

SELF-DETERMINATION

**What Is It, How Does It Differ
from Traditional Services, &
Is It Right for Me?**

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What's the Big Idea?

- Major changes to the Lanterman Act
- Creates a new way to access services
- Guided by this idea:

People with disabilities should have the ultimate authority to decide how money designated to support them should be spent.



The Five Principles of Self-Determination

Freedom

Authority

Support

Responsibility

Confirmation

Freedom

- To plan your own life and future
- To choose who helps you
- To control the services, supports or resources you use
- To select your providers and change when needed

Authority

- To control how you spend the money allocated to you
- To be seen as the employer
- To set your own standards for services and supports
- To make your own decisions

Support

- To be successful and productive in the life you choose.
- To be a valued member of your community.
- To make decisions and plan your own life.
- To create a network of friends, family, professionals, community members and others that you choose to help you.

Responsibility

- For making decisions and choices for your life and accepting responsibility for those choices and decisions.
- For developing your talents and gifts and for being as productive as possible, including earning income if you are able.
- For contributing back to others and to your community.
- For accounting for the wise spending of your funding.

Confirmation

- Close the circle
- Share your insights
- Be leaders in crafting this system



Another way to look at the principles...

Freedom
Support
Authority

RESPONSIBILITY

Confirmation

Responsibility is big. Get it? Like Spidey says...

WITH GREAT POWER COMES GREAT RESPONSIBILITY



Why?

- It may be your budget, but it's still taxpayers' money and you have the **RESPONSIBILITY** to spend it wisely.
- If there's a problem it's your **RESPONSIBILITY** to handle it.
- You can't ask the regional center to help because it's your **RESPONSIBILITY** now, not theirs.
- You wanted the **RESPONSIBILITY**, right?
- The buck stops with you because you have the...

Some History

- 1998: 5 Self-Determination (SD) Pilot Projects established including the Eastern Los Angeles Regional Center/Area Board 10 pilot.
- 2001: Pilots report high levels of satisfaction and recommend statewide expansion.
- 2002: Dot-com bubble bursts creating huge budget deficit, SD is put on hold.
- Three governors and 13 years later Senate Bill 468 passes making SD a reality.

Who Is Eligible?

You or your family member must:

- Have a developmental disability and receive services from a regional center OR be a new consumer of the regional center.
- Be over the age of 3.
- Live at home or in the community.
- Be a responsible participant by attending a required SD orientation, receive training on how SD works, and agree to work with a Fiscal Management Service.
- If you live in a licensed, long-term health facility such as a developmental center or an Intermediate Care Facility you are NOT eligible.

****Unless you are in the process of moving into the community, then you ARE eligible.***



How It Works: Your Budget

- The amount of your Individual Budget (IB) is based on how much was spent on you over the last 12 months.
- Re-determined each year, going up or down depending on changing needs
- You decide how it's spent; designate “chunks” of money for service categories
- Can move 10% from one category to another
- Budget pays for FMS and Facilitator
- With the help of people you trust, you develop a Person-Centered Plan (PCP) that reflects your vision in the different areas of your life and set goals.

How It Works: The Basics

- Ask for Self-Determination***
- Agree to abide by the rules and live within the limits of your individualized budget (IB).
- Hire a facilitator if you want.
- Hire a financial manager.
- With the help of people you trust, develop a Person-Centered Plan (PCP) that reflects your vision in the different areas of your life and set goals.
- Give your PCP and IB to your FMS.
- After background checks are completed, your FMS starts paying the people you hired.

*****The law allows each regional center to develop its own process for signing people up. You should try to be a part of the development process if you can.**

The Players

- You – the leader of the band
- Facilitator – if you want one
- Fiscal Manager – handles the money
- Your friends, family, paid supports, etc.

The Facilitator

- Helps the person with their Person-Centered Plan.
- Helps plan and maintain the individualized budget.
- Helps the person develop a network of support and be part of their community.
- Helps find providers, negotiates rates, hours of service, and working agreements, and makes sure providers live up to the agreements made.
- Helps mediate issues with providers.
- Helps the person and those around him or her to honor and live by the principles of Self-Determination.

****You pay for the facilitator out of your budget. But you don't have to hire a facilitator. It's up to you.***

Fiscal Management Service

****You must use a FMS to be in Self-Determination.***

- Receives funds allocated in the person's budget and makes payments to service providers.
- Keeps track of services provided and back up documentation.
- Maintains financial records.
- Takes care of taxes, workers' compensation, liability insurance, and makes sure all provider legal requirements are met (i.e. licenses and certification).
- Reports on expenditures.

