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March 13, 2017

Senator Scott Wiener, Chair
Senate Human Services Committee
State Capitol, Room 4066
Sacramento, CA 95814-4900

Honorable Senator Wiener,

The Association of Regional Center Agencies represents the 21 regional centers that advocate on behalf of, and coordinate services for, California's over 300,000 people with developmental disabilities.

Across health and social services systems, rates of service utilization by various ethnic, linguistic, and socio-economic groups differ considerably. The regional center system is no exception. The factors that lead to uneven utilization rates are complex and not yet entirely understood, despite efforts to explore and address them over the past several years.

In December 2011, the Los Angeles Times published a series of articles by Alan Zarembo examining California autism rates and public spending. In one article in the series titled "Warrior Parents Fare Best in Securing Autism Services,"[1] Zarembo summarizes service utilization within the educational and regional center systems largely along ethnic lines. As he notes, "it might be tempting to blame such disparities on prejudice, but the explanation is more complicated." ARCA agrees with this statement.

In April 2012, the Senate Select Committee on Autism and Related Disorders convened a hearing on fair and equal access to regional center services. Since that time, regional centers have focused efforts on understanding the problem of service utilization disparities, methods of improving service access, and making recommendations for the future. Each of these steps helps people served by regional centers and their families access the right services for their needs, regardless of ethnicity, native language, or socio-economic group.

What We Know About Disparities

Racial and ethnic disparities are present across health and human service systems. Zarembo's article also points to disparities in service levels to pupils diagnosed with autism in the Los Angeles Unified School District, noting distinctions along ethnic and socio-economic status lines. A study by the California Department of Mental Health[2] notes that foreign-born Latinos receive minimally adequate treatment at less than half the statewide average rate. An article in the Journal of the National Medical

[1] Alan Zarembo, "Warrior Parents Fare Best in Securing Autism Services," Los Angeles Times 12 Dec. 2011, 17 April 2012 < http://www.latimes.com/news/local/autism/la-me-autism-day-two-html,0,3900437.htmlstory>.
[2] California, UC Davis Center for Reducing Health Disparities, Community- Defined Solutions for Latino Mental Health Care Disparities (Sacramento, 2012) 4.

Association[3] states that "the real challenge lies not in debating whether disparities exist, because the evidence is overwhelming, but in the developing and implementing of strategies to reduce and eliminate them."

Additional evidence of this issue's presence across service systems is found in "Mental Health: A Report of the Surgeon General"[4] and its supplement, "Mental Health, Culture, Race and Ethnicity."[5] These reports document lower levels of access to, and receipt of, (quality) mental health care among racial and ethnic minorities, compared to Caucasians.

What We Have Learned About Service Utilization In Regional Centers

California has been working to understand differences in utilization of purchased regional center services for years. A study in 2002[6] found negligible differences in service delivery levels by ethnicity when accounting for age, client characteristics and residential setting. This sentiment was echoed in a report from the Department of Developmental Services (DDS) to the Legislature in 2003.[7] Additionally, several analyses of the issue have pointed to challenges associated with poverty, as well as limited English proficiency and literacy, as larger determinants of access to services.

Some driving forces regional centers recognize as contributing to uneven utilization of services include the attitude regarding services, belief systems, and language skills. Culture can impact how families perceive and respond to disabilities.

Socio-economic factors also impact service provision. For example, a single parent, low-income family may have less ability to focus on the developmental needs of a child due to work schedule or concerns related to housing or food insecurity. Many families rely on public transportation, which is inconvenient, time-consuming, and may be cost-prohibitive. They may move more frequently, which challenges service continuity. They may work in low-wage jobs that make taking time off of work to access services nearly impossible. Language and literacy challenges may also exacerbate the problem. It is important to note that regional centers do not systematically collect information regarding individual or family income.

Inadequate provider rates impact the availability of services. Many providers are struggling to sustain existing services. Modifying programs to hire bilingual staff, increase service hours, or expand the geographic areas served is oftentimes not financially feasible. Regional centers are employing targeted resource development as a strategy to make services more accessible. However, the efforts are severely limited due to a legislative prohibition against providing start-up funds for community programs,

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[3] Alan Nelson, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," Journal of the National Medical Association Aug. 2002: 666-668.

[4] U.S. Department of Health and Human Services. Mental Health: A Report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health; 1999.

[5] U.S. Department of Health and Human Services. Mental Health: Culture, Race, and Ethnicity-A Supplement to Mental Health: A Report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services; 2001.

