, individuals may experience delays in receiving the help they need or worse, become so overwhelmed and frustrated to the point of giving up, their needs go unmet.<sup>57</sup>

Families described this as facing “the culture of no” where they have to fail before getting the help they need. For example, one parent told the Commission, “When I went to the regional center I was told, no, no, no, no, no...so I sought out every generic service I could find. It took all my time and energy. It was a full-time job.” Another parent explained, “When we request services from the regional center we have to go to the services outside first. The regional center is the payor of last resort. I have been sent to access generic services [for three months] and have yet to be successful for one reason or another. The regional center is not able to provide the supports that my son needs until I can actually show that I tried to access the service and I was denied or it didn’t work for us. It’s a bummer that families or clients have

to fail before we can access any services from the regional center.”

This was not always the way. For many years, the State Council on Developmental Disabilities, an independent agency funded by Congress to advocate for people with intellectual and developmental disabilities, served as a resource to families overwhelmed by the system.<sup>58</sup> By acting as non-attorney advocates, the council provided direct, one-on-one support to individuals in their process of collecting “no’s” from the system of generic services, and during individualized program plan (IPP) planning meetings at regional centers or individualized educational plan (IEP) planning meetings at schools. Council staff also joined individuals and families in assessment meetings and often represented clients in the fair hearing process or in state level appeals. This assistance often helped resolve issues without the need for potentially adversarial intervention by attorneys – a step that some families consider intimidating. It also helped individuals with developmental disabilities learn how to advocate for themselves within the system more confidently and independently.<sup>59</sup>

In 2014 the federal government directed the State Council to stop using federal dollars for individual advocacy and instead to reorient its efforts around systemic change. Though funding for this work stopped, the need remained. In 2021, as many as 37,000 individuals sought one-on-one help from the council.<sup>60</sup>

Today the state contracts with Disability Rights California (DRC) for clients’ rights advocacy services, which it has done since 1999.<sup>61</sup> The DRC’s Office of Clients Rights Advocacy (OCRA) employs about 65 attorneys, lay advocates, and support staff to help people with intellectual and developmental disabilities advocate for services and pursue legal remedies when less formal approaches are not possible. OCRA staff can attend IPP and IEP meetings

with clients and advocate with other generic services organizations, such as social security, In-Home Supportive Services, and medical offices.<sup>62</sup> During fiscal year 2021-2022, OCRA resolved 8,386 issues for 5,474 clients, the majority of which were handled outside of a hearing process or court.<sup>63</sup> OCRA is limited in the number of cases it can take on by funding and resources. Community advocacy organizations also can help individuals and families advocate for themselves, though they do not have authority to walk a client “through the door.” This limitation prevents some individuals and family members from having trusted support available to accompany them in potentially confusing or contentious meetings.

**Though regional centers are supposed to provide service coordination, families and advocates suggest that the current model wrongly puts the onus on individuals in need of assistance to navigate these various, complex systems.**

It should not be so difficult for families to access support. Though regional centers are supposed to provide service coordination, families and advocates suggest that the current model wrongly puts the onus on individuals in need of assistance to navigate these various, complex systems. The process to navigate through this system of generic resources should not be so cumbersome and opaque. Instead, by coordinating relevant state service agencies, the state should provide a model of service integration and interagency cooperation between regional centers and their relevant county counterparts.

Additionally, individuals and families should have access to reliable, individualized assistance when they need it from someone who is knowledgeable about how the system works, the range of services available to them, and how they can access those supports. This support should be available across the state, aim to resolve issues before the need for litigation arises, and serve as a complement to existing clients' rights advocacy services. Specifically, the state should develop a competitive grant program to fund public and non-profit organizations capable of providing effective lay support to individuals and family members navigating the developmental disabilities system. These grants should be issued in three-year cycles and evaluated to ensure families issues are resolved.

Grants should be evaluated by the department to ensure effectiveness, with findings reported regularly to the Legislature. This work should be complementary to the clients' rights advocacy services already enumerated in statute.