****The FMS does NOT make decisions about how your money is spent.***

Traditional Services vs. Self-Determination

Example #1: Requesting a Service

Traditional

- Person wants Awesome Therapy (AT).
- Person has tried all programs offered and none meet needs. Person has letters from doctors to back up request for AT.
- Service coordinator says AT isn't "vendored" and takes request to "committee." 3 weeks later person gets a denial letter saying AT isn't vendored, is too expensive, and person doesn't need AT anyway.
- Person appeals denial and could wait up to 50 days for a decision - and might lose.

Self-Determination

- Person wants AT.
- Person makes sure there's enough money in budget to pay for AT.
- Person talks with AT and comes to an agreement about hours & rate.
- Person gives hours & rate info to FMS who makes sure AT has required certification and that staff don't have criminal records.
- Person starts receiving AT.
- Whole process takes a few days.

Traditional Services vs. Self-Determination

Example #2: Requesting a Service

Traditional Services

- Melissa asks for ABA for 10 year old son
- RC says POS policies stop ABA at 6 years old
- Melissa goes to fair hearing
- One year after request, she wins hearing
- ABA started
- RC tries every year to stop funding it

Self-Determination

- Melissa puts ABA therapy into her son's PCP
- Melissa contracts with preferred provider
- ABA therapy started within a few days
- Melissa decides when to start fading ABA therapy; keeps for as long as son needs it

Example # 3: Request for _____ Services

Traditional

- Person wants _____.
- Person has tried all programs offered and none meet needs. Person has letters from doctors to back up request for _____.
- Service coordinator says _____ isn't "vendored" and takes request to "committee." 3 weeks later person gets a denial letter saying _____ isn't vendored, is too expensive, and person doesn't need _____ anyway.
- Person appeals denial and could wait up to 50 days for a decision - and might lose.

Self-Determination

- Person wants _____.
- Person makes sure there's enough money in budget to pay for _____.
- Person talks with _____ and comes to an agreement about hours & rate.
- Person gives hours & rate info to FMS who makes sure _____ has required certification and that staff don't have criminal records.
- Person starts receiving _____.
- Whole process takes a few days.



Example #4:

See Examples #1, 2, & 3

Wash, Rinse, Repeat

Roles & Responsibilities: Service Coordination vs. You

Service Coordinator

- Has a caseload of about 100.
- Has limited authority to approve service requests and must get approval of supervisor for most.
- Must follow strict purchase of service standards that emphasize “cost-effectiveness.”
- Must pursue “generic services” first.
- Must follow all of the above or could lose his or her job.

You

- Have a caseload of one.
- Have complete authority and don't have to make requests or get anyone's approval.
- Must make sure there's enough money in budget.
- Can purchase generic or non-generic services.
- Have full responsibility and are answerable only to yourself.

Roles & Responsibilities: Budget

Regional Center

- Gets money from the Department of Developmental Services (DDS).
- Money comes in one lump sum for the year and must be divvied out to thousands of people in their catchment area.
- Must spend taxpayer money wisely and cost-effectively based on needs.
- Must keep records of expenditures for reporting purposes.

You & Your FMS

- Your FMS gets your budget money from your regional center.
- You get your money in one lump sum for the year to spend on services for one person.
- Must spend taxpayer money wisely and cost-effectively based on needs.
- Your FMS must keep records of expenditures for reporting purposes.

Roles & Responsibilities: Service Providers

Traditional

- Providers are vendored and under the legal and contractual authority of the regional center.
- Must provide services according to regional center policies.
- Rates of payment and hours of service are set by the regional center.
- Providers are forbidden to do things outside the scope of their vendor agreement.

Self-Determination

- Workers you hire can be vendored or not and are under your legal and contractual authority.
- Workers you hire must provide the type and amount of services you agreed to at the rate of payment you agreed to.
- You have the authority to tailor services and set your own standards.

When Will Self-Determination Be Available?

Here's a basic timeline based on what we know now:

- By **December 31, 2014**: The Department of Developmental Services (DDS) applied for federal Medicaid funding. This could take the feds six months to approve.
- **2015**: Regional centers receive guidelines from DDS and advice from local advisory committees on organizing their SD programs.
- **Sometime in late 2015-2016**: The feds approve Medicaid funding and SD becomes available to 2,500 people statewide during three-year phase-in period.
- **After 2018**: Once the phase-in period is completed SD will be available to everyone statewide with no limit on the number of participants.

