

# RIGHTS UNDER THE LANTERMAN ACT

## *Advocating for Yourself*

### Chapter 5

This chapter explains how to speak up and fight for your rights. This is called “advocacy.” You will learn how to:

- Advocate for yourself,
- Advocate for someone else, and
- Get support from an advocacy organization.



## Chapter 5: Advocating for Yourself

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# Chapter 5

## Advocating for Yourself

- *What is Advocacy?*
- *Advocacy Organizations*
- *Individual Advocacy Skills*
- *Systems Advocacy Opportunities*

### 1. What is advocacy?

Advocacy means speaking up and fighting for your rights. For example, you have the right to receive services that you are eligible for. You also have the right to receive the services and supports you need and choose in the most integrated setting.

The regional center – and all public agencies – must respect your rights. They must follow the law and certain rules. Many of the rules talk about how to get the services you need and choose.

If your regional center does not give you the services or supports you are entitled to receive, you can fight (appeal) their decision.

Important! There is a deadline to appeal. If you miss the deadline, you may not be able to appeal. See Supplement S at the end of this manual for a list of deadlines for regional center appeals.

If you are appealing a decision from another agency, ask them what their deadline is.

### 2. Who can be an advocate?

Anyone can be an advocate. You can be an advocate for yourself. You can be an advocate for someone else. Or, you can have someone else be your advocate. Be sure that you and your advocate agree on what you want. Put it in writing. Say that you want the person to be your advocate. Also write down what your goal is, like getting a new service or not having a service reduced.

### 3. Do I need a lawyer?

Not always. In some cases, you do not need a lawyer to be successful. But if your case is complicated, an advocate can help you. The advocate does not have to be a lawyer, even for a fair hearing. But, if you want to file a lawsuit in court, you will need a lawyer or you may file a lawsuit on your own. If you file a lawsuit on your own, called in pro per, you may be able to get help from a legal aid program.

#### **4. Who can give me help with advocacy, including a lawyer?**

Here is a list of places that can help you:<sup>1</sup>

- Call Disability Rights California or OCRA. They can give you a list of Clients' Rights Advocates. (Or see Supplement Z of this manual.)
- Call the State Council on Developmental Disabilities (SCDD) and its regional offices (formerly called "Area Boards"). (See Supplement AA of this manual for the contact information.)
- Join a self-advocacy group, like People First, to meet other consumers with developmental disabilities. Call your local Disability Rights California, OCRA, or SCDD Regional Office for the phone number of People First near you. (Also see question 11 below.)
- Call your local family resource center. You can find the phone number online at: [www.frcnca.org/directory.html](http://www.frcnca.org/directory.html).
- If you live in a developmental center (DC), call your DC Clients' Rights Advocate and the Volunteer Advocacy Services Coordinator. (Supplement BB of this manual lists the contact information.)
- If you are having problems with vocational services through the Department of Rehabilitation, call the Client Assistance Program (CAP) which is part of Disability Rights California at 1-800-776-5746 or TTY 1-800-719-5798 or go to <http://www.dor.ca.gov/CAP/index.html> (Also see Question 10 below.)
- For free or low cost legal help, call the legal aid office in your area. You can find a legal aid office in your area at <http://lawhelpcalifornia.org/>.

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<sup>1</sup> If you appeal a regional center decision, the regional center must give you the names and addresses of agencies or organizations that can help you. They should give you the address and phone number of your Clients' Rights Advocate, SCDD Regional Office, and the local Disability Rights California office.

