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**Little Hoover Commission
Hearing on the Developmental Disabilities System (Part 1)**

**Testimony from William Leiner
Managing Attorney, I/DD Practice Group
Disability Rights California**

October 6, 2022

Dear Commissioners:

Thank you for the invitation to participate in this critical study of California's developmental disabilities system. My name is William Leiner. I am a Managing Attorney at Disability Rights California, California's protection and advocacy agency and largest disability rights organization in the country.

Disability Rights California has a state and federal mandate to protect and advance the rights of people with disabilities. 42 U.S.C. § 15001 *et seq.*, 29 U.S.C. § 794e *et seq.*; 42 U.S.C. § 10801 *et seq.*, Welf. & Inst. Code § 4900 *et seq.* We also contract with the Department of Developmental Services (DDS) to provide clients' rights advocacy services to the over 400,000 individuals served by regional centers.

In my professional life, I support a dedicated team of attorneys and advocates that work at the intersection of individual advocacy, litigation, public policy, and community engagement to better the lives of people served by California's regional centers. On a personal note, I am also the brother of an individual served by a regional center.

My testimony will highlight the racial and ethnic disparities that exist in California's developmental disabilities system, examples of systemic barriers that drive these disparities, and ways the state can better respond to the needs of people and

communities most acutely impacted by this deeply inequitable system. I base this testimony on the experience and stories of disabled people and their families who seek legal assistance from our agency, the engagement we have with our communities, and on my 15 years of experience advocating for intellectually and developmentally disabled clients and their families.

Despite Years of Effort and Investment, Racial and Ethnic Disparities Have Not Improved

In 2013, the Legislature required regional centers to publicly report how much funding it authorizes and spends on services for people, broken down by different demographic characteristics. The resulting data revealed stark disparities in spending by race and ethnicity, with intellectually and developmentally disabled Latinx, Black, and Asian people receiving about half to two-thirds as much as White people.

Since then, the Legislature has passed several policy and budget bills aimed at ensuring equitable access to regional center services. These efforts have included requiring regional centers to translate Individual Program Plans and other documents into a person's native or preferred language, adding regional center performance objectives related to culturally and linguistically appropriate services, and expanding community engagement related to the public reporting of disparity data. In 2015, the Department of Developmental Services (DDS) also began providing \$11 million a year for grants to community-based organizations to address disparities. This year, the grants have been increased to \$22 million. These grants have largely been used to develop navigator programs, to fund parent-to-parent mentoring, and to train people and their families about how to access services from regional centers and other public assistance programs.

However, despite years of effort and investment, *racial and ethnic disparities in spending on regional center services have barely moved.*¹ Although the tens of millions in grant funding have been valuable in building local relationships and capacity, they simply have not been enough on their own to address disparities.

¹ Public Counsel, May 2022: [Examining Racial and Ethnic Inequities Among Children Served Under California's Developmental Services System: Where Things Currently Stand.](#)

Recent news coverage² and lawsuits³ also show that the state's failure to move the needle is harming those individuals for whom the spending disparities are most stark.

There is a simple reason disparities are not improving and people continue to clamor for change. For too long, DDS's focus has been directed towards helping *individual* people of color better understand and navigate a flawed system *as it exists today*. However, DDS has done little to also identify and dismantle the *systemic* practices at the root of spending disparities in order to create better, more equitable system *for tomorrow*.

Examples of Systemic Practices that Contribute to Racial and Ethnic Disparities

Below are three examples of systemic practices we have identified that warrant further study because of how they contribute to and hold racial and ethnic disparities in place.

Regional centers place the burden to exhaust generic resources on disabled people and their families

Legal mandates require people and their families to access all “generic” resources – i.e. those available from school districts, private insurance, and publicly funded programs like Medi-Cal and IHSS – before a regional center can purchase services for them. In other words, regional centers are the “payor of last resort.”

Unfortunately, in practice, “payor of last resort” requirements leads to an “all wrong doors” approach to service delivery. In other words:

² Los Angeles Times, 5/25/2022: [Racial disparities persist at California regional centers for disabled kids, report says](#); California Health Report, 1/27/22, [Latinx Families Ask for Equal Services for Their Children with Disabilities](#); California Health Report, 5/3/2021: [For Spanish Speaking Families, an Uphill Battle for Special Needs Services](#); California Health Report, 11/9/2020: [How Families are Fighting Racism and Disability Discrimination](#); California Health Report, 6/12/2019: [California Centers that Help Those with Disabilities Spend Less on Latino Children, Report Finds](#); Sacramento Bee, 5/29/2018: [That early help you need for your child doesn't come soon enough](#).

