



SB 468

(Emmerson and Beall)

Statewide Self-Determination Program Option for Individuals with Developmental Disabilities

Sponsors: Autism Society of Los Angeles and Disability Rights California

Frequently Asked Questions

1. What is self-determination?

Self-determination provides an alternative to the traditional method of providing regional center services to consumers. It allows individuals with developmental disabilities, with the support of family, friends, and professionals, to take charge of their future by gaining control over the services, supports and resources that they need.

Self-determination helps individuals with developmental disabilities gain a life that:

- Respects their own choices and fulfills their hopes and dreams;
- Fosters independence while encouraging interdependence;
- Allows them to choose services and supports that are not bound by what is currently available;
- Reaches farther than meeting basic needs and toward creating a meaningful life;
- Has services and supports based on their changing needs;
- Is not unique to individuals with disabilities.

2. Has California ever had a self-determination program?

Yes. In 1998, the California Legislature (SB 1038) amended the Lanterman Act to include a Self-Determination Pilot Project. The highly successful program was piloted in five regional centers across California and included 200 participants. The program continues to exist for the original pilot participants as long as they choose self-determination. This legislation will offer the self-determination program to consumers throughout the state.

3. Do other states have self-determination programs?

Yes. Self-determination has been enacted in some form in almost every other state. It has garnered international and bi-partisan support as a delivery model that provides consumers and families with greater control over their services and their future. Self-determination as a service delivery model is also being used with other service systems (elder care and veterans, for example) in many states.

4. Will consumers be required to be part of self-determination?

No. Self-determination will be a voluntary option, and individuals with developmental disabilities may choose to be part of the program. No one will be forced in or out of the self-determination program.

5. Can we have a statewide self-determination program without changes in current law through the Individual Program Plan (IPP) process?

No. The current IPP process limits consumer choice based on program restrictions imposed by the Legislature in the budget and regional center contracting procedures. Self-determination moves the decision-making responsibility to the individual and his or her team. The relationship between the

individual and the suppliers of services and supports (vendors) changes in that the vendor is now working for and accountable to the individual and not the regional center. Self-determination should lessen differences between regional centers and move from a system that is similar to managed care to one that is driven by consumer need and choice.

6. How will self-determination work for a consumer?

- After outreach to consumers and families in every regional center, with special efforts in underserved communities, individuals and their families who are potentially interested in self-determination will receive training about this service delivery model so they can make an informed choice about whether self-determination works for them.
- If an individual with developmental disabilities who is a consumer of a regional center is interested in self-determination, they can let their regional center know that they want to be part of the self-determination program.
- With the assistance of an independent facilitator (not associated with any provider or regional center), the consumer and his/her family will then develop a comprehensive and authentic person-centered plan to help them set life goals.
- The consumer and family will work with their regional center to determine a reasonable budget in order to work toward their goals for that year. This negotiation process should be cooperative and collaborative.
- Consumers and families will then choose the providers of services and supports (with the help of the independent facilitator, if desired), which will be paid through a state-approved fiscal intermediary.
- Consumers and families must work with the fiscal intermediary to keep track of their expenses in order to keep within their agreed upon budget.

7. What is a “Person-Centered Plan?”

The individual with the developmental disability must be at the center of the plan and of the plan development. This planning process can be led by an independent facilitator who is experienced in the broad range of services and opportunities in the community to assist the consumer in reaching their life goals. This process will lead to short and long-term goals, including laying out the types of services and supports that an individual will need to work toward their goals in the next year.

8. What kind of services can consumers purchase? Are there any restrictions?

A consumer can purchase services and supports that allow them to reach their life goals. Services and supports provided through self-determination must be eligible for federal matching funds under the Medicaid Home and Community Based Services (HCBS) Waiver program. These include services that are medically necessary as well those supports that allow an individual with a disability to participate fully in their community.

9. What is an Independent Facilitator?

An Independent Facilitator is not associated with any regional center or service provider and would work directly for the consumer and family with no conflicts of interest. Independent Facilitators will be trained by the Local Advisory Committees. A consumer and family can choose to use an Independent Facilitator to assist them in the following ways:

- Designing their person-centered plan;
- Participate in the budget negotiation process with the regional center;

- Assist them in selecting appropriate individuals, programs, and services in the community that will help them reach their life goals.