- If you are having problems with a licensed professional, contact:  
California Department of Consumer Affairs  
Consumer Information Center  
1625 North Market Blvd., Suite N-112  
Sacramento, California 95834  
800.952.5210 or 800.326.2297 TDD
- Call your local bar association for lawyer referrals in your area. Go to <http://www.statebarassociations.org/> for a list of all state and local bar associations.
- Contact one of these non-profit agencies for legal help:
  1. Disability Rights Education and Defense Fund  
3075 Adeline Street, Suite 210  
Berkeley, CA 94703  
Voice: 510-644-2555; Fax/TTY: 510-841-8645; [info@dredf.org](mailto:info@dredf.org)
  2. Mental Health Advocacy Services  
3255 Wilshire Blvd., Suite 902, Los Angeles, CA 90010  
Voice: 213-389-2077; [www.mhas-la.org](http://www.mhas-la.org)
  3. Deaf Counseling, Advocacy and Referral Agency (DCARA) provides a comprehensive range of programs and services to the Deaf community living in the Greater San Francisco Bay Area of California.  
VP/Voice 510-343-6670; Fax 510-483-1790; [www.dcara.org](http://www.dcara.org)
  4. Disability Rights Advocates  
2001 Center Street, Fourth Floor, Berkeley, CA 94704-1204  
Voice: 510-665-8644  
TTY: 510-665-8716  
Fax: 510-665-8511  
[www.draregal.org](http://www.draregal.org)
  5. Mental Health Advocacy Project  
Law Foundation of Silicon Valley  
152 North Third Street, 3rd Floor  
San Jose, CA 95112  
Tel. (408) 293-4790; Fax (408) 293-0106  
<http://www.lawfoundation.org/mhap.asp>
  6. Disability Rights Legal Center  
Loyola Law School Public Interest Law Center  
800 South Figueroa Street, Suite 1120

Los Angeles, CA 90017  
Voice 213-736-1334; nationwide toll free number 866-999-DRLC  
(3752);  
TTY 213-736-8310; video relay 866-912-8193  
<http://www.disabilityrightslegalcenter.org/>

## 5. How does Disability Rights California protect my rights?

Disability Rights California's job is to protect and advocate for the rights of people with developmental disabilities.<sup>2</sup> Disability Rights California can also give you referrals and information about other advocacy resources. To know how Disability Rights California can help you, call 1-800-776-5746 and ask for a copy of Disability Rights California's Advocacy Plan. Or, get it at <http://www.disabilityrightsca.org/connect/AdvocacyPlan/AdvocacyPlan2013to2017w2014to2015Obj.pdf>

Here are some of the ways Disability Rights California provides advocacy:

**Disability Rights California's Regional Legal Offices** – Disability Rights California has 5 regional offices that offer many types of help. You can go to one of their training sessions, get information booklets or call to get answers over the phone. In some cases, a lawyer or advocate from the regional office can represent you in court or at administrative hearings.

**Office of Clients' Rights Advocates (OCRA)** – Disability Rights California has a contract with DDS to provide clients' rights advocacy for regional center clients. Through this contract, OCRA makes sure that every regional center has a Clients' Rights Advocate (called CRA). Your CRA can help in many ways. They can give you information booklets, training, and answer questions over the phone. In some cases, OCRA's lawyers or advocates can represent you in court or at administrative hearings. (*See Supplement Z for a list of clients' rights advocates.*)

**Peer Advocates** – Peer Advocates offer support and help to people who advocate for their own rights. Peer Advocates are people with disabilities, which means that they understand the client's point of view. They can help you learn about your rights, the IPP process, and how to advocate for yourself.

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<sup>2</sup> Section 4902. All references in this manual are to the Lanterman Act unless it says otherwise.

**Disability Rights California’s Investigations Unit (IU) – Disability Rights California’s IU looks into reports of:**

- abuse and neglect in state hospitals and other facilities
- abusive or negligent care
- sexual assault
- physical abuse or neglect and
- improper use of seclusion and restraint.

They also find and document serious, systematic abuse and neglect. For more information about IU, call 1-800-776-5746 or go to:

[www.disabilityrightscalifornia.org/about/programs.htm](http://www.disabilityrightscalifornia.org/about/programs.htm).

**Disability Rights California’s Client Assistance Program (CAP) - CAP** provides advocacy to persons with disabilities who are seeking or receiving vocational rehabilitation (VR) services from the California Department of Rehabilitation (DOR), as well as individuals who are receiving services from independent living centers or other Rehabilitation Act funded programs. (See *Question 10 for more information on CAP*).

**6. What is the State Council on Developmental Disabilities?**

The State Council on Developmental Disabilities (SCDD) is an independent state agency. It makes sure that people with developmental disabilities get the services and supports they need.

There are 31 people on the Council, including members nominated by the SCDD Regional Offices (formerly called “Area Boards”), members from agencies like Disability Rights California and DDS, and regional center clients and family members. All of them are appointed by the Governor. The council must be made up of people from diverse socioeconomic, ethnic and geographic backgrounds. The Governor must consider that when he appoints its members.<sup>3</sup> If you want to advocate for the rights of people with developmental disabilities, ask to be appointed to the SCDD.