[6] California, Department of Developmental Services, A Statewide Descriptive Statistical Analysis of Variation in Purchase of Services Categories for 1995-1996 and 1999-2000: Volume 1(Sacramento, 2002) 1.

[7] California, Department of Developmental Services, Purchase of Services Study II: Report #1: Modeling the Variation in Per Capita Purchase of Services Across Regional Centers (Sacramento 2003) xi.

coupled with service rates that do not allow existing providers to expand. This problem is compounded by long-term rate freezes and rate limitations.

Since 2013, regional centers have posted information on their websites regarding POS spending across racial and ethnic lines, by language spoken, and by identified disability as well as an examination of those with no POS expenditures. Reports are now also produced regarding spending by residential setting and on funding for private insurance copayments. Regional centers also hold public meetings to report on the data and to ask for input on how to better serve diverse communities, followed up by reporting to DDS. While data must drive the discourse, as with any empirical study, certain caveats must be made.

The Purchase of Service data gathered by the regional centers has limitations, making simplistic generalizations incomplete at best, and dangerously misleading at worst. Four particular limitations should be noted:

Purchase Of Service Costs

The Purchase of Service (POS) data displayed in regional centers' annual reports represents the cost of services that individuals received that are paid for by the regional center. The expenditure data does not include the cost of services individuals receive that are paid for by other agencies, such as Supplemental Security Income, Medi-Cal, the school system, and other generic agencies. Different levels of generic services are available depending on individual and family income. Additionally, in some areas of the state, community services are available through various social service agencies that target their outreach to certain racial and ethnic groups or new immigrants.

Contract Purchase Of Services Expenditures

Due to the limitations of the regional center uniform fiscal system (UFS), POS expenditures data do not include payments paid under a contract that pays a service provider for supporting a certain number or individuals rather than on an individual basis. Examples of this include transportation, which may be paid by the route driven rather than the specific individuals that ride. Another example is supported employment group services, in which the hourly cost of the job coach is shared across all clients receiving support on that given hour of the work day. Currently, the regional center accounting system is unable to associate contract expenditures to specific individuals. Therefore, the total amount of POS expenditures reported will not match the actual POS expenditures.

Individuals With No POS Expenditures

Regional centers were developed as social work agencies to provide both an alternative to institutional care for people with developmental disabilities and support and resource linkages for clients and their families. Regional center OPS budgets have stagnated in response to state budget challenges, leading to service coordination staff juggling high caseloads and having less time to spend with each individual and family.

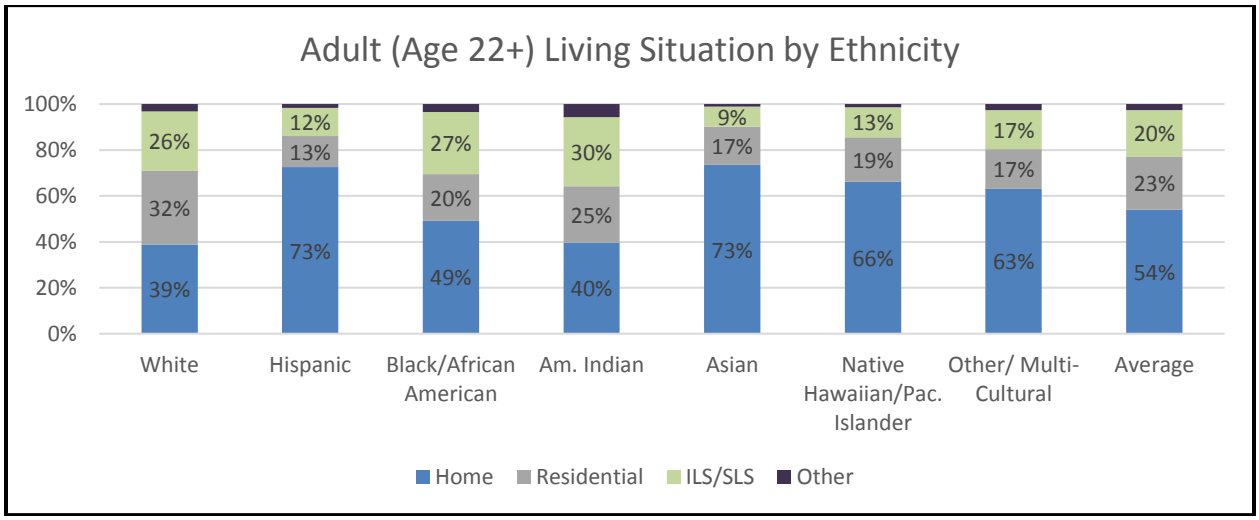
Unlike other publicly funded agencies, the provision of support, guidance and advocacy by regional center staff is in itself a valuable service to clients and their families. For this reason, it is not unusual for many families to have no purchase of service dollars expended on them but choose to remain

connected to the regional center system. In a 2004 report, DDS notes that "it is clear that the Hispanic families in this sample desired more interaction with their service coordinators." [8]

