

May 15, 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.

Beginning in the 2016-17 Fiscal Year, \$11 million annually became available to enhance services to diverse communities. Regional centers appreciate this targeted funding and look forward to utilizing it creatively in order to enhance communication and outreach and to pilot new services models with the ultimate goal of ensuring access to needed services to individuals from all racial and ethnic communities.

On March 14, 2017, the Senate Human Services Committee held a hearing on differences in purchase of service (POS) expenditures, titled "Moving Toward Equity: Addressing Disparities in Services Provided by the Regional Center System." During the hearing, you asked ARCA to complete and submit a report identifying solutions, including timelines for implementation, that would "move the needle" towards equitable spending. Regional Centers heard the concerns of the advocates, individuals, and their families during the hearing. The ARCA Equity Committee, comprised of representatives from a majority of regional centers, met and determined that the following steps would respond to the common themes expressed at the hearing and enhance ongoing efforts towards equitable spending across ethnic lines for people with developmental disabilities:

- Uniform Caseload Ratios;
- Community Placement Plan Start-Up Funds Flexibility;
- Reinstatement of Suspended Services; and
- A Comprehensive Independent Study.

For each of these proposals, ARCA provides information regarding the root problem, a description of the proposed solution, a timeline for implementation, and how this proposal would "move the needle."

Uniform Caseload Ratios

The current caseload ratio standards 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.

Concerns Raised

During the March 14, 2017 hearing, parents voiced concerns about the availability of information and the accessibility of Service Coordinators. Many families stated that they have a difficult time establishing contact with the Service Coordinator of their loved one. Some also expressed frustration regarding their lack of understanding regarding services available. One parent in particular voiced that the Service Coordinator should study the information on file before meeting in order to provide the family with information about the appropriate services available. Another expressed the belief that Service Coordinators seem particularly focused on meeting their paperwork deadlines. The regional centers understand that the key to a strong working relationship is sufficient time for Service Coordinators to help individuals and their families to navigate complex systems.

Defining the Problem

As a condition of federal funding, the state has assured the federal government that certain caseload ratios are being met for individuals served by regional centers. The mandated caseload for the state's nearly 40,000 infants and toddlers in the Early Start program is 1:62. For the approximately 125,000 individuals funded through the state's 1915(c) Medicaid Waiver, the mandated caseload ratio is also 1:62. For most others, the mandated caseload ratio is 1:66. The primary differences between the Medicaid Waiver (1:62) population and the group assigned a 1:66 caseload ratio are that those on the Medicaid Waiver have Medi-Cal and higher levels of regional center funded services. Immigrants are less likely to have Medi-Cal and those from diverse communities are less likely to access services funded by regional centers.

Regional centers have implemented a variety of mechanisms to try to meet the needs of diverse communities, ranging from multicultural family support groups to bilingual service coordination provided by either regional center staff also partner with other social service agencies that are well-established in underserved communities. Bilingual service coordination, while effective, is more time intensive due to translation and interpretation issues across settings. Higher caseload ratios for this population hamper these efforts.

In 1996, National Association of State Directors of Developmental Disabilities Services (NASDDDS) surveyed 42 states regarding caseload ratios for their developmental services system. The highest caseload was Washington at 1:175 and the lowest was Wyoming at 1:13. The median was 1:40 and California came in at 1:75, the fifth highest. Other states have much lower caseload ratio requirements which give Service Coordinators more time to address the individual needs of the clients.

In the case of California, recently collected data estimated that approximately 19% of individuals served by the developmental services system had no POS authorization. Individuals from diverse communities are less likely to access paid regional center services. Enrollment in the regional center system is voluntary. In most cases, individuals and families without regional center funded supports utilize the in-

depth service coordination offered by regional centers in order to access generic services (i.e., special education, In-Home Support Services, and Medi-Cal) that meet their needs. Unfortunately, due to caseload ratios in California statute, individuals receiving only these intensive and time consuming services are subject to service coordination on the highest caseloads.

Overall Service Coordinator effectiveness is dependent on a robust knowledge of available community resources. Effectiveness with specific individuals and their families is also dependent upon the development of a trusting relationship and understanding of unique hopes, dreams, needs, and dynamics. In an era of increased wariness related to interactions with government agencies, building rapport and trust takes additional time. Large caseloads diminish the success of the service coordination relationship and limit access to the most appropriate services.

Solution

The Service Coordinator's scope of activities has grown tremendously over the years due to federal and state regulations. The increase in bureaucratic activities, primarily paperwork, has lessened the opportunity for the Service Coordinator to meet face to face with consumers and assess the needs of the consumer. The Service Coordinator must balance a high caseload, increased bureaucratic activities, and attempts to build relationships with families reluctant to reveal concerns to people they do not intimately know.