SCDD creates and monitors the state plan for services for regional center clients. The plan finds areas that need improvement and services that need to

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<sup>3</sup> Section 4521.



be increased for people with developmental disabilities and their families.<sup>4</sup> Every five years, the SCDD conducts a “needs assessment” and then prepares a “State Plan.” This document is available to the public and updated every year. The SCDD asks all regional centers for information about the services and supports they are missing and the new, expanded, or converted services and supports they need. The SCDD must highlight new and different ways to deliver services to meet the needs of regional center clients. The SCDD can also use information from other sources, including public hearings. The SCDD also consults with DDS and makes a recommendation to the Department of Finance about the funding for developing new programs in the Governor’s budget, based on the needs assessment.<sup>5</sup>

You can contact the State Council on Developmental Disabilities at:

State Council on Developmental Disabilities

1507 21st Street, Suite 210

Sacramento, CA 95814

Telephone: (916) 322-8481

Toll Free: (866) 802-0514

TTY: (916) 324-8420

Fax: (916) 443-4957

## **7. What are the SCDD Regional Offices (formerly “Area Boards”)?**

There are 13 SCDD Regional Offices in California. These used to be called “Area Boards” but they changed their name.<sup>6</sup> They did not change the areas they serve, only their name. They are part of the State Council on Developmental Disabilities, which provides advice and recommendations to other state agencies and the legislature. SCDD Regional Offices provide public education and outreach. They encourage individuals to start advocacy organizations and help set them up. These advocacy organizations offer practical services to people with developmental disabilities and oversee the services that other agencies provide.<sup>7</sup>

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<sup>4</sup> Sections 4520, 4521, 4540, 4561, 4675, 4676 and 4677.

<sup>5</sup> Section 4677(b).

<sup>6</sup> Section 4544.

<sup>7</sup> Sections 4540 and 4548.

SCDD Regional Offices get advice about services in their area from developmental disability professionals, regional center clients and their families, and the representatives of regional center clients. They help the State Council prepare the state plan and may prepare a plan for their area.<sup>8</sup>

*(See Supplement AA for a list of the Regional Offices, with their addresses, telephone numbers and the counties they serve.)*

## **8. How do the Regional Offices protect my rights?**

Regional Offices have the legal power to protect the legal, civil, and service rights of people eligible to receive their services. They can use legal, administrative, or other solutions to do this. Some Regional Offices offer advocacy to individuals, if their budget allows.

Regional Offices work to stop all forms of discrimination against people with developmental disabilities. This includes discrimination in housing, recreation, education, employment, health and mental health care, and other programs. If they have enough resources, the Area Boards review the programs and practices of public agencies and investigate violations of rights. If they find a problem, they can ask the SCDD for permission to sue the agency. If the regional center believes an agency is not meeting its obligations, it can notify the SCDD Regional Office.<sup>9</sup>

## **9. Who are the Clients' Rights Advocates and Volunteer Advocacy Service Coordinators at the Developmental Centers?**

The State Council on Developmental Disabilities provide Clients' Rights Advocacy services to people in Developmental Centers (DCs).<sup>10</sup> There is a Clients' Rights Advocate (CRA) at each DC who can tell you your legal rights, including your right to evaluations and an IPP that lists the services and supports you need to return to the community. The CRA will also help you pursue administrative and legal remedies, and advocate for you while you are in a DC. Every DC also has a Volunteer Advocacy Service Program. If you

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<sup>8</sup> Section 4548.

<sup>9</sup> Section 4548.

<sup>10</sup> Section 4433.5.

need help at an IPP meeting, Volunteer Advocacy Services Coordinator can help you.<sup>11</sup>

*(See Supplement BB for a list of Clients' Rights Advocates and Volunteer Advocacy Service Coordinators.)*

## **10. What is the Client Assistance Program (CAP)?**

CAP can help you understand your rights and responsibilities related to services from the Department of Rehabilitation (DOR). CAP advocates can help you solve problems with your DOR counselor or help you advocate on your behalf for vocational services when you pursue legal, administrative, or other ways to protect your rights.<sup>12</sup>