#### **STRATEGIES FOR CHANGE:**

- a. The Department of Developmental Services should convene a taskforce with the Department of Social Services, the Department of Health Care Services, and other relevant state and county agencies to streamline the process of applying to and accessing generic services. The taskforce should designate representatives to foster interagency communication, develop memorandums of understanding to facilitate information sharing between agencies and regional centers, and develop formal interagency dispute resolution processes for clients seeking services from multiple service systems.
- b. The Department of Developmental Services should develop, and the Legislature should fund, a competitive grant program to provide enhanced navigation services for regional center clients. Service navigation grants should be issued competitively in three-year cycles to public or non-profit organizations capable of providing effective, individualized, lay advocacy services directly to individuals with developmental disabilities and their families navigating the developmental disabilities services system.

# Notes

1. Frank D. Lanterman Regional Center. “Strengthening the Commitment...Reinvesting in the System: A Journey of Community Partnership.” History of the Regional Centers in California. Page 2. [https://lanterman.org/uploads/info\\_resources\\_general/Lanterman-50thHistory-r6\(Blue\)\(web\)\\_final.pdf](https://lanterman.org/uploads/info_resources_general/Lanterman-50thHistory-r6(Blue)(web)_final.pdf).
2. Note: In 1968 the Legislature directed a study of available resources for the care of disabled individuals and found: “1) Lack of a single agency with responsibility and funds to assure services to those in need; 2) Lack of funds to purchase services; 3) Lack of essential services in many parts of the state; 4) Excessive reliance on the state hospital system; 5) Lack of coordination and planning on regional and state levels; 6) Inequities in fees imposed on parents of [developmentally disabled individuals]; 7) Failure to fully utilize federal funds available for services for the [disabled].” Source: State of California, Human Relations Agency. Lanterman Mental Retardation Services Act, information booklet. Page 5.
3. State of California, Human Relations Agency. Lanterman Mental Retardation Services Act, information booklet. Page 5.
4. State of California, Human Relations Agency. Lanterman Mental Retardation Services Act, information booklet. Page 3.
5. Lanterman Mental Retardation Services Act. Division 25. Services for the Mentally Retarded, Chapter 3. Regional Centers for the Mentally Retarded. § 38100. Cited in State of California, Human Relations Agency. Lanterman Mental Retardation Services Act, information booklet. Page 18.
6. Welfare and Institutions Code, Division 4.5, § 4500.
7. Frank D. Lanterman Regional Center. “Strengthening the Commitment...Reinvesting in the System: A Journey of Community Partnership.” History of the Regional Centers in California. [https://lanterman.org/uploads/info\\_resources\\_general/Lanterman-50thHistory-r6\(Blue\)\(web\)\\_final.pdf](https://lanterman.org/uploads/info_resources_general/Lanterman-50thHistory-r6(Blue)(web)_final.pdf). Also, State of California, Human Relations Agency. Lanterman Mental Retardation Services Act, information booklet. Page 5.
8. Frank D. Lanterman Regional Center. “Strengthening the Commitment...Reinvesting in the System: A Journey of Community Partnership.” History of the Regional Centers in California. Pages 8 and 14. [https://lanterman.org/uploads/info\\_resources\\_general/Lanterman-50thHistory-r6\(Blue\)\(web\)\\_final.pdf](https://lanterman.org/uploads/info_resources_general/Lanterman-50thHistory-r6(Blue)(web)_final.pdf).
9. Amy Westling, Executive Director, ARCA. October 24, 2020. Personal communication to Commission staff.
10. Note: Statutory amendments made in 1993 specified the “catchment areas,” or geographic boundaries within which a regional center should operate, for two regional centers: one to serve Inyo, Kern, and Mono Counties, and another to serve Riverside and San Bernardino Counties. Source Welfare and Institutions Code, § 4621.5. Added by AB 2277 (Harvey), Statutes of 1993. Chapter 364, Section 1.
11. Amy Westling, Executive Director, ARCA. October 24, 2020. Personal communication to Commission staff.
12. Note: As of December 2022, 399,605 consumers were served by the 21 regional centers, while an additional 21,268 individuals had provisional eligibility, were enrolled in the early start program, or were undergoing diagnosis and evaluation by a regional center. Source: Department of Developmental Services. Monthly