What to Do Now

- Think strategically
- Ask for all of the services you need now
- Go to fair hearing when denied
- Learn and share what you know
- Watch for public comment periods on regulations (see DDS website)

**Dear Regional
Center,
My child needs
X,Y and Z
services.**

Yours Sincerely,

Local Advisory Committees

- Each regional center will establish a Local Advisory Committee (LAC).
- The law says that the LAC “shall consist of the regional center Clients’ Rights Advocate, consumers, family members, and other advocates, and community leaders.”
- The regional center gets to appoint one half of the members and the Area Board gets to appoint the other half.
- A majority must be consumers and family members.
- The LAC must “reflect the multicultural diversity and geographic profile” of the people served by the regional center.
- The LAC monitors the progress of the SD Program and makes recommendations for improvement to the regional center and DDS.

Is Self-Determination Right for You?

Five Questions to Ask Yourself:

1. Do you get a lot of services?

People with complicated lives who receive services and supports from many different sources face unique challenges, especially during emergencies. Even something as simple as a change of service coordinators can cause a family's house of cards to come crashing down, and the regional center can be slow to respond.

If you have a complicated life that requires creative solutions and quick responses to unexpected challenges, then Self-Determination could be right for you.

2. Have you had a lot of fair hearings?

The regional center has the legal right to say “no” to any request you make. In fact, given recent changes to the law, they have the right to deny many services more easily now than ever before. If a service is denied by the RC the family member or consumer has the right to appeal – a process that can take months to complete.

With Self-Determination the details are worked out early on during comprehensive person-centered planning sessions, so there is a much better chance that disagreements and conflicts you experienced in the past can be avoided. If you have been forced to appeal regional decisions many times then Self-Determination could be right for you.

3. Have you lost valued services due to budget cuts and changes to the law?

Many consumers and families had important services taken away in 2009 as a result of the budget crisis. The law was changed giving the regional centers the authority to suspend or limit social and recreational programs, camp, non-medical therapies, and respite.

With Self-Determination these cuts don't apply. You are free to buy things like fitness club memberships, adaptive swimming classes, equestrian therapy, etc. if the service is in your plan and within your budget.

If you lost your child's summer camp, or the respite you and your family depended on was taken away, then Self-Determination could be right for you.

4. Do you have unique needs that require services your regional center doesn't offer?

The regional center doesn't have to pay for a service you ask for just because you think it will best meet your needs. If they feel the service is too expensive and/or another comparable service is available they can offer you that.

With Self-Determination you can buy any service that will meet your needs regardless of cost as long as it's in your plan and you have the money to pay for it.

If you've tried many programs and none of them have worked out, or if you have a program in mind that could be a perfect fit but the regional center won't pay for it, then Self-Determination might be right for you.

5. Do you want a good-paying job, or want to start a small business?

If you ask the regional center to help you get a good job or start a business they will refer you to the Department of Rehabilitation (DOR). It can take DOR months before they offer you something. Or they could decide not to help you at all because you're "too disabled." After all that, you can go back to the regional center and start from scratch. The RC will probably offer you a day program.

With Self-Determination you don't have to go to DOR first or settle for a day program. You can enroll in college, or take a vocational course, or use your money to buy the equipment and supplies you need to start a small business. If you've experienced any of the above, then Self-Determination might be right for you.

Common Questions

- ***Can I move money around in my budget?***

The law allows you to transfer up to 10% of your funds from one budget category to another with the approval of your planning team and the regional center.

- ***What happens if I move to a different regional center?***

You can stay in SD and keep your budget if you move as long as you are still eligible.

- ***What if I want to leave the Self-Determination Program or I become ineligible for some reason?***

The regional center must help you transition back to traditional services if choose to leave or become ineligible. Participation is voluntary.

- ***If I leave Self-Determination by choice can I return?***

If you leave by choice you have to wait 12 months to return.

Common Questions, cont'd

- ***What if I disagree with the regional center about my eligibility or the amount of money in my budget?***

You can appeal a regional center decision about your eligibility or your budget the same way you would under traditional services.

- ***What happens to the people in the Self-Determination Pilot Projects?***

They can continue in the Self-Determination Program under the new rules and regulations, or they can go back into traditional services if they choose.

What can I do now to get ready?

- Have Self-Determination included in your IPP. Having Self-Determination in your IPP won't guarantee that you will get it as soon as it's available. But it could improve your chances.
- Learn as much as you can about Self-Determination. Attend trainings. Read the law (SB 468). Ask the Area Board to do a presentation for your parent or self-advocacy group.
- Share what you learn about Self-Determination with others who might be interested.
- Volunteer to be on your regional center's Local Advisory Committee when it's formed. You can volunteer through your regional center or through the Area Board.



**Any MORE
questions?**

Resources

- Disability Rights California SD Publication:

www.disabilityrightsca.org/pubs/F07701.pdf

- The Center for Self-Determination:

www.centerforself-determination.com

- Senate Bill 468:

www.leginfo.ca.gov/pub/13-14/bill/sen/sb_0451-0500/sb_468_bill_20131009_chaptered.pdf