

November 4, 2022

Little Hoover Commission  
925 L St., Suite 805  
Sacramento, CA 95814

**RE: ARCA Recommendations for Little Hoover Commission on California’s Developmental Disabilities System**

Honorable Commissioners:

California’s regional centers are a network of 21 community-based non-profits, represented by the Association of Regional Center Agencies (ARCA). The regional centers coordinate services for, and advocate on behalf of, nearly 400,000 Californians with developmental disabilities, as defined in California law<sup>1</sup>. ARCA appreciates the opportunity to offer formal comments to inform the work of the Little Hoover Commission.

California’s developmental services system is the only one of its kind in the nation, as it promises services and supports to individuals with developmental disabilities from birth through death, regardless of family income, and without waitlists for entering the service system. The system is growing rapidly (approximately 5% a year) and serves people ranging from young children with autism, to young adults with intensive behavioral or psychiatric support needs, to people with aging parent caregivers. Approximately 1% of the state’s population is now served through regional centers.

The regional center system was created through the Lanterman Act to be locally responsive under the leadership of their boards of directors. These boards of directors, per state law, must be composed of people served, their families, and various professionals, who are representative of the area’s ethnic and geographic diversity.<sup>2</sup> Regional centers are held to a wide range of legal and contractual standards laid out in statute and regulation, as well as contracts with the State Department of Developmental Services. There are also multiple “good governance” mandates related to independent financial review, whistleblower protections, and other mechanisms to support board oversight of regional centers.

As noted during the recent roundtable discussion hosted by the Little Hoover Commission, California’s developmental services system is transitioning to become one that strives to measure and incentivize good outcomes rather than simply counting units of service.

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<sup>1</sup> Welfare and Institutions Code §4512(a)

<sup>2</sup> Welfare and Institutions Code §4622

Another change the system has undergone in recent years is asking those served to share their thoughts and experiences directly, and offer their opinions about what is and is not working in the current system. One mechanism for gathering this information is through the National Core Indicators study, which asks those served by developmental services systems in 48 states and Washington, D.C. about their experiences accessing developmental services. In California, surveys are done by an independent agency. Data from Fiscal Year (FY) 2020-21, which is the latest available, tells us the following from among approximately 5,000 respondents who were interviewed:

- 96% of people report staff respect them;
- 92% of people report they like where they live;
- 91% report their services and supports help them live a good life;
- 94% report they have enough choice about their daily schedules;
- 97% report their services are provided in such a way that they are respectful of their culture;
- 93% report their planning team meetings had people they wanted there; and,
- 85% report they can contact their service coordinator when they need or want to.

While no survey is perfect, the message here is clear. The experiences of the vast majority of people served in our system are positive. We have a strong foundation to build from that overall respects people, supports their choices, and helps them lead good lives.

ARCA appreciates the Little Hoover Commission's exploration of how California can better support the 400,000 individuals served by the regional centers, as well as those who will need their support in the future. In its simplest form, the answer to what people with developmental disabilities and their families need is respect, individualized person-centered planning, and access to the unique array of services and supports necessary to pursue their goals. Regional centers are committed to the pursuit of equity for those from all racial, ethnic, and linguistic backgrounds no matter where in the state they live.

ARCA's specific recommendations in the following areas provide a roadmap to enhancing both service access and equity:

- Systemic barriers;
- System capacity;
- Racial, ethnic, and linguistic equity initiatives; and,
- Opportunities for greater consistency.

### **Systemic Barriers**

Challenges in navigating the service system were a recurring topic during the October 27, 2022, Roundtable. There was a particular emphasis on how – and by whom – services are funded and the barriers that creates, including at times discouraging service access altogether. In some cases, eliminating statutory requirements may result in greater support and less bureaucracy separating individuals from services.

*Generic Services:* As various advocacy organizations, including ARCA, have noted, both state statute and federal funding rules require those served by regional centers and their families to first seek services from other public and private agencies (*e.g.*, Medi-Cal, In-Home Supportive Services, education, health insurance) for services that may be those agencies' responsibility. This has been a requirement since the

inception of the Lanterman Act. But it has become more complicated due to increasingly-complex funding rules at other agencies and regional centers' lack of systematic insight into the other services each person accesses. Separately, a Recession-era statutory change forces families to appeal service denials from other agencies.<sup>3</sup> ARCA recommends the statutory requirement requiring appeal of generic agency denials be reversed to make it easier to demonstrate the exhaustion of generic resources, and that data on each person's use of generic services be made available to regional centers.

*Least-Costly Vendor:* Another barrier created during the Recession was a requirement that regional centers purchase services from the "least costly available provider of comparable service," whether or not that provider is the one preferred by the individual and their support team.<sup>4</sup> This limits choice and inappropriately shifts the conversation away from individual preferences, to calculation of costs. While the impact of this will likely be reduced as the rate models standardize service rates, ARCA recommends the least costly vendor statutory requirement be reversed in order to more clearly prioritize and support individual choice and reduce unnecessary bureaucratic barriers.