CAP is a program of Disability Rights California. To get help from a CAP advocate, call DRC at 1-800-776-5746 or 1-800-719-5798 TTY. CAP also has many helpful publications about your rights to employment services. Visit CAP's publication page at <http://www.disabilityrightsca.org/pubs/PublicationsClientAssistanceProgram.htm>

## **11. What is People First and how do I join?**

*People First of California* is a self-advocacy organization made up of people with developmental disabilities. There is a statewide People First organization and local chapter in most areas. People First helps people with disabilities:

- speak for themselves,
- learn about their rights and responsibilities, and
- solve their own problems

People First organizations are leaders in advocating for the rights of regional center clients. They also provide information and materials to help you make your own life choices. They sponsor many events throughout the state. For more information and to join, contact:

**People First of California, Inc.**  
1225 8th Street, Suite 210

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<sup>11</sup> Section 4541(a)(3).

<sup>12</sup> 29 U.S.C. section 732.

Sacramento, CA 95814  
(916) 552-6625  
E-mail: [info@peoplefirstca.org](mailto:info@peoplefirstca.org)

To find your local People First chapter, go to  
<http://www.peoplefirstca.org/chapters.html>

## **12. Can the regional center help me be my own advocate?**

Yes. Your regional center may offer self-advocacy training, facilitation, and peer advocates.<sup>13</sup> They may also offer transportation to meetings, pay for conferences held by self-advocacy groups, or hire the facilitator you choose for your IPP meetings. If you live in a supported living arrangement, you can get advocacy, self-advocacy training, and facilitation services.<sup>14</sup>

Regional centers can also help you participate in civic activities, for example serving on a board of directors. They will help you with training, transportation, and facilitation. If you want these services and supports, they must be in your IPP.

## **13. How can the Family Resource Centers help me?**

If you have a child with a disability, a special health care need, or at risk of having a disability, you can get support from a Family Resource Center. They offer newsletters, resource libraries, websites, parent-to-parent groups, sibling support groups, and information and referral for parents and professionals.

You can find the phone number for your local Family Resource Center at:  
[www.frcnca.org/directory.html](http://www.frcnca.org/directory.html)

## **14. If I don't have someone to help me advocate for myself, can I get a representative?**

The SCDD Regional Offices can appoint a representative to help you say what you need and want, make decisions and advocate for you, if:<sup>15</sup>

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<sup>13</sup> Section 4512(b).

<sup>14</sup> Section 4689(c).

<sup>15</sup> Section 4541.

- You do not have a representative to help you, like a parent (if you are a minor), guardian or conservator, and
- You ask the SCDD Regional Office to appoint a representative, or
- The SCDD Regional Office decides that your rights and interests will not be protected if they do not appoint a representative.<sup>16</sup>

If you do not have a conservator or guardian, you can choose the person the SCDD Regional Office appoints to represent you. Or you can choose not to have a representative.<sup>17</sup> If you can't express what you want, the SCDD Regional Office will choose a representative, in this order of preference: a parent, involved family member, or a volunteer. Your parent or family member does not have to be your guardian or conservator to be your representative.

## 15. What do I need to know to be a good advocate?

**Collect the facts.** Use common sense. Think about what you would want to know about the situation, if you were hearing the facts for the first time. You can get facts by looking at all of the documents about the situation in your file at the agency or regional center. You can review your own file at any agency and make copies of everything. By law, it cannot cost more than 10 cents per page to copy your papers unless the law sets a different amount.<sup>18</sup> You do not have to pay for the time it takes to make the copies. Copy all of the files about the situation, even if they don't support what you want. You will want to refer to them later.

*(See Chapter 4, Question 19 for information about translating your IPP or other documents.)*

**Keep a diary.** If you have a meeting or phone call, write down everything that is said. Write down who was at the meeting and who said what. It will help to remind you later of what happened. Keep all the papers about the situation together in a file.

**If you don't understand, ask questions.** You have the right to get information from every agency in a way that you can understand and in a language you understand. If you don't understand what someone tells you,

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<sup>16</sup> Section 4541(a)(1).

<sup>17</sup> Section 4541(a)(2).

<sup>18</sup> Cal. Civil Code section 1798.33.

ask them to explain. Ask as many questions as you need to ask to understand.

