



**CALIFORNIA'S NEW SELF-DETERMINATION LAW
FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES**
Taking Control of Your Future by Directing Your Regional Center Service Dollars

(As of 2/4/14)

FACTS FOR CONSUMERS AND THEIR FAMILIES

In October 2013, California Governor Jerry Brown signed into law SB (Senate Bill) 468, creating a statewide Self-Determination Program that offers a voluntary alternative to the traditional way of providing regional center services. The bill was authored by Senators Emmerson and Beall and Assemblymembers Blumenfield, Mitchell, and Chesbro, and was sponsored by the Autism Society of Los Angeles and Disability Rights California. It was supported by every major disability organization in the state. SB 468 is the first law of its kind in the nation and a huge leap forward in the civil rights of individuals with developmental disabilities.

1. What is California's Self-Determination Program?

The Self-Determination Program provides regional center consumers (individuals with developmental disabilities who are eligible for regional center services) and their families with more control and flexibility over the services and supports they need. Self-determination is a voluntary program that provides consumers with an individual budget, which they can use to purchase the services and supports they need to implement their Individual Program Plan (IPP). For example, consumers and families may purchase services from providers or local businesses, hire support workers, or negotiate unique arrangements with local community resources.

Self-Determination is an international movement in the disability community. Its principles include freedom, authority, support, responsibility, and confirmation. (The full set of principles of self-determination are included at the end of this fact sheet.)

The new California Self-Determination Program is based on a 15-year old pilot program in which almost 200 individuals participated in a test of self-determination in five regional centers. The pilot program has been a resounding success and, after many attempts, it is finally being expanded throughout California.

Note: For consumers who choose not to take advantage of this voluntary program, traditional regional center services will continue to be provided.

2. When will the Self-Determination Program be available to me or my family member?

It will take several years for all of the elements of the Self-Determination Program to be fully running. Here is a basic timeline:

By December 31, 2014 - The Department of Developmental Services (DDS) in Sacramento must apply for federal Medicaid funding to establish and fund the program. It might take the federal government up to six months to approve the funding.

2014-2015 – Regional centers will be organizing their self-determination programs with guidelines from the Department of Developmental Services and advice from local advisory committees appointed by the regional centers and local Area Boards and consisting primarily of consumers and family members.

Sometime in 2015 - Once federal approval of matching funds is received, the program must be available in every regional center. For the first three years, the number of participants in the Self-Determination Program is capped at 2,500 individuals throughout the state so that any problems with implementation can be worked out.

After 2018 - After the three-year phase-in period, the program will be available to all eligible consumers on a voluntary basis with no limit on the number of participants.

3. Who is eligible for the Self-Determination Program?

To be eligible for the program, you or your family member must:

- Have a developmental disability and currently be receiving services from a regional center OR be a new consumer of a regional center.
- Be over the age of 3.
- Live at home, in the community, or in a group home. You are not eligible if you live in a licensed long-term health care facility such as a Developmental Center, unless you are transitioning from that facility.
- Be a responsible participant including attending an orientation/training and working with a Fiscal Manager.

Self-determination is available to you if you meet these qualifications, regardless of your qualifying disability, race, education, income, or native language. In fact, the law specifically says that participants should reflect the diversity of their communities and that regional centers are directed to ensure that individuals from underserved communities are informed of the Self-Determination Program.

4. What services and supports can I or my child get through the Self-Determination Program?

You or your child can set up a wide range of services and supports through the Self-Determination Program. These could include many services that are traditionally funded by regional centers, such as Independent Living Services, behavioral therapy, or supported living. Unlike traditional regional center service provision, you are not required to use agencies that are vendored with your regional center. (“Vendored” means that the regional center has chosen to work with this agency.) Additionally, you or your child can choose unique services and supports not traditionally funded by your regional center to help you meet your IPP goals. The Self-Determination Program will also allow you to access some services that have been suspended or limited since 2009 by the California legislature for budget reasons, such as social and recreation programs, camp, non-medical therapies, and respite.

There are some important requirements for the services you choose:

- First, you can only choose services and supports that qualify for matching funds from the federal government. Over the next two years, the Department of Developmental Services will work with the federal government to identify these services. However, based on self-determination programs in other states, the federal government has been open to a diverse set of services that supports the individual to live, work, and thrive in the community.

- Second, you can't choose a service that could be paid for by another government agency (this is called a "generic service"). For example, this could include educational services that might be paid by your school system, respite or personal assistance that might be paid by IHSS (In-Home Supportive Services), or medical supports paid by Medi-Cal or other health insurance.

5. How much responsibility will I or my family have if I choose to participate in the Self-Determination Program?

With the freedom and control of self-determination also comes additional responsibility. You and your family will need to be very active in creating the plan your future. Before you become part of the program, you will need to go through an orientation and training program conducted by your regional center and local community organizations. Then, with assistance from others if you choose, you will need to develop a person-centered plan and then select individuals and groups to help you implement that plan over the coming year. You will need to choose a Fiscal Manager with whom you will work to monitor your budget to ensure that you are spending state dollars appropriately. And you will need to oversee and supervise the staff and agencies you have hired to ensure that they are fulfilling the hours for which you have hired them and assisting you in meeting your goals.