In the 2015-2016 Fiscal Year, approximately 19% of individuals served by California's developmental services system had no individualized supports purchased from service providers. For this population, regional center service coordination support is the entirety of the developmental services they receive. Many times, these individuals require intensive service coordination to seek appropriate services from other agencies such as schools, the Social Security Administration, private insurance, or programs such as In-Home Supportive Services. It is oftentimes this intensive support that they receive that prevents them from needing to access regional center funded services. Unfortunately, under California law it is this group that sees the highest caseload ratios.

Living Arrangements

One of the largest cost-drivers in the regional center system is where an individual resides. 76% of Californians with developmental disabilities live with their families, including approximately 98% of children. An examination of the data for adults reveals significant differences across racial and ethnic lines. As illustrated below, data from the 2015-16 Fiscal Year reveals that overall 54% of adults with developmental disabilities live with their families. For the Caucasian population, this number falls to 39%, while for those from a Hispanic or Asian background the percentage is 73%.



Differences in living situations drive many of the variances in POS utilization. Family support services are less expensive than out-of-home residential care or supports provided to individuals with developmental disabilities who live in their own homes.

Unfortunately, the Legislature significantly limited family support services in 2009 with the suspension of camp and social recreation services and a cap on available respite. These limitations were intended to be temporary but have not been reversed.

Additionally, in response to changes at the federal level, the availability of respite services paid directly to families was eliminated in 2011. Many families preferred the informal nature of the old respite

[8] California, Department of Developmental Services, Purchase of Services Study II: Report #2: Determination of Service Variation Across Regional Centers: Implications for Clients and Policy (Sacramento 2004) 8.

payment system and the ability to easily choose and change their own trusted providers. The new system requires that chosen providers complete several steps, including formalized training, before providing needed care.

Both of these changes have limited the utilization of POS by families supporting individuals with developmental disabilities at home.

Local Efforts To Close The Gap

Regional centers are committed to ensuring their staff is responsive to and reflective of the communities they serve. Regional center staff focused on outreach and access to diverse populations can and do improve service utilization. The cultural competence of staff members allows them to identify individual needs and the unique barriers that impact each person's ability to request and utilize services, and to join with community partners to address these factors. Regional centers are using national standards for Culturally and Linguistically Appropriate Services (CLAS) to more effectively meet unique individual needs. For example, Tri-Counties Regional Center's Strategic Plan specifically focuses on culturally competent services and supports. Westside Regional Center is hiring additional staff to better address differences in service utilization. And Alta California Regional Center is providing ongoing training to staff to ensure services are provided in a culturally sensitive manner.

Since 2012, regional centers have implemented changes large and small to better meet the needs of their communities, and to overcome barriers to service.

- San Diego Regional Center partnered with UC San Diego and Rady Children's Hospital in a project titled "Innovation in Care Integration for Persons with Developmental Disabilities." It intends to improve screening, referral, and linkage to services for children in diverse communities. The center is also initiating a promotora project, employing and training lay members of the Latino community to assist Latino clients and families to comfortably and effectively navigate the SDRC system. SDRC also plans to use a tele-medicine model to improve services for minority groups residing in remote areas in Imperial County.
- Regional Center of Orange County collaborates with local English, Spanish, and Vietnamese language newspapers and broadcast media outlets to announce public meetings in order to increase awareness of their programs. The center also provides live, simultaneous translations services at all public meetings upon request; corresponding print materials are available in English, Spanish, and Vietnamese. Additionally, the center produces a tri-lingual community/information newsletter, distributed quarterly in print and digital format.
- Eastern Los Angeles Regional Center created service fact sheets in Spanish and Chinese, and provides a series of training sessions in Spanish, Chinese, and English for community members to learn more about the regional center system. It also sponsors a parent group, "Partners in Community Inclusion," which focuses on transition planning and inclusion. Its sessions are in Spanish, Chinese, and English.
- Redwood Coast Regional Center, in expanding its outreach to Latino communities, and has been arranging small group meetings at local sites used by community members. It is providing translation services, as well as transportation assistance, for the meetings. Additionally, the center is finalizing hiring for a Cultural Specialist.
- Alta California Regional Center is continuing to increase its outreach and identification of service needs in geographic regions with lower service utilization. It is hosting more community meetings within the greater Sacramento and outlying sections of the catchment area. ACRC will provide ongoing training for staff and consequently, the service providers to ensure that