³ [Latinx Parents Sue to Stop Discrimination by Harbor Regional Center](#), 11/9/21. *Padres Bucardo el Cambio v. Harbor Developmental Disabilities Foundation, Inc., et al.*, Los Angeles County Superior Court, Case No. 21STCP03671.

- A regional center will say NO to a service because there may be another generic resource that meets the same need.
- The regional center then requires the disabled person or their family, often without assistance, to secure a NO from the other agency before it will even consider whether to fund that service.
- The person served or their family will have the burden to prove that they have “exhausted” all possible generic resources. However, the level of required proof is left entirely up to the discretion of the regional center.
 - o Sometimes this means obtaining a written notice from the generic resource.
 - o Sometimes it means pursuing an administrative appeal.
 - o Some regional centers simply tell people to “keep trying” until they give up.
- In some cases, even after the person secures proof that the service is not available from the generic resource, they are again told NO by their regional center because the regional center didn’t think the person needed the service in the first place.

The impact of “all wrong door” practices like this have a disproportionate effect on communities of color, many of whom experience the impact of structural racism across many of these systems, and simply do not have the luxury of time to jump through the many, many hoops required by regional centers to prove that the generic resource at issue is not available to them. And all too often, the result is largely the same: people, already overwhelmed, give up, the need goes unmet, and the unmet needs are reflected in the vast racial and ethnic disparities we see in our developmental disabilities system.

Once generic resources are exhausted, regional centers have nearly unfettered discretion to determine the type and amount of services a person receives, which can lead to bias, unequal treatment, and contribute to the racial and ethnic disparities we see in our system

Recent reports from the California State Auditor revealed that despite the 2018 repeal of a state law limiting the authorization of respite services, regional

centers continue to limit the number of respite hours people can receive.⁴ The auditor also concluded that regional centers do not follow a consistent process for documenting how they determine the number of respite hours they authorize. Nor do regional centers document the rationale for the number of respite hours they authorize for people.

These findings speak to a larger problem in our system: even though regional centers authorize services on a case-by-case basis through the individual planning process, regional centers have nearly unfettered discretion to determine the type and amount of services they will authorize. In other words, people tell regional centers what they need, and regional centers decide what services will meet those needs, but without consistent or transparent standards about how they make these critical decisions about a person's life. This is where bias – usually unintentional – can inappropriately impact the decision-making process. And when left unchecked, bias leads to the very racial and ethnic disparities our system is trying to prevent.

We can look to how regional centers account for natural supports as an example of this dynamic. As part of the individual planning process, regional centers must consider whether non-parental family caregivers are available to support the individual served. This type of family assistance is often referred to as “natural supports.” Legally, natural supports must be voluntary, not compelled.⁵ And people served are supposed to decide whether they want to utilize natural supports and the extent of involvement of those supports.

In practice, however, regional centers often compel family assistance by denying services on the basis that natural supports are available to the person served, without regard to whether the natural support is willing or available to play this role. And we hear from our Latinx clients, who are more likely to live in intergenerational homes with the person served, that regional center service coordinators often expect families to “take care of their own” without an inquiry or assessment about whether natural supports are *actually* available.

⁴ Auditor of the State of California, August 30, 2022, [In-Home Respite Services: The Department of Developmental Services Has Not Adequately Reduced Barriers to Some Families' Use of In-Home Respite Services.](#)

⁵ Justice in Aging, 5/26/2016, [Voluntary Means Voluntary: Coordinating Medicaid HCBS with Family Assistance.](#)

New or restored services, like camping and social recreation, are implemented without an intentional focus on ensuring equitable access to those services

In July 2021, the Legislature restored the ability of regional centers to pay for camping and social recreation services. Disability Rights California applauded this restoration for two reasons. First, we know that a lack of access to healthy and stimulating recreational experiences can lead to negative health, social, emotional, academic and safety outcomes.⁶ For families with limited resources, sometimes due to structural racism or income inequality, these effects can be even more acute. Second, the suspension of social recreation and camping programs over a decade ago disproportionately impacted people of color, who were more likely to rely on regional center funding for these services. The restoration of these services was one of the few DDS initiatives squarely understood to address racial and ethnic disparities by increasing spending on new services for the people who need them most.