6. What is a Person-Centered Plan?

A Person-Centered Plan is a process that allows individuals with disabilities to determine their future. The individual with the developmental disability must be at the center of the plan and its development. Sometimes, individuals and/or their families invite a circle of people who know them and can help guide them in determining goals for the future to help create the plan.

This planning process can be led by an Independent Facilitator, experienced in the broad range of services and opportunities in the community, to assist the consumer in reaching his or her life goals. This process will lead to the creation of 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.

7. What is an Independent Facilitator?

You have the choice to hire an Independent Facilitator to assist you and your family with the person-centered planning and IPP processes. An Independent Facilitator must be a person who does not provide services to you and is not employed by a person who provides services to you. You may also choose to use a regional center service coordinator to serve this function.

An Independent Facilitator should be experienced in the types of services and supports available to you in your community and be able to "think outside of the box" when creating a plan to help you meet your goals. An Independent Facilitator can also advocate for you during a person-centered planning meeting and IPP, assist you in making informed choices about your budget, and help you identify and secure services. The cost of the Independent Facilitator is paid from your Individual Budget.

8. What is the difference between my IPP (Individual Program Plan) and the Self-Determination Program's Person-Centered Plan?

The IPP remains the central part of determining and working towards your or your child's goals. Your IPP team will use the person-centered plan to develop your IPP. The IPP will include the services and supports selected and directed by you or your family member to achieve the objectives in your IPP. The IPP team will

also decide whether there is a change in circumstances or needs that requires a change in your Individual Budget. If you choose, you can have your Independent Facilitator advocate for you in your IPP.

9. What is an Individual Budget and how is it determined in the Self-Determination Program?

The individual budget is the amount of regional center funding available to you to purchase the services and supports you need to implement your IPP and ensure your or your child’s health and safety. The individual budget is calculated once during a 12-month period but may be revised to reflect a change in your circumstances, needs or resources.

For current regional center consumers, the budget for Self-Determination Program participants will equal 100% of the amount of the total expenditures made by the regional center on your services during the past 12 months. This amount can be changed by the IPP team if they determine an adjustment is needed for one of the following reasons:

- There is a change in your circumstances, needs, or resources that would result in an increase or decrease in your budget amount; or
- There are prior needs or resources that were unaddressed in the IPP, which would have resulted in an increase or decrease in your expenditures.

For a participant who is new to the regional center system or does not have 12 months of previous expenditures, the IPP team will determine the services and supports needed and available resources. The regional center will use this information to identify the cost of providing the services and supports based on the average cost paid by the regional center unless the regional center determines that you have unique needs that require a higher or lower cost. This amount will be your individual budget.

Your Individual Budget will not be increased to include additional funds for either the Independent Facilitator or the Financial Management Services.

10. Who pays the individuals and groups that I choose to provide my services and supports? Who assists me with managing my budget so that my funds will last throughout the year?

A Financial Management Service (FMS) will be used to pay for all services and supports through the Self-Determination Program. Self-determination participants are required to choose and utilize a Fiscal Manager. Fiscal Managers are independent and do not work for the regional centers, but they must be authorized (called “vendored”) by your regional center. The Fiscal Managers help manage the funds contained in your individual budget and ensure you have enough left to implement your IPP throughout the year. Fiscal Managers will:

- Pay the bills from the individuals and organizations that provide support and services to you;
- Provide a monthly accounting of how you are spending your individual budget;
- Advise you on the hiring of service and support workers and ensure that all employment laws are being followed.

The cost of the Fiscal Manager is paid from your Individual Budget, except for the costs of any criminal background check. You and your regional center service coordinator will receive a monthly statement from the fiscal manager, which shows the budget amount in each category, the amount you have spent, and the amount remaining.

11. In the middle of the year, can I change how the money in my Individual Budget is being spent?

Your annual Individual Budget will be divided into Budget Categories. (Those categories have yet to be decided and will be determined through a community input process over the next year by the Department of Developmental Services.) If you want to change your Individual Budget in the middle of the year, you are allowed to transfer up to 10% of the funds into another budget category without permission. If you need to move a larger amount into a different category, it must be approved by your IPP team or the regional center.

12. How can I or my child sign up to be in the Self-Determination Program?

Each regional center will have its own process for signing up for the Self-Determination Program, although this will likely not begin until 2015. Because the program is capped for the first three years, there will be a limit on the number of consumers that can participate at each regional center. Your regional center will have an Advisory Committee made up of consumers and family members like you that will help them design the program. Your regional center will be required to work with local consumer or family-run organizations to develop materials and informational meetings to make individuals and their families aware of the program. Those materials and meetings are supposed to be “culturally competent,” which means they should be available in language that you understand.

