

Background and Process for Developing Disparity Measures

Disparities in the Regional Center (RC) System

Data for California's developmental disabilities system shows notable differences in service access among racial/ethnic and language communities. For example, in Fiscal Year (FY) 2015/16, average annual Purchase of Service (POS) expenditures were \$11,952 for consumers who identify with a racial/ethnic group other than White, while POS expenditures for White consumers averaged \$22,140.¹

Some differences in POS expenditures likely reflect the values of specific cultural groups. For instance, individuals in one group may tend to prefer to care for family members at home, while individuals in another group may more often select out-of-home residence. In addition, broad measures, such as comparisons of POS without regard to age or residence, fail to account for differences in service need among consumers. A larger share of Hispanic consumers are age 3 through 21 years than is true for White consumers, for example; those younger consumers likely receive many services through the school system rather than through POS, reducing average POS for Hispanic consumers as a group.

However, our diverse communities have identified a number of cultural and linguistic barriers in the RC system that are seen as impediments for service delivery. Examples of issues identified by stakeholders include: lack of clear descriptions of services available; limited availability of materials in consumers' primary language; service providers not being able to communicate in a language the family speaks; assumptions about families' preferences, which may not reflect the families' cultural values; and incorrect expectations that all families are equally comfortable asking for help and following up when services are denied, while in fact norms about those behaviors vary considerably among cultures.

Developing Measures to Track Progress in Reducing Disparities

On March 14, 2017, the Senate Human Services Committee requested that the Department of Developmental Services (the Department) identify ways to track progress in reducing disparities in service access in the RC system. The Department was also asked to set short- and long-term improvement targets for those measures.

The Department's goal in developing the measures is to identify a relatively small number of key indicators that may serve as bellwethers for system change. A tremendous quantity of data about the RC system is available on the DDS and RC websites – more than can easily be monitored to see overall progress or areas of concern. In contrast, the disparity measures provide a concise summary that is easy to compare over time.

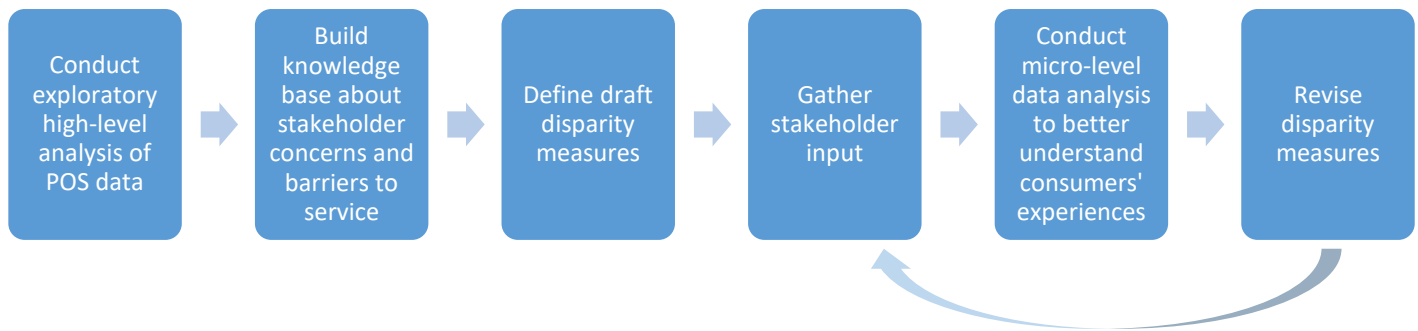
¹ Department of Developmental Services analysis of regional center data as of October 18, 2018. Excludes consumers with missing or multiple race/ethnicity, generic services provided outside the regional center system, services funded through contracts, and some services provided through private insurance.

Some measures center on a small segment of the RC consumer population, such as the ethnic group with the lowest POS expenditures for a certain service, with the expectation that if that group experiences positive change, other groups probably do too. The disparity measures explore differences in consumers' experiences with RCs, focusing on concerns or critical service needs identified by consumers, families and stakeholders. The measures assess communities' status at several key points in their engagement with RCs, including initial assessment; services received at different ages (birth through two years, three through 21 years, and adults); and supports for critical consumer development goals such as adaptive and independent living skills. In many cases, outcomes for one or more communities of color are compared to outcomes for Whites, under the assumption that outcomes for Whites are the highest that any group is likely to achieve.

The Department used an iterative methodology to inform findings from data analysis with input gathered from families and stakeholders, as illustrated in Figure 1.

- The process began with a high-level analysis of POS data to identify where significant differences occur.
- Those initial findings were checked against current information about causes and consequences of service disparities from sources such as the Department's *Purchase of Services Study II*, legislative hearing materials, research studies and material from stakeholders.
- Information about consumer, family and stakeholder concerns was obtained from testimony at the March 14, 2017 Senate Human Services Committee disparities hearing; public statewide disparity meetings hosted by the Department in August 2016 and November 2017; themes and comments reported by RCs from public disparity meetings and RC disparity plans submitted to the Department; discussion with the Association of Regional Center Agencies, the Department's Director's Disparities Advisory Group and California's Community of Practice Transformation Leadership Team; proposals from RCs and community-based organizations for two rounds of disparity project funding under Assembly Bill (AB) X2 1 (Chapter 3, Statutes of 2016, 2nd Extraordinary Session); and ongoing community engagement by Department staff with a broad range of stakeholders.
- A draft set of disparity measures was developed.
- Additional data analysis responding to community input and feedback from advisory groups helped focus on indicators of specific inequities in service access.
- The Department anticipates that RCs, working within existing resources, will substantially reduce disparities. The measures' continued validity in reflecting consumers' experiences will be assessed on an ongoing basis using stakeholder input and data analysis, and the measures will be revised as appropriate.

Figure 1: Process for Developing and Revising Disparity Measures



Identification of disparity measures was also guided by a set of principles related to relevance and data quality. According to these principles, measures should:

1. Reflect concerns articulated by consumers, families and other stakeholders;
2. Use data currently being collected for all regional centers (RCs) to allow for comparisons within the RC system and over time, while recognizing the limitations of available data;
3. Focus on consumers' outcomes rather than relying on measures of RC program inputs;
4. Be transparent and easy to understand while providing a broad, succinct and meaningful view of disparities; and
5. Be sensitive to demographic differences between racial/ethnic and language groups that affect consumers' need for RC services, such as the share of each racial/ethnic group that is school-age.

The Department also judged that measures should be calculated at a fairly high level of aggregation of ethnic communities: namely, African-American, Asian, Hispanic, Other and White. While the RC system serves an enormously diverse consumer population whose individuals identify with more than 20 detailed ethnic groups, data for smaller groups are much less robust than data for larger groups; data for small groups may present a misleading picture of consumers' experiences.

Each measure will be reported on the Department's website semi-annually at the state level and, as data allows, for each regional center.² It is important to recognize that the measures may not be particularly relevant for all RCs, because RC consumer populations vary substantially by ethnicity and language, as well as by the need for and access to a given service. Improvement targets will be established and reported at the state level indicating the

² Data confidentiality protections may prevent reporting some information for small consumer subpopulations. In addition, findings for small groups are often highly influenced by one or two consumers with very unusual POS expenditures, and will be suppressed.

anticipated impact of Department and RC efforts, within existing resources, to reduce service barriers and disparities.

Improvement Targets

The Department established improvement targets for most of the disparity measures. The targets reflect the Department's goals and the anticipated impact of RC and community efforts. The baseline year for the targets is FY 2015/16 – the year before ABX2 1 disparity project funding began.

For some measures that show little or no disparity at the state level, the Department has not established improvement targets.