**Be a good listener.** After you ask for a service or ask a question, listen to the response. Ask yourself if it answers your question. If you are not sure what something means, ask more questions. Listen to what the other side says. You should both be talking about the same issues. What facts does the other side have or say it has? Only argue about things that are important in this situation. Only talk about the facts in this situation to make the issues as clear as possible. If the issues are clear, it is more likely that your arguments will be heard.

**Be prepared.** Before you go to a meeting, look over your file. Know what you want, and why you want it. Make a list of questions you want answered. Have all the information you need about what the other side thinks. Draw a line down the middle of a piece of paper and list the facts and evidence you have on one side and facts or evidence the regional center or other agency has on the other side. This may help you see where you may need for evidence to counter evidence the regional center or other agency has.

**Share information.** Your opinions are valuable. You know your needs at least as well as the professionals who evaluated you. Don't be afraid to say what you think.

**Be assertive.** You have a right to receive services. The agency is there to help you get services. You don't need to be angry, but you do need to speak up for yourself.

**Get help when you need it.** If you don't feel comfortable going to a meeting alone, get someone to go with you. Take a friend, relative or a representative from an advocacy organization. You always have the right to take someone with you. That person can help you stay focused and take notes at meetings. Moral support always helps.

## **16. How can I become a better negotiator?**

Negotiation is two sides working to come to an agreement. Usually, you must talk, make offers, and be flexible. All of the meetings you have with the regional center or other agencies involve some negotiation. All of the IPP meetings and even less formal meetings can be a negotiation.

But, sometimes there are disagreements that cannot be solved with negotiation. If that happens to you, you can have a formal hearing or use the agency's complaint process.

Follow these steps to help you prepare for a negotiation:

**Step 1:** *Write a one-paragraph description of the problem.* Your paragraph should:

- Describe the problem
- Say what causes the problem
- Say what changes you want
- Say what you are willing to accept as a solution

What you are willing to accept as a solution is your bottom line – the point you will not go below. If you do not get this, you will go to a hearing or file a complaint instead.

**Important!** Do not give your notes to the regional center or agency. These are *your* notes to help you negotiate.

**Step 2:** *Figure out who you need to negotiate with.* Look for someone with authority who is closest to the problem. For example, if the problem is a disagreement with your service coordinator about the need for a service, you may be able to negotiate with him or her. If the service is denied because of a regional center policy, you need to negotiate with someone with more authority, like a supervisor or administrator. You cannot negotiate with someone who does not have the power to say “yes.” Demand to speak with someone who has authority to give you the services you need. The Lanterman Act gives you this right.<sup>19</sup>

**Step 3:** *Analyze the strengths and weaknesses of your case and of the regional center's or agency's case.* To figure out if you have a strong case, think about:

- What the law says
- The facts of your situation

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<sup>19</sup> Section 4646(d).

- If there are other cases where similar services were provided

You can also make your case stronger by:

- Asking other regional center clients and family members to support you, and
- Asking elected officials or the media to support your case.

**Step 4:** *Make two lists:* One with the explanation that the regional center (or agency) gave you about why they disagree, and another with other reasons they may have.

Here are some of the reasons the regional center or agency may be against what you want:

- They do not agree that you need the service.
- They do not want to go against an existing policy for buying services.
- They are afraid to set a precedent. If the regional center gives you this support, other people will want it too.
- They are afraid of liability. This means they're scared that something bad will happen to you and you will sue them.
- They do not understand what you need.
- They do not take your request seriously.
- They are set in their ways, always use the same procedures or do not want to give you a new or innovative support.
- They think it costs too much money.

**Step 5:** *Make a plan and stick to it!* Write a plan that says how you will try to get the regional center to agree to what you want. Concentrate on the reasons the regional center has, especially reasons they have not talked about. If you can give them what they want and still get what you want, you have a good chance of success.

To make your plan:

- Research the facts.
- Figure out your bottom line.



- Figure out the compromises you are not willing to make (non-negotiable points).
- Figure out the compromises you are willing to make (fallback position).
- Set up a date, time, and place for the negotiation.
- Write an outline and rules for the negotiation.
- Set a deadline for coming to an agreement. If you can't agree by the deadline, go to a hearing.

You can ask someone to help you in the negotiation, or bring an expert who supports your case. You can also ask someone with more authority from the regional center to come to the negotiation.