- Consumer Caseload, Regional Center Caseloads by Status, December 2022. <https://dds.ca.gov/transparency/facts-stats/>.
13. Department of Developmental Services. State-Operated Services. <https://www.dds.ca.gov/services/state-facilities/>.
  14. Charlene Harrington, Ph.D., and Taewoon Kang, Ph.D., Department of Social and Behavioral Science, University of California San Francisco. "Disparities in service utilization and expenditures for individuals with developmental disabilities." *Disability and Health Journal*. 2008. 184-195. Also, Harrington and Kang, "Variation in types of service use and expenditures for individuals with developmental disabilities." *Disability and Health Journal*. 2008. 30-41. Also, Harrington and Kang, "Disparities in Service Use and Expenditures for People with Intellectual and Developmental Disabilities in California in 2005 and 2013." *Intellectual and Developmental Disabilities*. 2016, Vol 54, No. 1, 1-18. Also, the Senate Select Committee on Autism & Related Disorders. 2013-2014 Legislative Session. "A Preliminary Report by the Taskforce on Equity and Diversity for Regional Center Autism Services." Also, Public Counsel. May 2022. "Examining Racial and Ethnic Inequalities Among Children Served Under California's Developmental Services System: Where Things Currently Stand." Also, Disability Voices United. October 26, 2022. "A Matter of Race and Place: Racial and Geographic Disparities Within California's Regional Centers Serving Adults with Developmental Disabilities."
  15. Public Counsel. May 2022. "Examining Racial and Ethnic Inequities Among Children Served Under California's Developmental Services System: Where Things Currently Stand." Also, Disability Voices United. October 26, 2022. "A Matter of Race and Place: Racial and Geographic Disparities Within California's Regional Centers Serving Adults with Developmental Disabilities."
  16. Nancy Bargmann, Director, Department of Developmental Services. November 10, 2022. Testimony to the Commission.
  17. Nancy Bargmann, Director, Department of Developmental Services. January 11, 2023. Written testimony to the Commission.
  18. William Leiner, Managing Attorney, Disability Rights California. October 6, 2022. Written testimony to the Commission.
  19. Department of Developmental Services. 2018-19 and 2019-20 RC Allocations. December 16, 2022. Personal communication to Commission staff.
  20. Public Counsel. May 2022. "Examining Racial and Ethnic Inequities Among Children Served Under California's Developmental Services System: Where Things Currently Stand." Also, Disability Voices United. October 26, 2022. "A Matter of Race and Place: Racial and Geographic Disparities Within California's Regional Centers Serving Adults with Developmental Disabilities."
  21. Charlene Harrington and Taewoon Kang. "Disparities in Service Use and Expenditures for People With Intellectual and Developmental Disabilities in California in 2005 and 2013." *Intellectual and Developmental Disabilities*, 2016, Vol. 54, No. 1, 1-18. Also, Taewoon Kanh, Ph.D., Charlene Harrington, Ph.D., Department of Social and Behavioral Sciences, UC San Francisco. "Variation in types of service use and expenditures for individuals with developmental disabilities." *Disability and Health Journal* 1 (2008) 30-41.
  22. Note: Since 2016-17, lawmakers have annually allocated \$11 million from the General Fund to provide "Service Access and Equity Grants" to regional centers and community-based