services are provided in a culturally sensitive and responsive manner. ACRC will also provide monolingual orientation sessions to the existing culturally and linguistically diverse populations in the system about services and supports that the regional center offers and how to obtain them. The same orientation sessions will be provided to those who are going through the intake and eligibility process. The center's service coordinators have fluency in a total of 16 languages.

- Harbor Regional Center is developing a database of service providers with bilingual capacity to ensure identified linguistic service needs can be met, and is encouraging providers to develop and expand multilingual and multicultural capacity.
- North Los Angeles County Regional Center is collaborating with CSU-Northridge on a "Family Empowerment Team in Action (FETA)" project. FETA consists of CSUN faculty members working alongside graduate student interns, a CSUN Family Focus Resource Center coordinator, and a NLACRC lead staffer to directly assist regional center clients. It will also provide cultural sensitivity training for regional center vendors, as well as advocacy training to encourage clients to utilize educational services. The graduate students work with racially and ethnically diverse populations in identifying needs and facilitating community members in accessing the appropriate services. The regional center is also increasing staff capacities in cultural competency, outreach to underserved populations, and culturally appropriate services and delivery models. Additionally, the center is sponsoring a community education project where they work to educate and engage consumers and their family members on regional center issues and how to advocate for change.

Regional centers have also explored novel approaches to meeting community needs through local partnerships. Each of these unique projects sought to identify service barriers and ways to overcome them, either through the use of existing channels, or the development of new ones.

The Promotora Project[9] *– Frank D. Lanterman Regional Center (FDLRC)*

"Promotoras" are "trained in comprehensive health education curriculum and are uniquely linked to the cultural and regional connections in the community."[10] The Promotora model has been effective in delivering health services to underserved and hard-to-reach monolingual families. FDLRC used this model in its 2013 pilot project and contracted with Esperanza Community Housing Corporation in Los Angeles to address observed disparities in services. The project selected a group of economically disadvantaged Spanish-speaking families. It involved 52 families with at least one member receiving regional center services. The project hired two promotoras who each worked with 26 families. The promotoras provided extra supports to the family with the goals of increasing their access to regional center services, increasing their understanding, knowledge and access of all available generic resources, and providing them with self-advocacy skills through training. The project was successful in increasing the utilization of services offered by FDLRC. It also increased families' access to generic services like In-Home Support Services, Medi-Cal, food banks and transportation available through a generic funding source. It demonstrated that significant gains can be achieved with individualized attention and a greater focus on helping families to overcome barriers such as food insecurity. The program was cost-effective and tremendously successful. The program's success was such that FDLRC has converted the pilot project into a permanent and expanded program. Additionally, the center is developing an analogue of these outreach methods to address similar core service access issues in the Korean community.

[9] The Promotora Project: A Collaboration of Lanterman Regional Center and Esperanza Community Housing Corporation. A report, n.d.

[10] Ibid, pg. 1

Stanford "Design Thinking Process"[11] *– Golden Gate Regional Center (GGRC)*

GGRC was invited by Stanford University's School of Design to participate in their Executive Education program. A "design thinking process" is a methodology for innovation combining creative and analytical approaches, and requires collaboration across disciplines.[12] It draws on engineering and design methods, and combines them with ideas from the arts, tools from the social sciences, and insights from the business world. The process is then learned, internalized, and applied to each participant's organizational challenges to create possible solutions. GGRC staff used the design thinking process in determining areas of need within the agency. Interviews were conducted among different user groups and the results were analyzed to determine the underlying reasons for differences in service utilization. Participants included staff from Family Resource Centers (FRCs), families with children, vendors, pediatricians, psychologists, and GGRC staff. The results and analysis of the interviews pointed to the fact that inaccessibility or lack of initiative to engage in services was not a result of prejudice or discrimination on the part of GGRC, but primarily due to the following factors:

- Constituents don't know about GGRC;
- Distrust of government;
- Disability is a private family matter;
- Process takes too long;
- Socio-economic concerns;
- System is difficult to understand;
- Serious shortage of bilingual service providers; and,
- High caseloads result in focus on "squeaky wheel".