10. What is a Fiscal Intermediary?

The fiscal intermediary is like an accounting and/or bookkeeping service. The fiscal intermediary actually receives the funds to be used to support the implementation of the individual's plan, disburses the funds in accordance with the plan and rules, and maintains financial records as required. The fiscal intermediary needs to be accessible to the individual being served and the Independent Facilitator, if one is used. The fiscal intermediary will know the program requirements and be vendored by the state.

11. Will self-determination cost the State more money?

The legislation specifically states that the program must be cost-neutral in the aggregate. The budget for the regional centers will be the same, but for some consumers, there will just be a different way of distributing it. Self-determination will redirect existing resources and allow individuals to have more control of the way state dollars are being spent on them. In addition, self-determination programs around the country have shown a cost savings over time because the services are more directly meeting the needs of consumers and they have better outcomes and need fewer supports in the future.

12. What will be the role of the regional centers with consumers in the self-determination program?

Self-determination should be considered as an alternative within the regional centers to the traditional or case managed system of care that is now used throughout California. Regional center staff will still hold Individual Program Plan (IPP) meetings and will work together with consumers and families to determine a reasonable budget for the individual to work toward their life goals for the following year. This negotiation process should be cooperative and collaborative. Regional centers, however, will not be able to select specific services or providers for consumers in the self-determination program.

13. What if emergencies happen and a consumer's budget is not sufficient?

Self-determination recognizes that consumers' needs may change. If they do, consumers can request an IPP with their regional center to adjust their budget to address the emergency or significant changes. The person centered plan will be appropriately amended or redeveloped and a new or revised budget established.

14. How can we ensure that low-income and traditional minority consumers take advantage of this option?

The bill requires that self-determination be available to consumers and their families who reflect the diversity of consumers served by the regional centers. Because self-determination allows for flexibility, the model will likely be of interest to individuals who because of their culture or disability prefer different services. SB 468 calls for special outreach to underserved communities to make sure that consumers and families are aware of the self-determination option and to provide them orientation and training that is culturally competent.

15. What kind of training will be provided to consumers and families who want to be part of self-determination?

Local training will be provided by community-based organizations and advocacy organizations unaffiliated with providers or regional centers. The trainers will focus on the administrative details of self-determination and ensuring that consumers and families understand the different role of the regional centers, how to make the most of their person-centered plan, work with an independent facilitator and

fiscal intermediary, and monitor their annual budgets. Special outreach will be made to underserved communities to ensure that families are made aware of the self-determination option and provided the support to participate if they choose. Trainings and materials should be made available in multiple languages.

16. How will the program prevent fraud and abuse?

In the pilot, there was very little evidence of fraud or abuse. In addition, all services provided through self-determination will have to be HCBS waiver eligible and meet certain federal requirements. Independent facilitators will be trained on the types of programs and services that qualify. All payments will be made by a fiscal intermediary who will also understand the program requirements and whose work is subject to audit.

17. What kind of oversight will be provided?

Person centered plans may be audited either individually or collectively. Budgets will be reviewed and are subject to audits. The work of the fiscal intermediary is also subject to audit. The regional centers and DDS have oversight over the program. Since Medicaid funds will help fund the services and supports, federal requirements also must be met.

18. Are people who choose Self-Determination going to get more services from the regional center than people who stay in the traditional system?

Self-determination is not about getting more or less services -- it is about getting the right services. It is about how services are accessed and controlled.

19. Why is there a cap of 2,500 for the first three years?

Currently there are approximately 200 consumers participating in the original pilot project. Regional centers will need time to adjust to this new service delivery system and ensure that the program remains cost neutral and is effectively implemented. After the three-year phase-in period, the cap will be lifted and self-determination will be available to all consumers who choose it.

20. What is the role of the Local Advisory Committees?

The bill establishes local advisory committees to provide oversight of the entire program, including the role of the regional centers, the budget negotiation process, and consumer outcomes. The committee will also train Independent Facilitators. Members of the Local Advisory Committees will be appointed by the Area Boards, the Office of Clients' Rights, and the regional center. The majority of the committee should consist of consumers and family members and reflect the make up of the surrounding community.

21. How is this different from a voucher program?

Consumers and families will not be receiving any vouchers. All programs and services will bill the fiscal intermediary who will pay them directly.

22. What is the difference between this Self-Determination Program and Self-Directed Services or the Individual Choice Budget?

This legislation expands statewide the Self-Determination Pilot Project with its philosophy of consumer choice and control. The Self-Directed Services and Individual Choice Budget programs have different structures and have never been implemented.