- organizations to reduce disparities in service authorizations, utilization, and expenditures. The 2021-22 Budget also included an additional \$11 million for the Department of Developmental Services to evaluate the outcomes of these grants and identify promising practices. Source: AB X2 1, Chapter 3, Statutes of 2016. Also, AB 107, Chapter 18, Statutes of 2017.
23. Alan Zarembo, Los Angeles Times. December 11, 2011. Part 1: An epidemic of disease or of discovery? Part 2: Services go to those who fight hardest. Part 3: Families chase the dream of discovery. Part 4: Finding traces of autism in earlier eras.
  24. Vivian Haun, Senior Attorney, Disability Rights California. October 27, 2022. Little Hoover Commission Advisory Committee Roundtable on California's Developmental Disabilities System.
  25. Charlene Harrington. September 29, 2022. Personal communication with Commission staff. Also, October 27, 2022. Little Hoover Commission Advisory Committee Roundtable on California's Developmental Disabilities System.
  26. Brian Capra, Senior Staff Attorney, Children's Rights Project, Public Counsel. October 27, 2022. Little Hoover Commission Advisory Committee Roundtable on California's Developmental Disabilities System.
  27. Vivian Haun, Senior Attorney, Disability Rights California. July, 29, 2022. Personal communication with Commission staff. Also, Areva Martin, President and CEO, Special Needs Network. November 4, 2022. Personal communication with Commission staff.
  28. Vivian Haun, Senior Attorney, Disability Rights California. October 27, 2022. Little Hoover Commission Advisory Committee Roundtable on California's Developmental Disabilities System.
  - Also, Elizabeth Gomez, Co-Founder and Director, Integrated Community Collaborative. October 13, 2022. Testimony to the Commission.
  29. Welfare and Institutions Code, § 4690.
  30. Nancy Bargmann, Director, Department of Developmental Services. November 10, 2022. Testimony to the Commission. Also, Department of Developmental Services. December 19, 2022. Background: DDS Authority: Regional Centers. Personal communication with commission staff.
  31. Welfare and Institutions Code, § 4639.6.
  32. Welfare and Institutions Code, § 4685.8 and § 4519.10. Note: Other examples include Welfare and Institutions Code, § 4642 (distribution of information packets), § 4685.8 (nonvended service providers criminal background check), §4685.10 (compliance with Title 42 Code of Federal Regulations), § 4688.06 (Coordinated Family Support Services Pilot Program), § 4688.3 (state plan amendments), § 4699.7 (Developmental Services Workforce Stabilization), § 4870.1 (Competitive Integrated Employment program requirements), § 4870.2 (Competitive Integrated Employment Postsecondary Education and Career readiness Pilot).
  33. Welfare and Institutions Code, § 4690.
  34. California Code of Regulations, Title 17 § 5432, Types of Service. Also, California Code of Regulations, Title 17 § 54340, Vendor Identification Numbers, Service Codes, and Subcodes.
  35. California Code of Regulations, Title 17 § 54356, Miscellaneous Services.
  36. Department of Developmental Services. December 19, 2022. Background: Service Codes. Personal communication with commission staff.