Caseloads that are manageable provide Service Coordinators with more opportunities to engage with families. By establishing a uniform caseload ratio of 1:62, like the 1915 (c) federal program, a Service Coordinator would be allowed more time to devote to each client and family.

Timeline for Implementation

Decreasing caseload ratios is dependent upon the Budget process. In order to decrease the caseload ratios, regional centers would need to have to hire new staff. It is incumbent upon the state to prioritize caseload ratios, in order to address the issue of uneven service coordination resources as soon as possible.

Moving the needle

Decreasing the caseload ratio, will allow the Service Coordinator more time to develop an in-depth Person Centered Plan. The more time allowing for exploration of individual needs, will lead to services that are tailored and often times more creative and culturally responsive. Therefore, the natural consequence of reducing the caseload ratio, is higher utilization rates of individualized services.

It is important to note that historic underfunding of Service Coordinator salary and benefits has resulted in higher caseloads than allowed for in California statute. Currently, 95% of the regional centers are not able to meet the mandated 1:66 caseload ratio for those not enrolled on the Medicaid Waiver. While enacting a uniform caseload ratio of 1:62 would significantly improve this situation by providing funding for over 130 new Service Coordinators, this step alone would not ensure that each individual was served on a caseload of no more than 62 people.

Community Placement Plan Start-up Funds Flexibility

The Community Placement Plan (CPP) is a program designed to support individuals exiting the developmental center by providing funding for resource development solely for individuals that recently resided in or are at risk of entering one of the state's developmental centers or another institutional setting. In its 2017-18 Fiscal Year Budget, the Administration has proposed allowing these funds more flexibly for additional populations. ARCA supports this proposed Trailer Bill Language, as it provides an opportunity to develop programs needed to support a wider range of individuals. 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. One challenge in serving individuals from diverse communities is the lack of available programs with necessary language access and culturally competent service models, which is exacerbated by the inability of regional centers to offer start-up funds to assist with needed program development.

Concerns Raised

During the hearing, many families from throughout the state voiced concerns about the lack of services available in rural communities. More specifically, parents expressed that even though their child was approved for behavioral services or supported living services, there was no provider available to provide the service in their area. These concerns have been recognized by the Administration, and ARCA hopes that this issue can be resolved by the implementation of policy that allows the regional center the opportunity to utilize Community Placement Plan funds more flexibly to support needed community programs.

Defining the problem

Prior to 2003 Program Development Funds were a critical resource to jumpstart the establishment of services to meet emerging or unmet community needs. Since 2003, however, Welfare and Institutions Code §§ 4781.5 and 4781.6 have restricted regional centers from using funds to start new programs for individuals who are not exiting or at risk of entering institutional settings. For almost the last fifteen years, the ability to offer start-up funding for other populations has been limited to just two circumstances – the protection of client health and safety, or “extraordinary circumstances.” The regional center must receive prior written approval from DDS in either case. Starting programs to meet the general needs of diverse communities typically will not rise to these thresholds.

There are a number of different reasons start-up funding is helpful in establishing services within a given geographic area (as indicated by a needs assessment). The ability to establish services closer to where individuals live improves access to services in their own communities, lessens the potential for a language barrier, and can be more cost-effective by decreasing the need for an extensive transportation network and its related travel time for individuals and families.

Solution

Many individuals supported by regional centers require services that are responsive to their linguistic and cultural needs. The Individual Program Plan process requires that services be tailored to the person. New models of service delivery are needed that focus on more integrated systems that deliver better value to these beneficiaries. There is a need to focus on resource development that will address the needs of diverse communities and a mechanism to provide start-up funding and reasonable rates to support the identified services. Services need to be able to meet language needs and be culturally congruent. Start-up funding to develop these services and supports are needed. The ability to provide on-going funding to recruit and retain staff that can both speak and provide culturally competent

services is needed. Regional centers would like to work with the communities to identify innovative models of service that meet the cultural and linguistic needs of individuals and families.

DDS has recognized that resource development for all individuals is essential (not just individuals residing in state developmental centers). In fact, DDS is proposing in Trailer Bill Language “a plan to provide dedicated funding for increasing community capacity to provide services and supports to other consumers who live in the community.” If approved, this proposal would establish an avenue for additional funding to develop the programs in diverse communities. Moreover, since there is not a "one-size-fits-all" treatment regimen, programs must be designed and tailored to each individual. The absence of programs in some of California’s most diverse communities is contributing to disparity in service delivery.

