

Date of Hearing: April 29, 2025

ASSEMBLY COMMITTEE ON HUMAN SERVICES

Alex Lee, Chair

AB 1220 (Arambula) – As Amended March 24, 2025

SUBJECT: Developmental services: denials of services and notices of actions

SUMMARY: Requires regional centers to document the consumer's denials of services, notices of action, and appeals in the individual program plan (IPP); and requires the Department of Developmental Services (DDS) and regional centers to include denials of services, notices of action, and appeals in their annual purchase of service, utilization, and expenditure report.

EXISTING LAW:

- 1) Establishes an entitlement to services for individuals with developmental disabilities under the Lanterman Developmental Disabilities Services Act (Lanterman Act). (Welfare and Institutions Code [WIC] § 4500 *et seq.*)
- 2) Requires DDS to:
 - a) Post data relating to purchase of service authorization, utilization, and expenditure across various demographics on a statewide aggregate basis;
 - b) Provide trend analysis on the changes observed in this data over time, and to post this information;
 - c) Maximize transparency whenever possible, including aggregation by region; and,
 - d) Consult with stakeholders twice a year to review purchase of services data and identify barriers to equitable access to services and supports among individuals and develop recommendations to help reduce disparities in purchase of service expenditures. (WIC § 4519.5)
- 3) Requires decisions concerning the consumer's goals, objectives, and services and supports included in their IPP to be made by agreement between the regional center representative and the consumer or, when appropriate, the consumer's parents, legal guardian, conservator, or authorized representative, at the program plan meeting. (WIC § 4646(d))

FISCAL EFFECT: Unknown, this bill has not been analyzed by a fiscal committee.

COMMENTS:

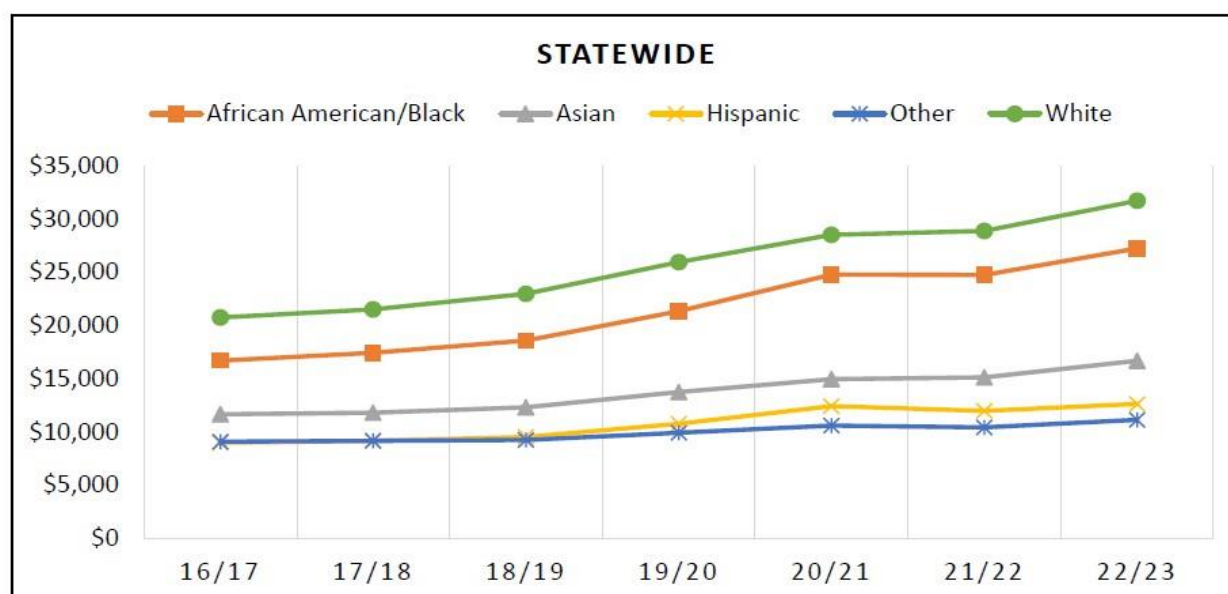
Background: *Inequitable Service Delivery for the Intellectually and Developmentally Disabled Population.* In recent years, lawmakers and advocates have sounded the alarm to mitigate the disparities in services. In 2016, the Legislature authorized the Service Access and Equity grant program through ABX2-1 (Thurmond), Chapter 3, Statutes of 2016, which allocated \$11 million in ongoing General Fund resources for DDS to assist regional centers in reducing Purchase of Service (POS) disparities. In 2017, AB 107 (Committee on Budget), Chapter 18, Statutes of 2017, additionally allowed community-based organizations to receive Service Access and Equity grant funding. These grants funded projects such as community navigators and promotoras;

multilingual parent education, training, and outreach; cultural competency trainings; person-centered planning within diverse communities; and bilingual pay differentials to support workforce capacity, among other projects.

Unfortunately, the available data suggest relatively little movement in terms of reducing spending disparities since equity grants were first introduced. The Little Hoover Commission reported that they found inconsistencies in data reporting, technologies, vendorization processes, support for regional center governing boards, and availability of client support (*A System in Distress: Caring for Californians with Developmental Disabilities*, 2023). To address the lack of consistent and clear data, SB 138 (Committee on Budget and Fiscal Review), Chapter 192, Statutes of 2023, was enacted. SB 138 required common data definitions for race and ethnicity, preferred language, residence codes, sexual orientation, gender identity, and legal status as well standardization for assessments, IPP procedures, intake, and vendorization.