37. Welfare and Institutions Code, § 4519.8. Also, Department of Developmental Services. December 19, 2022. Background: Service Codes. Personal communication with commission staff.
38. California Department of Developmental Services, Community Services Division, Program Services Branch, Services and Supports Section. July 2000. Booklet: The Supported Living Service Regulations Companion. Third Edition. On file.
39. Welfare and Institutions Code, § 4631.
40. Welfare and Institutions Code, § 4641.5.
41. Department of Developmental Services. Budget Change Proposal. Fiscal year 2023-24. Uniform Fiscal System Modernization (UFSM) and the Consumer Electronic Records Management System (CERMS) Project Planning. [https://esd.dof.ca.gov/Documents/bcp/2324/FY2324\\_ORG4300\\_BCP6772.pdf](https://esd.dof.ca.gov/Documents/bcp/2324/FY2324_ORG4300_BCP6772.pdf).
42. Department of Developmental Services. Budget Change Proposal. Fiscal year 2023-24. Uniform Fiscal System Modernization (UFSM) and the Consumer Electronic Records Management System (CERMS) Project Planning. [https://esd.dof.ca.gov/Documents/bcp/2324/FY2324\\_ORG4300\\_BCP6772.pdf](https://esd.dof.ca.gov/Documents/bcp/2324/FY2324_ORG4300_BCP6772.pdf).
43. Nancy Bargmann, Director, Department of Developmental Services. January 11, 2023. Written testimony to the Commission.
44. Department of Developmental Services. Budget Change Proposal. Fiscal year 2023-24. Uniform Fiscal System Modernization (UFSM) and the Consumer Electronic Records Management System (CERMS) Project Planning. [https://esd.dof.ca.gov/Documents/bcp/2324/FY2324\\_ORG4300\\_BCP6772.pdf](https://esd.dof.ca.gov/Documents/bcp/2324/FY2324_ORG4300_BCP6772.pdf).
45. Department of Developmental Services. Budget Change Proposal. Fiscal year 2023-24. Uniform Fiscal System Modernization (UFSM) and the Consumer Electronic Records Management System (CERMS) Project Planning. [https://esd.dof.ca.gov/Documents/bcp/2324/FY2324\\_ORG4300\\_BCP6772.pdf](https://esd.dof.ca.gov/Documents/bcp/2324/FY2324_ORG4300_BCP6772.pdf).
46. Nancy Bargmann, Director, Department of Developmental Services. January 11, 2023. Written testimony to the Commission. Also, Department of Developmental Services. December 19, 2022. Background. Consumer Electronic Records Management Systems (CERMS) and Uniform Fiscal System (UFS). Personal communication with commission staff.
47. Barry Jardini, Executive Director, California Disability Services Association. October 27, 2022. Little Hoover Commission Advisory Committee Roundtable on California's Developmental Disabilities System. Also, Harry Bruell, President and CEO, PathPoint. October 6, 2022. Written testimony to the Commission.
48. Department of Developmental Services. Vendorization Process. <https://www.dds.ca.gov/rc/vendor-provider/vendorization-process/>.
49. Nancy Bargmann, Director, Department of Developmental Services. January 11, 2023. Written testimony to the Commission. Also, Amy Westling, Executive Director, Association of Regional Center Agencies. November 4, 2022. Written communication to the Commission.
50. Amy Westling, Executive Director, Association of Regional Center Agencies. October 27, 2022. Little Hoover Commission Advisory Committee Roundtable on California's Developmental Disabilities System.
51. Welfare and Institutions Code, § 4626 and § 4626.5.
52. Welfare and Institutions Code, § 4622.

53. Amy Westling, Executive Director, Association of Regional Center Agencies. October 27, 2022. Little Hoover Commission Advisory Committee Roundtable on California's Developmental Disabilities System.
54. Judy Mark, President, Disability Voices United. October 27, 2022. Little Hoover Commission Advisory Committee Roundtable on California's Developmental Disabilities System.
55. Welfare and Institutions Code, § 4644.
56. Welfare and Institutions Code, § 4659(f).
57. William Leiner, Managing Attorney, Disability Rights California. October 6, 2022. Written testimony to the Commission.
58. 42 USC Section 15021. Also, Welfare and Institutions Code, § 4520.
59. Aaron Carruthers, Executive Director, State Council on Developmental Disabilities. October 3, 2022. Personal communication with Commission staff. Also, Aaron Carruthers. Written testimony to the Commission.
60. Aaron Carruthers, Executive Director, State Council on Developmental Disabilities. October 3, 2022. Personal communication with Commission staff.
61. Welfare and Institutions Code, § 4433. Also, Disability Rights California, Office of Clients' Rights Advocacy. <https://www.disabilityrightsca.org/what-we-do/programs/office-of-clients-rights-advocacy-ocra>. Shannon Cogan, Director, Office of Clients Rights Advocacy, Disability Rights California. December 8, 2022. Public comment to the Commission.
62. Disability Rights California. OCRA Annual Report. July 1, 2021-June 30, 2022. <https://www.disabilityrightsca.org/system/files/file-attachments/ANNUAL%20-%20Directors%20Report.pdf>.

# ■ Little Hoover Commission Members

## **CHAIRMAN PEDRO NAVA | Santa Barbara**

Appointed to the Commission by Speaker of the Assembly John Pérez in April 2013 and reappointed by Speaker of the Assembly Anthony Rendon in 2017 and again in 2021. Government relations advisor. Former State Assemblymember from 2004 to 2010, civil litigator, deputy district attorney and member of the state Coastal Commission. Elected chair of the Commission in March 2014.