Timeline for Implementation

The Governor has included this Trailer Bill Language in his January Budget proposal. ARCA appreciates the Administration’s proposal and the careful consideration the Administration has given this issue. After the passage of the Trailer Bill Language, Requests for Proposal (RFP) will be issued. Statewide meetings that have been held will inform the services that will resonate with the communities and encourage utilization. It is important to note, that the (RFP) process, development of a vendor pool, and the subsequent implementation of services generally takes 1-2 years following the approval of funding for these functions.

Moving the Needle

Statewide, linguistically diverse and culturally competent programs will be developed following the enactment of Trailer Bill Language. Progress will be made through creative, collective and systematic thinking about culturally appropriate service development. There must be active engagement with the community, stakeholders and individuals in order to assure the resulting services are congruent with the desire of the people. The people will participate in and utilize services they request.

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 the Senate Budget Hearing and the regional center POS data stakeholder meetings have expressed the value of these services and the support they offered to their families.

Concerns Raised

The most mentioned service during the hearing was respite. However, families also spoke of their ongoing interest in accessing camp and social recreation programs. Many families and advocates expressed how they have been negatively affected by the Trailer Bill Language of 2009 that limited family support service options.

Defining the Problem

In response to budgetary challenges in 2009, Trailer Bill Language was implemented to temporarily limit respite services and suspend the regional centers' ability to purchase most camp and social recreation services. These critical family support services were to be restored after the state implemented the Individual Choice Budget which it is no longer pursuing. Even years later, the restrictions on these services continue to hurt individuals and their families. They disproportionately harm minority communities, yet have a very modest impact on the Budget. Families continue to fight to receive these services – often the only services they need or want. According to DDS data, during the first half of 2015, regional centers received 10 fair hearing requests related to camp services, 64 related to respite, and 17 related to social recreation services.

Individuals requesting these services generally reside with their families. Keeping families together supports the choice of the individual and family, while saving the state significant money. Those from ethnically diverse backgrounds are far more likely to live with their families in adulthood. 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.

Solution

Recently collected data indicates that 39% of Caucasians live at home with their family, for Hispanics and Asians the rate is 73% and 49% for African Americans. Recently collected data also indicates that individuals more likely to stay at home have historically used respite, social and recreational program at a much higher utilization rate. In 2007-2008, per capita spending for Caucasians using socialization programs was \$4,377, while it was \$5,032 for Hispanic and \$6,936 for African Americans. This is further evidence that upholding the suspension of these services, is not conducive to the state's goal of equitable across racial lines for people with developmental disabilities.

Changes which impacted regional centers' ability to purchase many services have had a permanent and negative impact on families and children with developmental disabilities. Regional Centers must have flexibility to provide whatever a family needs in a culturally responsive manner. Regional Center's ability to support families is becoming very challenging without the ability to provide services to families that choose to take care of their loved one in their family home.

Timeline for Implementation

These programs have not been available for over seven years, so vendors may not be available to carry out the restored services and therefore would be required to undergo the vendorization process. Regional centers system will collaborate with community agencies in order to notify individuals throughout the state of the availability of the services and the need for an adequate vendor pool to meet the needs. While respite services could likely be expanded to meet increased service authorizations relatively quickly, it is worth noting that developing an adequate vendor pool for services that are currently unavailable, and subsequently implementing them is a 1-2 year process.

Moving the Needle

In regards to the respite cap, the effect of the reinstatement will be evident almost immediately by removing the limitations. After development of the social and recreational programs, data will show a decrease in the number of individuals without an open Purchase of Service Authorization and an increase in service utilization.

Comprehensive Independent Study

It is without question, that Purchase of Service (POS) expenditure data is flawed and incomplete. The data provides 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.

Concerns Raised

There was a great deal of testimony expressing that more should be done to determine the reasons for the gap in spending between individuals of different racial and ethnic groups. Some individuals suggested that the disparities are due to macro issues related to overall state funding allocation practices, while others suggested that the service system as a whole is not sensitive to differing cultural norms and values.

Defining the Problem

A closer examination of the statewide data reveals that expenditure patterns by ethnicity change with age. For instance, while per capita spending for all groups increased between school-age and adulthood, the rate of increases for different ethnicities is not uniform. These trends suggest a complex interrelationship between age, ethnicity, utilization of paid regional center supports, and other factors.