*Median Rates:* At the start of the Recession, regional centers' ability to negotiate rates with service providers was limited to the lower of either the statewide or local median rates.<sup>5</sup> The calculations behind this drive any new rate down towards a mathematical midpoint that is disconnected from local business costs. As updates to service provider rates are driven by local labor costs, this requirement makes it harder for regional centers in high-cost areas to develop services needed in their communities. ARCA recommends this requirement be eliminated or changed to allow the use of the higher of either the local or statewide median rates.

*Family Fees:* The Annual Family Program Fee (AFPF) was introduced during the Recession as a revenue-generating measure. It requires parents of infants, toddlers, and children to pay a fee to the state because they access needed services for their children with developmental disabilities (e.g., behavior services, speech therapy). Separately, the Family Cost Participation Program (FCPP) began in 2005 but was expanded to include Early Start children during the Recession. It makes families pay a portion of the cost of their child's respite, daycare, and camp services. In both cases, these fees act as a barrier to needed services, and can create an adversarial relationship between service coordinators and the families whom they are supporting. Both fees have been suspended since the beginning of the pandemic. ARCA recommends the permanent elimination of both fees.

### **System Capacity**

Commissioner Aroner noted during the Little Hoover Commission's October 13, 2022, hearing that there is a disconnect between an entitlement to services and limited funding. While sufficient funding would not address all of the developmental services system's challenges, stopping short of full funding ensures it will continue to struggle in several key areas.

*High Caseloads:* As the State Auditor noted in its June 2022 report, after reviewing operations at three regional centers it found "they have neither sufficient staff nor funding." The heart of the problem is service coordinators have to support too many people, while the system continues to grow more

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<sup>3</sup> Welfare and Institutions Code §4659

<sup>4</sup> Welfare and Institutions Code §4648(a)(6)(D)

<sup>5</sup> Welfare and Institutions Code §4691.9(a)(2)

complex. This means they don't have enough time to invest in building relationships with individuals and their families, or to more deeply understand their unique needs. The time crunch also undercuts service coordinators' ability to help families navigate and access services through generic agencies – a particularly strong need for diverse communities. The root cause is an antiquated formula that funds regional centers for new positions at salaries that are approximately 50% of the actual cost. Investments were made in FY 2022-23 to begin reducing caseload sizes, but ARCA recommends modernizing the Core Staffing Formula to ensure it adjusts with time to improve individual support and outcomes.

*Inadequate Service Provider Network:* While California does not have a waitlist for entering into its service system, wait times for accessing day-to-day services have, in many instances, become the norm. In response to this, the state is now phasing in updated rate models that are more consistent, and are designed based on cost assumptions. This will include a Quality Incentive Program, which is intended to financially reward service providers that help individuals achieve better outcomes. The first phase of implementation has shown there are some assumptions that need to be revisited and corrected – for instance, consideration should be given to better support service access in rural areas. ARCA recommends California commit to keeping rates consistent with costs over time and measure the impact of this effort on overall service capacity, including for diverse communities.

*Data Needs:* As noted during the Little Hoover Commission Roundtable, the systematic measurement of quality outcomes, as well as real-time monitoring of regional centers by DDS, would be improved with better data systems. The regional center accounting system is nearly 40 years old and can't meet modern business needs. This means various third-party programs are used to conduct business, including paying service providers. Separately, case management systems lack uniformity, and most don't offer individuals and their families access to their records. Recognizing these issues, the state provided one-time funding in FY 2021-22 to develop a replacement plan. The actual software still needs to be purchased and brought online. ARCA recommends the authorization of funding to acquire and implement new data systems.

### **Racial, Ethnic, and Linguistic Equity Initiatives**

Given California's intentional focus on greater equity in service delivery along racial, ethnic, and linguistic lines over the last few years, several recent initiatives targeted this outcome, including lifting the cap on respite hours and allowing Independent Living Skills training to be provided in the family home. Other initiatives (*e.g.*, bilingual stipends for Direct Support Professionals, regional center staff implicit bias training, Coordinated Family Support Services) are being developed. ARCA supports these efforts and recognizes as DDS recently stated, "as a state, we are closer to the beginning of this process than the end." Regional centers continue to strive for improvement in this area.

*Equity Data:* Since 2013, regional centers have posted data regarding their spending on individuals according to their race, ethnicity, language, and other factors.<sup>6</sup> These requirements have expanded over time. Separately, DDS developed [Statewide Equity Measures](#) that measure spending on specific services, intake timelines, and other elements. California has not yet identified the specific discrete data elements that will be used to evaluate success in racial, ethnic, and linguistic equity. This lack of clarity makes it challenging to develop and evaluate policies meant to address shortfalls in this area. ARCA recommends

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<sup>6</sup> Welfare and Institutions Code §4519.5

the state identify a valid, reliable, and consistent set of data elements that will be used to measure progress in service equity to those across racial, ethnic, and linguistic lines.

