Assembly Bill 1147 The Disability Equity and Accountability Act

FACTS FOR SELF-ADVOCATES AND FAMILIES



Authored by Assemblymember Dawn Addis (San Luis Obispo/Monterey)

Co-Sponsors: Disability Voices United and the Integrated Community Collaborative



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The Need for this Bill

California's regional center system has big problems.

Almost everybody seems to agree that the developmental disabilities system is very troubled. Self-advocates and family members still report they feel subjected to the system, rather than served by it. For example:

- despite millions of dollars spent on reducing systemic racism and disparities for people of color, Latinos still get less than half the amount of services that white people get
- some regional centers give way more services than others, meaning there are geographic disparities too
- when we have questions or want to change things, it takes months to get answers about our services
- we're told to get generic resources to pay for our services first, but we don't get the help to do that, even though current law says we should

The bottom line is that these problems have been known for years, and the Department of Developmental Services (DDS) is not holding regional centers accountable. Many of us have lost our trust in regional centers and in the system.

The Right Time for this Bill

In just the past year, the **California State Auditor** conducted two audits of the system and found a number of issues that negatively impact services, especially for people of color. **The Little Hoover Commission** held four public hearings on the regional center system and will issue a report soon with recommendations to improve the problems they uncovered. The media have also taken notice. From the *LA Times* to the *The Sacramento Bee*, many news agencies have published reports exposing the system's many issues.

At the same time, the legislature is considering spending a record \$14 billon on the system. Regional centers recently received funding to add 900 new service coordinators, and service providers got billions of dollars in rate increases. DDS has spent \$88 million to eliminate disparities and is leading several separate, often uncoordinated, efforts to develop performance measures for regional centers and providers. *Self-advocates and families are waiting to feel the benefits from these huge investments.*

Because money and good intentions don't fix broken systems! Systemic problems require systemic solutions. And this system has a lot of problems. It needs transformative change, informed by true experts - the self-advocates and family members who this system is supposed to serve.

Bold Solutions for Big Problems

Big problems require bold solutions, not just small fixes around the edges of an issue. Here are just some of the things that AB 1147 will do for people with developmental disabilities:

A More **Equitable** System

Compels regional centers to be more responsive by:

- requiring staff to call you back within two business days
- shortening the time it takes to get eligibility and services

Impact: Assessments must be done within 60 days (instead of 120) and if services are recommended, they must be authorized in a week. So instead of families being on hold for months, regional centers must provide services faster.

Makes regional center processes fairer by:

- ensuring the IPP experience is personcentered, self-directed, and culturally respectful
- making sure everyone learns about the Self-Determination Program

Impact: You can hold your IPP any time or place you want (including on Zoom). That means that if you want your IPP at Denny's on Sunday morning with your friends and family, you can do it!

Requires regional centers to actually help you get generic resources to pay first by:

- making staff write down exactly how they will assist you
- removing the requirement to appeal denials from other resources
- requiring regional centers pay for the service if the resource doesn't decide within 45 days

Impact: If you have to ask your school district to pay for speech therapy, the regional center should attend your IEP meetings and advocate for you. If the school doesn't fund the therapy within 45 days, the regional center must pay.

Makes services more available, no matter where you live by:

- requiring all regional centers to offer at least a common set of services
- creating a statewide system to contract with service providers

Impact: If you need supported living services, you could get that service no matter what your regional center and choose whatever provider you want from around the state.

A More **Accountable** System

Tells DDS to hold regional centers accountable by:

- meeting certain standards, with rewards for exceeding standards
- putting the regional center on probation for failing to meet the standards

Impact: If your regional center exceeds the standard around equity measures, it will get rewarded with a financial incentive. But if your regional doesn't meet the minimum standard, it will be put on probation and need to provide a correction action plan.

Makes sure that regional center boards of directors are trained, protected, and representative of the people they serve by:

- requiring DDS to provide extensive training and support to board members
- limiting how long a board member can serve on the board
- ensuring board members are not retaliated against by their regional center

Impact: Board members would get better training and support so they can fully participate and not be fearful of what might happen to them if they speak up.

Reduces conflicts of interest at regional centers by:

- prohibiting service providers or others to give gifts worth more than \$10 to staff
- requiring a policy around nepotism if a senior staff hires their family to work there

Impact: Regional center staff can no longer receive an expensive gift from a service provider because they might unconsciously be biased in favor of that service provider.

A More **Transparent** System

Allows the public to find out more about regional centers by:

 making them subject to the Public Records Act, which lets anyone file a form to get non-private information about the policies and procedures of a regional center

Impact: You could file a request to get information on service provider rates, staff salaries, service policies, disparity data, or anything that does not violate the privacy of a person served.

Ensures that self-advocates and families are fully involved in the new DDS technology system by:

 requiring DDS to work with selfadvocates and families to develop a written project charter or plan that lays out a set of principles and strategies

Impact: The State will likely spend hundreds of millions of dollars on a new technology system and the charter will ensure that it will help us get all information regional centers keep about us.

Lets us understand the problems with disparities by

- eliminating the racial category called "Other"
- more clearly identifying the races and ethnicities of each person served by a regional center

Impact: Regional centers must ask us what races/ethnicities we identify as and the public will have better information about where service disparities lie.