*(Supplement R of this manual has a worksheet that can help you plan your negotiation.)*

## **17. What is evidence?**

Evidence is anything that can prove a fact. In regional center hearings, the rules for evidence are more relaxed than in court.

Evidence includes:

- What you say or another person says in a hearing,
- Records, and
- Reports from doctors, psychologists and/or schools.

For example, if you need to prove that you are eligible for regional center services, submit the evaluations and assessments done by psychologists. The results of tests, like psychological tests, are evidence. If a psychologist testifies at your hearing, what she or he says is also evidence.

Some evidence is more important. For example, if a psychologist testifies, it has more weight than the psychologist's report on its own.

The other side will present evidence to prove their version of the case. You want to know in advance what type of evidence they have. You can see their evidence through "discovery."

## **18. How does “discovery” work? How can I find out what the regional center’s or agency’s position is?**

There are different ways to get the regional center or agency to say their position and their reasons for it.

Ask the regional center or agency to give you a copy of:

- The facts they think support their position
- The laws or rules they use to support their position
- The exact changes they want to make to your service
- A list of their witnesses, and a summary of what the witnesses will say
- Any documents they want to present at the hearing
- An explanation of their decision in a language you can understand. You have the right to have the appeals process explained in your language.

The regional center must give you this information at least five days before the hearing. And, five days before the hearing, you must give the regional center representative a list of the witnesses and documents you want to present.

## **19. How can I change the regional center system so that it works better for everyone with developmental disabilities?**

It is important that people with developmental disabilities, their friends, and families work on the “system” so that state agencies and regional centers do their jobs well.

There are many ways to do this, including:

- Offer your opinion at the regional center’s public meetings, especially when they are making their plan for the next year.
- Offer your opinion at the regional center’s “POS Disparity Data” meeting. The law says that regional centers now have to tell the public how they spend the money they get. They have to report about how much they spend based on your age, race/ethnicity, language you speak, your disability, and the type of place where you live.

- Offer your opinion when your State Council on Developmental Disabilities (SCDD) Regional Office collects information about needed services and supports.
- Testify at legislative hearings about the budget for the developmental disabilities system and about services and supports for people with developmental disabilities in California. To learn more about how to get involved, go to <http://www.disabilityrightsca.org/legislature/index.htm>
- Join People First or another self-advocacy group.
- Join groups like Californians for Inclusive Communities (CAIC), ARC California, Harambee Educational Council, or Fiesta Educativa. To see a list of links to various disability organizations, go to <http://www.disabilityrightsca.org/pubs/PublicationsOtherResources.htm>
- Join local task forces or advisory groups working on an issue you are interested in.
- Join a state “stakeholder” group or task force. *(See Question 21 and 22 for more information.)*
- Volunteer to do National Core Indicator (NCI) Assessments for other people who have developmental disabilities. *(See Question 25 for more information.)* Write letters to your newspaper or call your radio station if you do not agree with their coverage of disability issues.

**20. How can I make sure my regional center has the services and supports that people want?**

Over the last 10 years the types of disabilities and the services and supports the community needs have changed. For example:

- The Autism rate in California is rising. People with Autism need special services and supports, like smaller settings or settings with little stimulus.
- California does not offer services to people with some types of disabilities or combinations of disabilities. For example, people with developmental and psychiatric disabilities or people with chronic medical problems who need special technology.

- Many consumers want to live, work, and play in integrated settings. Many people want to work at regular jobs with supports instead of working in sheltered workshops. Others want to go to the local “Y” in the summer instead of a camp for people with disabilities.

New and successful ways to serve people are being developed around the country. You can help to make sure the services in your area meet the changing needs.

The regional center works to develop new types of services and make their services available to more people.<sup>20</sup> The regional center should collect information about the types of services and supports that are missing in their area. Ask your regional center if it does this. And ask for a copy of their list of needed services that are not currently available.

Your service coordinator should help you think about the supports you need, even if they are not available yet. The regional center’s development unit can add this information to their list of missing services. This will help them see the “big picture” and decide the best way to develop new services.