In response to the above findings, GGRC is now engaged in robust resource development of bilingual and bicultural services providers. They are holding stakeholder meetings in Cantonese and Spanish. GGRC is planning to establish mobile assessments, restructure their intake/assessment unit, send out welcome cards, advertise on local television and radio stations, translate available services in languages representative of their populations, and to access grant funding for innovative study and services.

Stanford "Design Thinking Process" – San Andreas Regional Center (SARC)

SARC was invited and participated in the Stanford School of Design Executive Education program in early 2015 and 2016. A team of service coordinators and managers worked with Fellows from the School of Design to determine better ways of connecting with the community. General community members, consumers, and their families, as well as service coordinators, were all interviewed on their perceptions of the regional center and their services. SARC's review and analysis of their data also led to the realization that the community perceived SARC as a faceless bureaucracy rather than a partner in meeting consumers' needs. To address this, SARC designed a series of "coffee socials" and community events (fairs and other language/ethnicity based events) for outreach. SARC also introduced "seize the facetime," which is incorporated into the planning team meetings where personal, positive stories were infused into the process. The activities were well-received and significant positive feedback was given. SARC organized outreach to more distant and vulnerable populations in their service areas such as migrant workers in Santa Cruz and southern Monterey counties. These activities were successful in facilitating increased awareness of and access to SARC services.

[11] Disparity and Design Thinking. Stanford University and Golden Gate Regional Center, n.d., Print. 6 Aug. 2015

[12] "Our Point of View." Dschool. Stanford University School of Design. Web. 15 Sept. 2015. <http://dschool.stanford.edu/our-point-of-view/#design-thinking>.

Westside Regional Center (WRC) – Transition-Age Youth Service Integration Project

During this project, funded through the Mental Health Services Act, WRC worked with the Los Angeles County Department of Mental Health, North Los Angeles County Regional Center, and local service providers to identify the needs of youth and young adults as they transition to adulthood. Specifically, the group examined service needs, patterns of use, barriers to entry into each agency's service system, and challenges in moving between service systems. As a result, the group created a user-friendly, online resource directory to identify and locate services, organization, and general information that support transition-age youth (available at http://reachacrossla.org/programs/la-taysip). In addition, the group organized a series of training events for service coordinators and counselors who work with transition-age youth. Staff learned about Motivational Interviewing, a client-centered communication tools, to assist families in making timely decisions about housing, post-secondary school options, health care, etc.

Community Partnered Research Project By Four LA Regional Centers And The Boone Fetter Clinic[13]

This research project was launched by FDLRC, Eastern Los Angeles Regional Center, South Central Los Angeles County Regional Center, and Westside Regional Center, in partnership with the Boone Fetter Clinic. The project sought to understand the challenges that families in the Los Angeles area faced in accessing developmental screenings, and diagnostic services for their children. The clinic joined with the partner regional centers in identifying 56 African American and Latino parents of children with Autism Spectrum Disorder (ASD) in focus group discussions to help identify and address barriers to care. The three overarching needs identified were: Parent education, assistance navigating complicated service systems, and the need for parental advocacy training. As a result, the clinic is now focused on creating new resources and programs to address the concerns. One program identified that could be implemented to reach out to monolingual Spanish-speaking families is the promotora program; the success of previous iterations of the project were so well-matched to local needs that the clinic is working to convert it into a permanent program.

Enhancing Cultural Competence In Clinical Care Settings[14] *– Central Valley Regional Center (CVRC)*

CVRC partnered with Central California Children's Institute (CCCI) at CSU-Fresno to provide training programs for infant mental health professionals under a Mental Health Services Act grant. With the funding, CCCI developed and implemented a multi-county, multidisciplinary training program for professionals already working with families with young children. The training program provided basic infant-family and early childhood mental health curricula to 320 practitioners of several large public agencies in the CVRC six-county catchment area. Part of the training is Enhancing Cultural Competence in Clinical Care Settings ("The 4Cs"). The 4Cs is a year-long training program in support of the social and emotional needs of young children and their families. It is designed to help professionals who work with young children more effectively address complex needs using evidence-based trainings. The 4Cs focuses on culturally responsive approaches such as Dr. Valerie Batts' "Use of Self as a Cultural Being" and Dr. Connie Lillas' Neurorelational Framework to engage participants in increasing recognition, understanding, and appreciation of differences at the personal, interpersonal, institutional/systemic, and cultural levels. This project increased the number of mental health practitioners in the CVRC area who are skilled in working with populations with non-traditional service delivery needs.

