Joint Recommendations to Address Race and Language Disparities In Regional Center Funding of Services for Children
Senate Human Services
March 14, 2017

1. DDS’ POS budget and allocation methodology must be reformed.

Our review of the purchase of services (POS) disparity data indicates that there are vast differences in the distribution of authorized services among regional centers; overall, regional centers that provide the lowest amount of POS are those with larger Hispanic and Black/African-American populations. DDS’ current method of allocating funding among regional centers does nothing to address POS disparities among the regional centers – and indeed perpetuates them.

In April 1998, the Bureau of State Audits (BSA) issued a report concluding that DDS has been unable to ensure that all developmentally disabled people throughout the State have equal access to and receive the same level of regional center services. The BSA made recommendations which included calling for DDS to develop and pilot a revised POS budget and allocation methodology based on client need.

This issue was raised during the Senate Select Committee on Autism & Related Disorders on April 30, 2012, when Senator Darrell Steinberg raised the issue of disparities across the various regional centers in the amount of services received by low-income families. Terri Delgadillo, then Director of DDS, testified at the hearing about DDS’ current budget and allocation methodology. Ms. Delgadillo explained that DDS determines each regional center’s POS budget based on what the regional center spent from the prior year, and any additional money is distributed for caseload and for utilization growth. Ms. Delgadillo acknowledged that this methodology was problematic, and that the goal was to move towards a client needs based methodology that “would be blind to ethnicity.”

The Equity and Diversity Taskforce, convened by Senator Steinberg’s office, recommended in 2013 that DDS report to the legislature on the status of the budget and allocation methodology for regional center funding, and that DDS create a
process for developing a new budget methodology that is transparent and provides opportunities for consumer and public input. These Taskforce recommendations have yet to be pursued by the Legislature.

The Legislature should appoint an independent task force, accountable directly to the Legislature and not to DDS, and provide sufficient operational funds for that task force, to address the disparate impact that DDS’ POS budget and allocation methodology has had on minority families, which has persisted for decades as a result of the inequitable allocation of POS funds by DDS among the regional centers. This task force should provide its recommendations to the Legislature by December 31, 2017, and a new POS budget and allocation methodology should be implemented for the next fiscal year so that the underlying funding system will hereinafter be “blind to ethnicity” as the former Director of DDS previously testified. The status quo is unacceptable.

2. The statutes which suspended certain services and instituted restrictive respite service standards should be repealed.

Under the current statutes, the lifting of the limitations on accessing these services is contingent upon DDS developing, implementing and certifying an Individual Choice Budget purchase of services budget methodology, something which has been dormant for years with no foreseeable date of completion. California Welfare and Institutions Code (WIC) §§ 4648.5, 4648.6, and 4685.5. The restrictions on these services were supposed to be temporary, per DDS’ Budget Summary of 2009. The State has broken its promise to consumers and the families that these were temporary restrictions. These services should be fully restored to their pre-2009 status.

3. If the statutes are not repealed, consumers and their families must be provided with written information on how to access these services through the exceptions and exemptions processes before the program planning meeting.

Law was enacted in 2010 (SB 853) to require regional centers to explain through adequate notice after a service denial has been made whether the consumer is eligible for an exception or exemption and to provide a citations to the laws themselves, which are very complex. WIC § 4701.1. However, regional centers should provide this information in writing in accessible, understandable language in advance of the planning meeting so that families can be better informed and engaged in the planning process. Currently, families are forced into a dichotomy of having to make their case hastily for these services through the formal adversarial fair hearing process, where timelines to appeal such denials are only 30
days from the date of receipt of the adequate notice. The current law places unnecessary pressure on families and literally puts them on the defense in simply trying to be better informed on how to access services for their children.

4. **Consumers and their families must be provided with a complete list of all services available before the program planning meeting.**

The Lanterman Act establishes a person-centered approach for the provision of services to persons with developmental disabilities. It is developed through the process of individualized needs determinations centered on the consumer and his/her family and is intended to provide them with opportunities to choose where and with whom they want to live, with whom they socialize, how they spend their time, what jobs or activities they will have, and other aspects of their daily lives. Consumers and their families cannot effectively plan for their own future unless they are fully informed of the services and supports available to them. The IPP is a contract between the consumer and the regional center\(^1\), not a shell game. Critical information such as what services and supports are available through the regional center must be disclosed **before** this contract can be formed.

5. **Consumers and their families must be provided with written information about the appeals and complaints processes before the program planning meeting.**

A fundamental aspect of the IPP process is the right afforded to consumers and their families to appeal any decision made by the regional center which they disagree with or believe is not in their best interests. The right includes the option for a fair hearing, voluntary informal meeting, an opportunity for voluntary mediation, and the consumer compliant process.

Law was enacted in 2008 (AB 1402) to require each regional center to conspicuously post on its Internet website a link to DDS’ Internet website that provides a description of the appeals procedure and a department telephone number available for answering consumer and supplicant appeal procedure questions. WIC § 4704.6. However, not all consumers and families have access to the Internet and/or are able to understand the posted online procedures. The regional centers should provide this information in writing in accessible, understandable language **in advance** of the planning meeting so that families can be better informed and engaged in the planning process. Considering the overall

\(^1\)“While it is true that regional centers have ‘wide discretion’ in determining how to implement the IPP, they have no discretion at all in determining whether to implement it; they must do so. (§4648).” *Association of Retarded Citizens- California vs. Department of Developmental Services* (1985) 38 Cal.3rd, 384, 390. (italics in original).
goal of the IPP is to facilitate consumer participation and advocacy, this additional requirement should only further that goal.