Beginning in 2013 each regional center began meeting with stakeholders in their community to discuss prior fiscal year Purchase of Service (POS) expenditures for different ethnic and linguistic groups. Since then, each regional center has conducted these meetings, discussed the information, requested input from attendees, and subsequently made program improvements in an attempt to close the funding gap between groups. Additionally, legislative mandates have been enacted targeting this same issue. For example, beginning in 2015 SB 1093 (Liu) allowed a person living with family to receive independent living services. SB 555 (Correa) mandated the provision of increased interpreter and translation services beginning in 2014. These efforts have not produced significant enough progress towards achieving the goal of equitable spending, suggesting the presence of lingering unanswered questions that better explain the roots of the problem.

Previous statewide studies on this topic have hypothesized regarding potential social and economic factors that could be contributing to the POS disparity, but have not been thorough enough to answer the question at hand. One study conducted in 2004 noted that “cultural differences were likely correlated with education, income and general knowledge about the service system” in service delivery. Another in 2006 “found that children in families with higher incomes have an advantage in obtaining services and in identifying unmet needs. Higher-income families *may* have greater education and knowledge and may be better able to obtain services or to advocate for their services needs” (emphasis added). A March 2016 study found “CDDS (California Department of Developmental Services) does not collect data on family income. It *could be* that the racial disparities observed in these data reflect low income of minorities rather than purely racial or ethnic differences” (emphasis added). That study also noted that the total value of services being received by an individual through other sources could not be accounted for due to a lack of available data.

Various other studies have similarly posed the following questions related to this topic:

- Is family income, ethnicity, or limited English proficiency (also known as “linguistic isolation”)ⁱ the better predictor of the level of regional center-funded services that an individual will access?
- Are there differences in care-seeking behavior due to differing cultural beliefs and preferences?
- Does personal or family choice drive the level of regional center funded services that are accessed?
- Are there inequities prevalent in the developmental disabilities services system based on a lack of culturally competent services, linguistic barriers, socioeconomic, access to other community resources, or other factors that in some way limit access to services and negatively impact utilization of services?
- Why are expenditure patterns different between different ethnic groups when examining them by age group?

Solution

ARCA proposes a study to better understand the root causes and implement effective strategies to address barriers to access and service utilization. Statewide data from the Department of Developmental Services illustrates that individuals who are not Caucasian access, on average, fewer paid supports through regional centers. While no study is needed to establish that disparities exist, little information is available about the root cause of these differences. A study is needed to identify the underlying reasons for variances in utilization of regional center-funded services by different ethnic/racial groups and recommend solutions for ameliorating this.

As noted above, there are several unanswered questions related to the impact of ethnicity and other factors on utilization of regional center-funded services.

A study could better shape service delivery on the local and statewide level, provide a detailed analysis specific to each region of the state, and connect community leaders throughout the region. It is time to seek the direct input of individuals and families to the barriers that directly affect service delivery.

Timeline for Implementation

Regional centers will utilize the information provided through these various avenues to inform their efforts to make the services provided at the local level more responsive to the needs of individuals from diverse communities. A thorough academic study could be completed within two years. Depending on the results, programmatic changes informed by the outcomes of the study would follow.

Moving the Needle

An effective and thorough study will ensure that advocates and individuals are offered the opportunity to contribute information that may result in changes to practice that results in changes in their community. Individuals and families are more likely to use those services they had a hand in shaping and creating, resulting in increased utilization of POS funded services.

ARCA commends the Administration and the Legislature for its continued interest in this topic and their efforts to assist the regional centers in implementing the necessary programs to promote equity and reduce disparities at the local level through the funding initiated in ABX2 1. After consultation with their communities, every regional center submitted proposals to DDS to improve equitable service access. DDS approved and allocated funding to support many of the proposed projects. Regional centers have begun to implement these promising programs, but as it is the first year of the available funding, it is important to note that these programs are in their infancy. As these projects mature and develop, ARCA is confident that they will positively impact the lives of many individuals and their families from a variety of racial and ethnic backgrounds. It is imperative that we evaluate the programs over time and look to data and stakeholder feedback to determine which ideas and projects have the most promise and should be continued and expanded.

Regional centers take the concerns raised during the hearing very seriously and remain committed to ensuring all Californians with developmental disabilities receive the culturally sensitive services and supports they need. ARCA extends its utmost gratitude to the families, individuals and advocates that testified at the “Moving Toward Equity: Addressing Disparities in Services Provided by the Regional Center System” hearing who shared their personal experiences and insights. We would like to thank the Senate Human Services Committee for convening this hearing and promoting equitable spending for all individuals with developmental disabilities. The regional centers look forward to working with the Administration, the Legislature, advocates, individuals, and their families in order to create opportunities to meet the needs of all served.

Sincerely,

/s/Amy Westling
Interim Executive Director

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