However, it has been over a year since the restoration of camping and social recreation, and many families are struggling to access these programs.⁷ Even though regional centers had the authority to purchase these services as of July 1, 2021, DDS and regional centers lacked the necessary urgency and accountability to implement these critical policy changes in a timely way.

More troublingly, regional centers have not implemented the restoration of these services with an intentional, equitable lens, leading to practices that have a disparate impact on the very people and communities who needs these programs most. For example, we are aware of regional centers that:

- Categorically refuse to fund transportation to camping and social recreation activities for families with children.
- Categorically refuse to fund aides or other necessary supports to help people access these programs.

⁶ National Academies of Science, Engineering, and Medicine, 9/26/2019, [Summer Offers Opportunities for Social and Academic Growth, But Can Also Put Disadvantaged Children at Risk.](#)

⁷ California Health Report, 6/21/22, [California Finally Pays for Summer Programs for Children with Disabilities, But Access Hurdles Remain.](#)

- Implement policies that automatically remove one hour of respite services for every hour of approved camping or social recreation, without regard to the person's needs.
- Only authorize the costs of social recreation activities at private businesses when families front the cost for those activities and agree to seek reimbursement later.

These practices are the antithesis of service access and equity and demonstrate how regional center practices can, even unintentionally, hold racial and ethnic disparities in place.

Disrupting Disparities and Fostering Equity Through Community-Based Participatory Research

The examples I describe above are not exhaustive and *cannot* be considered exhaustive. They are informed by the experiences of our clients, but deeper community engagement remains necessary. For this reason, I urge policy makers to consider community-based participatory research as a way to critically examine the root causes of longstanding racial and ethnic disparities in our system and to develop targeted interventions to address them.

Community-based participatory research is a well-established model that has been used in the health and human services field to foster health equity for people served by those systems.⁸ In short, community-based participatory research does more than treat people as data points to analyze. This approach instead engages people and community stakeholders as *equal partners* in all steps of the research process, such as an intentional examination of the ways in which structural bias and systemic racism can affect practices, procedures, and decision-making processes. Treating people as equal partners also helps ensure that research-based interventions have credibility with the community and are actually responsive to the community's needs.

⁸ University of Michigan School of Public Health, 6/28/19, [Fostering Health Equity through Community-Based Participatory Research](#); American Journal of Public Health, 9/2014, [The Promise of Community-Based Participatory Research for Health Equity: A Conceptual Model for Bridging Evidence with Policy](#); Annual Review of Public Health, 1/10/2020, [Partnerships, Processes, and Outcomes: A Health Equity-Focused Scoping Meta-Review of Community-Engaged Scholarship](#).

Systemic barriers can only be eliminated through systemic solutions, and community-based participatory research is a path towards identifying these solutions. Some of the solutions to the systemic barriers I have raised in this testimony that warrant further discussion or study might include:

- Developing data systems that allow regional centers to seamlessly track the status of referrals to generic resources so that the burden to prove exhaustion of generic resources does not rest entirely on individual service coordinators, people served, or their families.
- Requiring regional centers and other Health and Human Services agencies to develop interagency dispute resolution processes so that people served are not caught in the middle of agency disputes when attempting to navigate multiple service delivery systems.
- Addressing bias in discretionary regional center decision-making by piloting equity-focused assessment criteria that regional centers must use during the individualized planning process for certain services, such as the number of respite hours a person receives or whether and to what extent natural supports are available.
- Bringing greater transparency and accountability to the developmental disabilities system by making regional centers subject to the California Public Records Act or otherwise requiring regional centers to publicly disclose all regional center policies, practices, and internally held procedures related to how regional centers assess, approve, and coordinate services and supports for people.
- Requiring the rollout of new programs and services, such as the restoration of camping and social recreation, to include an equity plan of action that explicitly and intentionally identifies underserved communities that could benefit from the service or program, details strategies for ensuring access for those communities, and establishes benchmarks and timelines for service access.
- Establishing an equity-based grant program that earmarks new spending on purchasing services for communities for whom disparities are most acute *and* requires regional centers to work with those communities to develop a plan about this funding should be spent.

We appreciate and support the investments and progress over the last decade to address disparities in the developmental disabilities system. But unless California commits to disrupting how the developmental services system operates —by identifying and shifting the policies, practices, and norms that hold racial and ethnic disparities in place —the work will remain incomplete.

Thank you for this opportunity to address the commission, and for your attention to these these critical issues.

With gratitude,

A handwritten signature in black ink, appearing to read 'William Leiner', with a stylized flourish at the end.

William Leiner
Managing Attorney
Disability Rights California