## **VICE CHAIRMAN SEAN VARNER | Riverside**

Appointed to the Commission by Governor Edmund G. Brown Jr. in April 2016 and reappointed in January 2018. Managing partner at Varner & Brandt LLP where he practices as a transactional attorney focusing on mergers and acquisitions, finance, real estate, and general counsel work. Elected vice chair of the Commission in March 2017.

## **DION ARONER | Berkeley**

Appointed to the Commission by the Senate Rules Committee in April 2019. Partner for Aroner, Jewel, and Ellis. Former State Assemblymember from 1996 to 2002, chief of staff for Assemblymember Tom Bates, social worker for Alameda County, and the first female president of Service Employees International Union 535.

## **DAVID BEIER | San Francisco**

Appointed to the Commission by Governor Edmund G. Brown Jr. in June 2014 and reappointed in January 2018. Managing director of Bay City Capital. Former senior officer of Genentech and Amgen, and counsel to the U.S. House of Representatives Committee on the Judiciary.

## **ANTHONY CANNELLA | Ceres**

Appointed to the Commission by the Senate Rules Committee in March 2022. Civil engineer and principal with Northstar Engineering Group. Former State Senator from 2010 to 2018. Previously served on the Ceres City Council and was twice elected mayor of that city.

## **ASM. PHILLIP CHEN | Yorba Linda**

Appointed to the Commission by Speaker of the Assembly Anthony Rendon in October 2021. Elected in November 2016 to represent 55<sup>th</sup> District. Represents portions of Los Angeles, Orange and San Bernardino counties and the cities of Brea, Chino Hills, Diamond Bar, La Habra, Industry, Placentia, Rowland Heights, Walnut, West Covina and Yorba Linda.

## **BILL EMMERSON | Redlands**

Appointed to the Commission by Governor Edmund G. Brown Jr. in December 2018. Former senior vice president of state relations and advocacy at the California Hospital Association, State Senator from 2010 to 2013, State Assemblymember from 2004 to 2010, and orthodontist.

## **GIL GARCETT | Los Angeles**

Appointed to the Commission by Governor Gavin Newsom in November 2021. Professional photographer and author of ten books. Former Los Angeles County District Attorney, teaching Fellow at Harvard University's Kennedy School, and president of the California Science Center Foundation's Board of Trustees.

## **SEN. DAVE MIN | Irvine**

Appointed to the Commission by the Senate Rules Committee in September 2021. Elected in November 2020 to represent the 37<sup>th</sup> Senate District. Represents Anaheim Hills, Costa Mesa, Huntington Beach, Irvine, Laguna Beach, Laguna Woods, Lake Forest, Newport Beach, Orange, Tustin, and Villa Park.

## **ASM. LIZ ORTEGA | San Leandro**

Appointed to the Commission by Speaker of the Assembly Anthony Rendon in March 2023. Elected in November 2022 to represent the 20<sup>th</sup> Assembly District. Represents Hayward, San Leandro, most of Union City, portions of Dublin and Pleasanton, and several unincorporated communities.

## **JANNA SIDLEY | Los Angeles**

Appointed to the Commission by Governor Edmund G. Brown Jr. in April 2016 and reappointed in February 2020. Partner at Ichor Strategies and appointed to the Board of the Los Angeles City Employee Retirement System ("LACERS"). Former general counsel at the Port of Los Angeles and city attorney at the Los Angeles City Attorney's Office.

**Full biographies are available on the Commission's website at [www.lhc.ca.gov](http://www.lhc.ca.gov).**

**“DEMOCRACY ITSELF IS A PROCESS OF CHANGE, AND SATISFACTION AND COMPLACENCY ARE ENEMIES OF GOOD GOVERNMENT.”**

By Governor Edmund G. “Pat” Brown,  
addressing the inaugural meeting of the Little Hoover Commission,  
April 24, 1962, Sacramento, California



Milton Marks Commission on California State  
Government Organization and Economy

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