Regional centers must get the opinion of their clients and other local stakeholders when they prepare their annual Outcome-Based Performance Plan. (*See Question 23.*)

When it develops its annual Community Placement Plan, the regional center uses its experience with people at risk of being placed in a developmental centers (DC) to identify the services and supports that will help prevent placement in a DC. The regional center receives funding specifically to develop these services and supports.<sup>21</sup>

*(See Chapter 9 for more information about the Community Placement Plan.)*

Every five years, the State Council on Developmental Disabilities (SCDD) asks regional centers and consumers for information about the services and supports they are missing and the new, expanded, or converted services and supports they need. They must highlight new and different ways to deliver services to meet the needs of regional center clients. The SCDD can also use

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<sup>20</sup> Section 4648(e).

<sup>21</sup> Section 4418.25(c).

information from other sources, including public hearings and surveys for the public to take. You can participate in this process.<sup>22</sup>

*(For more information, see Question 6 above. Also see Chapter 1, Question 9.)*

## **21. What is Self-Determination?**

The statewide Self-Determination Program is a voluntary alternative to the traditional way of providing regional center services.<sup>23</sup> Consumers and their families can have more control over the services and supports they need. Self-determination provides consumers, and their families, with an individual budget, which they can use to purchase the services and supports they need to implement their IPP. To read Disability Rights California's fact sheet on the statewide Self-Determination Program, go to <http://www.disabilityrightsca.org/pubs/F07701.pdf>

## **22. What is a “stakeholder organization,” and how can I join one?**

A “stakeholder organization” is a state organization that represents the interests of “consumers, family members, service providers, and statewide advocacy organizations.”<sup>24</sup> DDS or legislative committees often ask stakeholder organizations to give their opinions on important system policy issues.

Some stakeholders are self-advocacy organizations, like People First, Disability Rights California, California Alliance for Inclusive Communities, the SCDD Regional Offices, and service provider organizations. You can join a group that represents your views and make a difference.

To see a list of links to various disability organizations, go to <http://www.disabilityrightsca.org/pubs/PublicationsOtherResources.htm>

## **23. What are task forces and advisory groups? How can I participate?**

DDS, state legislators, SCDD Regional Offices, and regional centers use task forces or advisory groups to study issues, make a policy, or evaluate new

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<sup>22</sup> Section 4677.

<sup>23</sup> Section 4685.8.

<sup>24</sup> Section 4512(k).

services. These agencies must make their best efforts to include consumers and family members. Task forces or advisory groups must also reflect their community's diverse cultures.

If you want to participate, let them know. These groups are formed when an issue or question comes up and a regional center needs community advice. If you contact your regional center ahead of time, you have a better chance of participating.

#### **24. What does my regional center's Outcome-Based Performance Plan look at?**

The Lanterman Act says that regional centers must have annual performance goals that:

- Develop services and supports necessary to meet local needs,
- Help consumers to have a better quality of life, and
- Make significant progress in the regional center, above the current level of performance.<sup>25</sup>

The regional centers must follow DDS' performance measures, including:

- Lowering the number of regional center clients in developmental centers
- Increasing the number of children who are regional center clients and live with families
- Increasing the number of adult regional center clients who live independently in supported living or in small community homes and work for wages in competitive or supported employment

The performance measures also talk about access to medical and dental care, abuse, and regional center operations. The 2006 DDS guidelines say that regional centers must submit Outcome-Based Performance Plans every year. The plans must say what the regional center has done, with input from the local community, to meet each of DDS' measures.

The activities can include developing new resources or expanding existing resources. The regional center must determine how much of one service or

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<sup>25</sup> Section 4629(c).

support they offer now and how much they commit to develop in the next year. The difference should show “meaningful progress” over the services now available.<sup>26</sup> Regional centers can also develop their own performance measures.

*See Question 24 to find out how you can participate in this process.*

Every regional center publishes a report that shows the services it had at the beginning and end of the year. You can ask your regional center or the Community Service Division at DDS for a copy. The report will also list the DDS Performance Contract Guidelines, your regional center’s Annual Outcome-Based Performance Plan, the activities it committed to, and the Year-End Report.

## **25. How can I help develop my regional center’s annual Outcome-Based Performance Plan?**

The Outcome-Based Performance Plan and the activities needed to meet DDS’ public policy measures are developed through a public process. Each regional center must:

- Give the community information it can understand about budget and the services and supports available now.
- Collect information from the community. They can use focus groups or surveys and must hold at least one public meeting.
- Ask the community for opinions on a draft of the performance plan.
- Give the public a chance to express their opinions at their board of directors meeting, before the board adopts the plan.<sup>27</sup>

The Plan is made once a year, from August to October. The regional center must give it to DDS by November 1st. If you want to be involved, let your regional center know as soon as possible.