Children and families participating in the Early Intervention program should already be receiving this information before the IFSP in order for the State to be compliant with federal IDEA special education law, which requires prior written notice to be provided before these meetings. 34 C.F.R. § 300.503.

6. **Consumers and their families must be provided with a list of the services agreed upon and their anticipated start dates and those services for which final agreement is still outstanding at the end of the program planning meeting.**

The regional centers should provide this information at the end of the program planning meeting so that families can be better informed and engaged in the planning process. ELARC and NLACRC’s current practices of providing a one-page document provide to examples of how this can be done. See attached.

When DDS conducted its statewide stakeholder meetings in August 2016, one of the key issues identified was the lack of trust, and history of mistrust, between families and the regional centers, and families and the service providers. See attached. Providing consumers and their families with a short summary of the services agreed upon and services for which final agreement has not been reached at the end of the IPP meeting should help to restore trust. Consumers and their families will have a tangible document that they can refer to in getting agreed-upon services implemented prior to receiving the written IPP document itself, which can take anywhere from 45 days to 60 days to receive under the law. Additionally, this document will help remind families to timely pursue services for which there is still outstanding agreement with the regional center and thus protect against service requests falling through the cracks.

7. **Regional centers should be required to ensure no gaps in services occur when a consumer has been denied medical or dental services by a generic agency that have been agreed upon through the program planning process.**

Regional centers are ‘payers of last resort and should cover services that consumers cannot obtain through other sources such as Medi-Cal, private health insurance, schools, etc. In 2009, however, DDS imposed stricter rules to require consumers not only to pursue other sources for medical and dental services before seeking these services from regional centers, but also to provide documentation of service denial, and of the consumer’s efforts to appeal the denial. The result is
that families are required to appeal decisions denying their child access to critical services such as occupational or physical therapy, speech or language services, or dental services before the regional center will agree to pay for these services. Although regional centers may pay for the service pending the outcome of the appeal with the generic agency, regional centers rarely do so despite clear need.

Regional centers apply these requirements even though the state would not save any money in many cases because the services are Medicaid eligible regardless of which agency provides the services. The consequence is that low-income families that use Medi-Cal do not have the time, resources or skills to appeal an adverse Medi-Cal decision and thus, forego the service. The law should be changed to require the regional centers to pay for medical and dental services pending coverage by the generic agency.

8. **Regional centers must be prohibited from denying, delaying or reducing ABA or intensive behavioral intervention services due to the lack of parent or caregiver participation.**

Current law allows regional centers to deny behavioral intervention services to children whose parents cannot meet demanding requirements to attend group instruction classes, because the parents work two jobs, lack transportation or child care, have their own medical issues, or face similar hardships. The law should be changed to require regional centers to help facilitate parent participation whenever possible, but not deny, delay, or reduce behavioral services due to the lack of parent or caregiver participation. The California Health Benefits Review Program, in analyzing SB 1034 (2016), concluded that “behavioral health treatment improves outcomes regardless of the extent of parent involvement.” Special Needs Network and Public Counsel strongly believe that children should not be deprived of necessary services simply because of their family circumstances.

Considerable variance exists among the twenty-one regional centers on the parent participation criteria for authorizing intensive behavioral intervention services. Intensive behavior intervention services are services billable under the HCBS Waiver. Yet, California has not sought a waiver of the federal Medicaid requirement of “statewideness” as part of its 1915(c) or 1915(i) Waivers. Under the statewideness provision, services must operate uniformly across the state. *Morgan v. Cohen*, 665 F. Supp. 1164 (E.D. Pa. 1987).

Additionally, regional centers may be imposing stricter standards for accessing these services than what the Medi-Cal managed care plans are requiring of families under WIC § 14132.56, thereby implicating the Medicaid provisions of

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2 For example, see *Claimant vs. Eastern Los Angeles Regional Center, Case No.:2015040222* (2015).
“single State agency.” Each state plan must designate a single State agency to administer and supervise implementation of the Medicaid plan. 42 U.S.C. § 1396a(a)(5). Once designated as the single state agency for Medicaid, this agency may not delegate the administration of the program or any activities related to rule-making and policy development to any entity other than its own officials. 42 C.F.R. § 431.10. In California, the single State agency is the Department of Health Care Services, not DDS or in-fact delegated regional centers.

9. Portions of the Managed Care Organization (MCO) Tax revenue earmarked for reducing POS disparities should be redistributed.

Last year, the Legislature passed through special session a managed care organization (MCO) tax which now taxes all healthcare plans in the State, thereby generating approximately $1.35 billion dollars to the State. With this additional revenue, the Legislature concurrently passed AB 2 X 1, which brought over $400 million into the regional center system, including $11 million allocated specifically to address POS disparities. Another $400 million is expected to be allocated to the regional center system in 2017, with another $11 million of that earmarked to address POS disparities.

WIC § 4519.5 requires regional centers to implement recommendations and plans to promote equity and reduce disparities in the purchase of services. AB 2 X 1 amended section WIC § 4519.5 to require DDS to allocate funding to the regional centers in order to assist with the implementation of the recommendations and plans. Allocated funding may be used to fund activities including, but not limited to, pay differentials supporting community-based service providers direct-care bilingual staff, parent or caregiver education programs, regional center staff cultural competency training, outreach to underserved populations, and additional culturally appropriate services types or service delivery models.

Some of targeted annual funding to reduce POS disparities relating to parent or caregiver education programs should be redistributed from the regional centers and instead be made available to nonprofit groups by way of requests for proposals (RFPs) to DDS so that those organizations who have established working relationships and trust with marginalized communities can address POS disparities through this means with conflict-free independence.