[13] "Cultural Factors Influence How We Experience Autism." The Developing Mind 2015, Winter Edition ed., Research Highlight sec. Print.

[14] "Fresno State." *Enhancing Cultural Competence in Clinical Care Settings (4C)*. Web. 3 Sept. 2015.

Projects In Development
In 2016, the Legislature and the Administration collaborated to provide additional funding to the developmental services system. Some of the additional resources were earmarked for efforts to close the gap in utilization of regional center POS across racial and ethnic lines. $10 million was set aside for grants to fund innovative projects in local communities. Additionally, regional centers each received funding to hire a Cultural Specialist to guide their center in outreach and implementation of cultural programs to promote equity and increase service access.

All twenty-one regional centers submitted proposals to DDS for creative ways to address the issue of POS disparity in their local communities. In late 2016 DDS approved funding for each center to address this challenge in a variety of ways, including:

- Expanded cultural sensitivity training;
- Contracting with community outreach specialists;
- Increased translation and interpretation services;
- Purchase of translation equipment for public meetings;
- Translation of webpages;
- Development of adult services for monolingual consumers;
- Consumer and family promotora projects;
- Korean Community Health Worker project; and,
- Promotion of cultural competency via a network of service providers.

The availability of these funds presents an exciting opportunity to develop theories, test projects, and analyze the results. Regional centers are grateful that funding appears in the Governor's Proposed 2017-2018 Fiscal Year Budget to continue these projects and to expand them.

It should also be noted that the state is in the final stages of revising its application for federal funds for its Self-Determination Program. This is a program that will allow individuals and their families to seek services outside the traditional regional center service delivery model and to better customize their supports to meet their unique needs. This provides another opportunity for members of diverse communities to explore alternative service delivery models.

A Path Forward
While local initiatives are promising, and can address the specific issues that drive utilization differences in specific areas, there remain systemic barriers to additional progress statewide. ARCA proposes the following steps to enhance ongoing efforts:

- Comprehensive Independent Study – As noted earlier, current examinations of POS expenditure data are flawed and incomplete. They provide only hints as to the root causes of the variances in service utilization and few clues regarding next steps. An independent in-depth analysis of the data coupled with community focus groups would provide greater insight into the various reasons for identified differences as well as suggestions based on data and best practices for logical next steps.

- CPP Start-Up Expansion – ARCA supports the proposed Trailer Bill Language that would allow regional centers to fund start-up costs for needed community programs by using Community Placement Plan funds more flexibly. In order to be most effective, these funds should be

available for start-up costs and to allow regional centers to pay sufficient rates for these services. As noted earlier, identified challenges in serving individuals from diverse communities include the lack of available programs with necessary language access coupled with the inability of regional centers to offer start-up funds to assist with program development.

- Reinstatement Of Suspended Services – Restoring camp and social recreation, in addition to lifting the cap on respite, will improve regional centers' ability to provide critical family support services. Participants of regional center POS data stakeholder meetings from diverse communities have expressed that they valued these services and the support they offered to their families.

- Caseload Ratio – The current caseload ratio standards that provide a 1:62 caseload ratio for Medi-Cal eligible individuals with the most regional center funded services and a 1:66 caseload ratio for others, should be modified to ensure that all individuals have equal access in this area. Monitoring of paid supports is critical and time intensive, whether an individual has Medi-Cal or not. Helping individuals to understand systems and to access the services they need, whether funded by the regional center or not, also deserves equal time and attention.

ARCA appreciates the opportunity to participate in a hearing on this critical topic, and the Legislature's interest in better understanding this complex issue. Differences in service utilization are not unique to the regional center system. Regional centers have a strong commitment to ensuring equal opportunity and access to services that are tailored to diverse ethnic, linguistic, and socio-economic needs. This work is driven by empirical data, a recognition of data limitations, and a focus on the needs of individuals and their communities, meeting them where they – and their needs – are. With the ongoing support of the Legislature, regional centers in partnership with DDS can continue to explore new, innovative, and creative ways to better serve all Californians with developmental disabilities.

Sincerely,
/s/Amy Westling
Interim Executive Director

Cc: Members, Senate Human Services Committee
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