*Equity Grants:* Beginning in 2016, the state began investing \$11 million annually in projects to improve service access and equity for individuals served by regional centers from diverse racial, ethnic, or linguistic groups. These grants began as opportunities to try out novel ideas at the local level to improve service access. ARCA believes the best of these innovative programs should become permanent and universally available. For instance, [the Enhanced Service Coordination Project](#) started as a grant at Eastern Los Angeles Regional Center. It let service coordinators spend more time with families whose primary language is not English and who were accessing few or no regional center-funded supports. ARCA and the regional centers are extremely pleased to see that, in response to robust data regarding its success, this is now an option statewide. ARCA also appreciates the detailed and data-driven analysis Georgetown University is conducting on the effectiveness of these efforts. ARCA recommends the prioritization of future projects for funding that lend themselves to evaluation and replication.

*Individualized Services:* Improving service access means meeting individual needs with greater flexibility and responsiveness. During the pandemic, more emphasis was placed on allowing individuals to have those closest to them, such as relatives or family friends, support them through Participant-Directed Services (“employer authority” in federal terminology). The Self-Determination Program includes this flexibility and takes it one step further by allowing individuals to better customize and prioritize services by moving funding between them (“budget authority”). ARCA recommends eliminating barriers to these individualized services without compromising their federal funding, including through streamlining enrollment for those with adequate base budgets in the Self-Determination Program and exploring alternative data-driven budgeting methodologies for the program.

*Social Recreation:* ARCA was a proud sponsor of the restoration of services suspended during the Recession, including social recreation. The data has long shown how popular these services are among diverse communities. As services are now more integrated into communities than at the time of the suspension, this “restoration” is more accurately framed as a “reimagining.” However, some integrated recreation programs (e.g., community karate classes) have been hesitant to go through the contracting process to allow them provide services to those served by regional centers (commonly known as “vendorization”). Another barrier is the fact that regional centers are required to pay for services after they are provided – normally, the typical participant in a community program pays up front. ARCA recommends statutory flexibilities for these service providers to promote greater service access.

### **Opportunities for Greater Consistency**

Rather than state-run offices, regional centers were intentionally designed by the Lanterman Act to be community-facing organizations that are responsive to local needs. As noted during the Little Hoover Commission Roundtable, California’s remarkable geographic diversity doesn’t lend itself to a singular state system. Regional centers continuously work to strengthen the knowledge and capacity of regional center boards; ARCA began work in this area as well, starting in early 2020<sup>7</sup>. While every regional center is committed to meeting the unique needs of those it serves, part of the evolution of the service system

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<sup>7</sup> Materials and recordings available at <https://www.cal-collab.net/web-academies/>

requires a greater level of statewide consistency. As all regional centers are members of ARCA, the organization commits to developing proposals in the following areas by the end of 2023:

- Family Supports – The amount of support a family needs does not typically change when they move from one geographic area to another. ARCA commits to the development of a standardized assessment tool that evaluates overall family support needs, while allowing the particular array of services (*e.g.*, respite, after school programs) to be locally-informed.
- Website Transparency – Regional centers are required to post a variety of data on their websites to allow the public to better understand their services and practices. ARCA commits to the development of a consistent structure for this information to simplify the navigation of regional center websites. When possible, preference will be given to ensuring data generated by regional centers is machine-readable.
- Vendorization Process – While there are clear requirements for vendorization, service providers' experiences completing the vendorization process should not vary significantly between regional centers. Regional centers will work to streamline and standardize vendorization processes, including exploring opportunities to improve the "courtesy vendorization" process and developing recommendations for sharing statewide vendorizations for remote services, including to support telehealth.
- Intake – As intake is the first introduction of individuals and their families to the developmental services system, it is essential that barriers to entry be minimized. Regional centers will implement standardized intake forms and data tracking, once their development is finalized in the ongoing DDS-led Regional Center Performance Measures effort. Regional centers will also explore ways to better share scarce clinical resources. Additionally, for foster children, who may move frequently during the intake process, regional centers commit to developing processes to allow the regional center that began the intake process to complete it.

Support for these proposals would allow the Commission to advance practical solutions that promote greater consistency without creating additional bureaucracy or eroding the community-facing foundation of the Lanterman Act.

ARCA and its member regional centers remain committed to equitably serving Californians with developmental disabilities and their families. ARCA understands needed changes to the service system cannot be carried out in isolation. We have worked collaboratively with stakeholders, advocacy organizations, the Legislature, and the Administration for many years to advocate for improvements to services for those served by regional centers and their families. We look forward to the recommendations of the Little Hoover Commission and are committed to ongoing discussions about how working together we can all propel the service system forward.

If you have any questions regarding ARCA's recommendations or perspectives, please do not hesitate to contact me at [awestling@arcenet.org](mailto:awestling@arcenet.org) or (916) 446-7961.

Sincerely,



Executive Director