Purchase of Service. As required by the Lanterman Act, regional centers are responsible for assisting persons with developmental disabilities and their families in securing services and supports which maximize opportunities and choices in living, working, learning and recreation in the community. While there are different ways to measure the equity in the delivery of Intellectual and Developmental Disabilities services of the distribution of these services and supports, many advocates point to the clear disparity in dollars spent. Overall, the Hispanic population has the lowest dollars spent, as demonstrated below, while White consumers spent significantly more. The graph illustrates the trends from Fiscal Year 2016/17 – Fiscal Year 2022/23:

Trends in Average POS by Race/Ethnicity



Data Source: Client Master File and State Claims File records. Run date: January 30, 2024. Data reflects all consumers with active status (1,2,3,8,U), regardless of whether or not services were received. Note: Although most claims are received within 6 months of service receipt, FY 22/23 data may not include all claims.

An important nuance is that expenditures differ greatly depending on whether a consumer lives at home (i.e., in the family home) or in a licensed residential setting. For consumers of all ages,

the average annual POS for consumers living out-of-home in 2022-23 was approximately nine times higher than POS for consumers living at home versus consumers living in a licensed residential setting, at \$80,293 and \$9,063, respectively.

Currently, DDS and regional centers are required to compile an annual report which includes: purchase of service authorization, utilization, and expenditure broken into age of the consumer, race/ethnicity, preferred language, disability, residence, number of instances an IPP was requested and provided, and effective 2023-24, the numbers, percentages, and total and per capita expenditure and authorization amounts for specified services. *This bill* would add denials of services and notices of action to this report. The following is the Total Annual Expenditures and Authorized Service by Race/Ethnicity from the 2023-24 Purchase of Service Report:

All ages						
	Individuals Count	Total Expenditures	Total Authorized Services	Per Capita Expenditures	Per Capita Authorized Services	Utilized
American Indian or Alaska Native	1,718	\$ 45,549,399	\$ 67,909,120	\$ 26,513	\$ 39,528	67.1%
Asian	44,747	\$ 852,815,052	\$ 1,246,386,409	\$ 19,059	\$ 27,854	68.4%
Black/African American	40,142	\$ 1,174,713,377	\$ 1,642,533,499	\$ 29,264	\$ 40,918	71.5%
Hispanic	215,937	\$ 2,951,769,305	\$ 4,446,694,016	\$ 13,670	\$ 20,593	66.4%
Native Hawaiian or Other Pacific Islander	979	\$ 20,375,432	\$ 28,472,576	\$ 20,812	\$ 29,083	71.6%
White	125,572	\$ 4,331,102,127	\$ 6,261,057,457	\$ 34,491	\$ 49,860	69.2%
Other Race/Ethnicity or Multi-Cultural	75,733	\$ 876,624,429	\$ 1,421,191,007	\$ 11,575	\$ 18,766	61.7%
Total	504,828	\$ 10,252,949,121	\$ 15,114,244,084	\$ 20,310	\$ 29,939	67.8%

Individual Program Plans. IPPs are developed by a series of planning discussions and interactions with the IPP team—including, among other individuals, the consumer, their legally authorized representative, and one or more regional center representatives—and is based on the consumer's needs and choices. IPP meetings are designed to help people with developmental disabilities outline in a person-centered manner a “preferred future” by identifying a preferred place to live, favorite people with whom to socialize, and preferred types of daily activities, including preferred jobs.

As required by the Lanterman Act, the IPP promotes community integration and maximizes opportunities for each consumer to develop relationships, be part of community life, increase control over their life, and acquire increasingly positive roles in the community. The IPP must give the highest preference to those services and supports that allow minors to live with their families and adults to live as independently as possible in the community. The recommendations set forth in each IPP are the foundation for each individual's care as it guides services received, eligibility for services, and can help assist in the quality of life for that individual.

Each regional center operates independently. As such, the development of each IPP varies in forms and specific processes used; however, the general guiding steps are similar and are as follows: Once an individual or their representative contacts a regional center there is an initial basic intake and then the family will wait up to 120 days for an assessment. Proceeding the diagnosis and eligibility determination, an IPP meeting will take place to determine services needed and desired. The IPP can take multiple meetings or discussions until a plan is settled on. Federal law dictates that this plan is to be renewed annually, and should be determined by the guiding rules stated above. However, families can request an IPP meeting at any time.

This bill will now require the IPP to include all of the consumer's denials of services, notices of action, and appeals.

Author's Statement: According to the Author, "Californians with developmental disabilities have the right to live independent and full lives. Historically, the Regional Centers of California have facilitated key access to support and services through local providers. This bill will ensure equitable access to services for individuals with developmental disabilities."

Equity Implications: *This bill* seeks to collect more data on the discrepancies in services accessed by consumers by requiring data to be reported annually and documented in the consumer's IPP. Increased transparency may help DDS and regional centers close access gaps by understanding where there might be inequities occurring.

RELATED AND PRIOR LEGISLATION:

SB 138 (Committee on Budget and Fiscal Review), Chapter 192, Statutes of 2023, see comments above.

AB 107 (Committee on Budget), Chapter 18, Statutes of 2017, see comments above.

ABX2-1 (Thurmond), Chapter 3, Statutes of 2016, see comments above.

REGISTERED SUPPORT / OPPOSITION:

Support

El Arc de California (Sponsor)
AbilityFirst
California Respite Association
California State Council on Developmental Disabilities (SCDD)
Easterseals Northern California
Exceptional Family Resource Center
GANAS
Ives Torres Foundation
The Arc of Ventura County
15 private citizens

Opposition

None on file.

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