13. What happens if I move from one regional center to another?

You will continue to participate in the Self-Determination program if you transfer to another regional center area, provided that you remain eligible for the program. The law requires the remaining funds in your Individual Budget to be moved to your new regional center.

14. What happens if I no longer want to participate in self-determination or am no longer eligible for the program? Can I return to the program if I leave it?

If you voluntarily choose to leave the Self-Determination Program, your regional center will move you back into the traditional regional center system. If you leave the program voluntarily, you cannot return to the program for at least twelve months. If the regional center finds you ineligible for the Self-Determination Program, you can return to the program if you once again become eligible and your IPP team approves.

15. Can my regional center require me to participate in self-determination if I don't want to?

The Self-Determination Program is fully voluntary. A regional center cannot make you or your family member participate in the program.

16. What if my family member or I live in a licensed long-term care facility and want to participate in the Self-Determination Program?

If you or your family member currently live in a licensed long-term care facility (such as a Developmental Center), you are not eligible for the Self-Determination Program. However, you may request that the regional center provide person-centered planning services in order to make arrangements for transition to the Self-Determination Program, provided that you are reasonably expected to transition to the community within 90 days. In that case, the regional center shall begin a person-centered planning process within 60 days of the request. If you are not ready to transition to the community, you may ask that your interest in self-determination be reflected in your IPP and request the regional center help you participate in self-determination as part of the transition process.

17. How does the Self-Determination Program ensure your safety or the safety of your family member?

The Self-Determination Program requires non-vendored (not previously authorized) providers to submit to a criminal background check. This includes individuals who provide direct personal care services to a participant as well as organizations or groups that have not been vendored by the regional center. The criminal background check includes a fingerprint requirement for all prospective providers. The cost of the background check is paid by the provider of services.

18. What happens to the individuals who are participating in the Self-Determination Pilot Program?

Individuals receiving services and supports under the self-determination pilot projects can either continue to receive them under the new Self-Determination Program or transition to the traditional model of having services and supports provided within the regional center system. The new Self-Determination Program's rules will apply to the pilot program participants.

19. What steps can I take if I disagree with a regional center's decision regarding my eligibility for the Self-Determination Program or in determining my Individual Budget?

You will continue to have the same due process rights under The Lanterman Act, which is the law that created IPPs and the regional centers. This means, for example, you will receive notice if the regional center finds you ineligible for self-determination or proposes to change your budget. It also means that you can request a hearing if you disagree with a regional center decision such as your right to participate in self-determination or the amount of your budget.

20. How do we make sure the Self-Determination Program in my regional center is being put into effect the way the law says it should?

Each regional center is required to have a volunteer Advisory Committee, the majority of whose members must be consumers and family members appointed by the regional center and the local Area Board. (The Area Board is a local government-funded organization that exists to make sure that individuals with developmental disabilities are being treated fairly.) Clients' rights advocates (lawyers and advocates that work with Disability Rights California) are also part of the committee. The state Developmental Disability Council will also convene a statewide advisory committee to identify best practices, design effective training materials, and make recommendations for improvements in the Self-Determination Program. DDS is also required to collect and report outcome data to the State Legislature.

21. What can you do now to learn more or help your regional center implement the Self-Determination Program?

- Volunteer now to be on your regional center's Advisory Committee when it is formed. You can volunteer through your regional center or your local Area Board. In Los Angeles County, contact Area Board 10 at (818) 543-4631.
- Join the Autism Society of Los Angeles' email list to find out about upcoming informational meetings and to get the latest materials. Go to www.autismla.org for more information.
- If you are part of a self-advocacy group or family member group, you can ask your Clients' Rights Advocate or Area Board to do a training about self-determination for your group.
- Share information about the Self-Determination Program with other consumers and families.
- At your next IPP meeting, ask your regional center to note on your IPP that you are interested in participating in self-determination.

PRINCIPLES OF SELF DETERMINATION

- **Freedom**, which includes the ability of adults with developmental disabilities to exercise the same rights as all citizens; to establish, with freely chosen supporters, family and friends, where they want to live, with whom they want to live, how their time will be occupied, and who supports them; and, for families, to have the freedom to receive unbiased assistance of their own choosing when developing a plan and to select all personnel and supports to further the life goals of a minor child.
- **Authority**, which includes the ability of a person with a disability or their family to control a certain sum of dollars in order to purchase services and supports of their choosing.
- **Support**, which includes the ability to arrange resources and personnel, both formal and informal, that will assist a person with a disability to live a life in his or her community that is rich in community participation and contributions.
- **Responsibility**, which includes the ability of participants to take responsibility for decisions in their own lives, to be accountable for the use of public dollars, and to accept a valued role in their community through, for example, competitive employment, organizational affiliations, spiritual development, and general caring of others in their community.
- **Confirmation**, which includes confirmation of the critical role of participants and their families in making decisions in their own lives and designing and operating the system that they rely on.