## **26. How can I volunteer to do National Core Indicator (NCI) Assessments?**

The SCDD Regional Offices coordinate National Core Indicator (NCI) Assessments for some adult consumers who do not live with their families.

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<sup>26</sup> Section 4629(c).

<sup>27</sup> Section 4629(c).

They need consumers, family members, and advocates to volunteer to do the assessments.

If you volunteer, you will get training. And, you and the coordinator decide how many assessments you will do. For every assessment, you set up a meeting with the consumer, interview them for 1-2 hours and prepare a written report. If you cannot write, you can get help writing the report.

To volunteer, call your SCDD Regional Office to volunteer. (*Supplement AA at the back of this manual lists all Regional Office phone numbers.*)

## **27. How can I make sure the system considers the opinions of people of different ethnicities?**

The system needs input from the different groups that make it up to meet the needs of all of its members. The Lanterman Act says that a regional center must do all it can to make sure that its task forces and advisory groups have consumers and family members from different cultures.<sup>28</sup> You can also attend your regional center's meeting where they talk about the money they spend based on consumers' ages, disabilities, ethnicities/races, and languages.

If you want to participate, notify your regional center or SCDD Regional Office. You can also join organizations like Harambee Educational Council or Fiesta Educativa.

## **28. How can I get on my SCDD Regional Office (formerly "Area Board") Regional Advisory Committee?**

The Governor of California appoints some of the people on the SCDD Regional Advisory Committee. The SCDD office appoints the others. More than half of the people chosen by the county must be people with developmental disabilities, or their parents, guardians or conservators. The rest can be members of the general public.<sup>29</sup>

If you want to be on a Regional Advisory Committee, you must show interest and leadership in human services. Regional Advisory Committee appointment terms are for three years and you can serve two terms. Contact your local

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<sup>28</sup> Section 4640.8.

<sup>29</sup> Section 4521.



SCDD Regional Office for an application and information. (See Supplement AA for contact information.)

## **29. How can I get on the regional center's board of directors?**

At least half of regional center board members must be people with developmental disabilities, their parents, or legal guardians. At least a quarter of the members must have developmental disabilities. Members must represent the different types of disabilities served by the regional center.<sup>30</sup> If you want to be a board member, tell your service coordinator or regional center administrator that you are interested.

## **30. Can I get a facilitator through the regional center to help me advocate for myself or participate on boards or at meetings?**

Yes. The regional center can pay for self-advocacy training, facilitation, and "peer advocates" if they are included in your IPP.<sup>31</sup> Facilitation means giving you materials or equipment, or helping you make and express your choices and decisions.<sup>32</sup>

If a friend or relative cannot help you, the regional center can pay for a facilitator.<sup>33</sup> If your IPP includes support from a facilitator, you can choose the facilitator.<sup>34</sup>

## **31. What are local and state advisory committees?**

Local advisory committees give advice to the regional center's board of directors.<sup>35</sup> The people on the committees have developmental disabilities.

The state also has its own consumer advisory committee that gives DDS information about issues that affect consumers in California.

If you want to participate, contact DDS:

California Department of Developmental Services  
P.O. Box 944202,

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<sup>30</sup> Section 4622.

<sup>31</sup> Section 4512(b).

<sup>32</sup> Section 4512(g).

<sup>33</sup> Section 4512(g).

<sup>34</sup> Section 4648(a)(12).

<sup>35</sup> Section 4622.

Sacramento, California 94244-2020

Tel. (916) 654-1690

TTY: (916) 654-2054

[www.dds.ca.gov](http://www.dds.ca.gov)

### **32. How can I get on Disability Rights California's board of directors?**

Disability Rights California is a non-profit agency that gives legal help and other advocacy to people with disabilities. There are 15-19 people on Disability Rights California's board of directors. The people who are on the board of directors reflect the diversity of the people that Disability Rights California serves.

If you want to apply for a position on Disability Rights California's board of directors, you can fill out an application at any time. If there is an opening on the board, it is posted at [www.disabilityrightsca.org](http://www.disabilityrightsca.org). For more information, call Disability Rights California or OCRA.