

# RIGHTS UNDER THE LANTERMAN ACT

## *The Lanterman Act*

### Chapter 1

This chapter explains the Lanterman Act and how this law:

- Protects your rights
- Helps you get and pay for the services and supports you need
- Helps you get Medi-Cal



**Disability Rights California** is a private, nonprofit organization that protects the legal, civil, and service rights of Californians with developmental or mental disabilities. Disability Rights California provides a variety of advocacy services, including, information and referral, technical assistance, and direct representation.

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The **Office of Clients' Rights Advocacy (OCRA)** is a statewide office run by Disability Rights California, through a contract with the California Department of Developmental Services. OCRA employs a Clients' Rights Advocate (CRA) at each regional center. The CRA is trained to help protect the rights of people with developmental disabilities. To find the CRA at your regional center, see Supplement Z.

To find your regional center, call **OCRA: 800.390.7032** Toll free

# Chapter 1: The Lanterman Act

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# The Lanterman Act

This chapter explains the Lanterman Act, the California law that helps people with developmental disabilities lead productive lives in the community. We explain what the law says and important things you should know about the legal system.

We also explain how the Lanterman Act: Protects your rights, helps you get and pay for the services and supports you need and helps you get Medi-Cal. You may have to refer to the law to get the services you need. When you see § 4512(a), for example, it means that information comes from the Lanterman Act, section (§) 4512, part a.

## 1. What is the Lanterman Act?

The Lanterman Act<sup>1</sup> is the California law that gives people with developmental disabilities the right to the services and supports they need to live a more independent and normal life. The Act is part of the California Welfare and Institutions Code, starting at § 4500 – § 4905.<sup>2</sup> If you want to read the Lanterman Act, go to: <http://www.dds.ca.gov/Statutes/LantermanAct.cfm>

The law says that it is very important that each person get the services and supports that meet their needs and choices.<sup>3</sup>

The Act recognizes that people with developmental disabilities may need help to live full, productive lives.

Here is what the Legislature said:

*“An array of services and supports should be established which is sufficiently complete to meet the needs and choices of each person with developmental disabilities, regardless of age or degree of disability, and at each stage of life, and to support their integration into the mainstream life of the community.”<sup>4</sup>*

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<sup>1</sup> The full name is “the Lanterman Developmental Disabilities Act.” Sometimes it is just called “the Act.” California’s regional center system was created because of this important law, which was introduced by Assemblyman Frank D. Lanterman in 1969. The Act has been amended and updated over the years by several legislators, including Senators McQuorquodale, Thomson, and Chesbro.

<sup>2</sup> To get a copy of the Lanterman Act and related laws, go to the Department of Developmental Services web site: [www.dds.cahwnet.gov/statutes/laws\\_main.cfm](http://www.dds.cahwnet.gov/statutes/laws_main.cfm). Sections 4400-4906 contain related provisions regarding DDS and the rights of people residing in developmental centers.

<sup>3</sup> §§ 4501, 4512(b). Unless otherwise noted, all references in this manual are to the Lanterman Act in the California Welfare & Institutions Code. The § symbol means “section.”

<sup>4</sup> § 4501.

The law and this publication use terms and abbreviations that you may not know. Supplement A at the end of this book explains the meaning of these terms.

## **2. Has the California Supreme Court explained what the State has to do to follow this law?**

Yes. In 1985, there was a case called, “Association for Retarded Citizens-California (ARC) v. Department of Developmental Services (DDS).<sup>5</sup> The California Supreme Court used this case to explain the purposes of the Lanterman Act and the state’s obligations to people with developmental disabilities.

The Court said that the Lanterman Act required that the state provide a “pattern of facilities and services sufficiently complete to meet the needs of each person with developmental disabilities, regardless of age or degree of [disability], and at each stage of life.”

These required services include:

- Identifying people with developmental disabilities,
- Assessing their needs, and
- Selecting and providing services to meet each person’s individual needs.

The Court also explained that the purpose of the law is to:

- Prevent or minimize the number of developmentally disabled people living in institutions and removal from their family and community, and
- Enable people with developmental disabilities to have the same kind of lives as people of the same age without disabilities, and to lead more independent and productive lives in the community.

The Lanterman Act says that the “State of California accepts a responsibility for its developmentally disabled citizens and an obligation to them which it must discharge.” In so doing, the Legislature recognizes that “[p]ersons with developmental disabilities have the same legal rights and responsibilities [as those] guaranteed all other individuals by the Federal Constitution and laws and the Constitution and laws of the State of California.” It also grants people

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<sup>5</sup> 38 Cal.3d 384 (1985).

with developmental disabilities certain legal rights, including the right to treatment and habilitation state expense.

### **3. Who can receive services under the Lanterman Act?**

There are three groups of people who can get services under the Lanterman Act:

- People who meet the Lanterman Act's definition of developmental disability in the Lanterman Act,<sup>6</sup> including people with a substantial disability because of their cerebral palsy, epilepsy, autism, mental retardation, and other conditions closely related to mental retardation or that require similar treatment. (See Chapter 2.)
- People who are at high risk of having a child with a developmental disability. (See Chapter 2.)
- Babies and children under age 3 who are at risk of becoming developmentally disabled. (See Chapter 6, Question 7.)

### **4. How does the Lanterman Act serve and protect the rights of people with developmental disabilities?**

The Lanterman Act provides for services and protects rights in five ways:

The law says a person with a developmental disability has the same rights as other Californians.<sup>7</sup>

The law also protects you with other rights, including the right to:

- make choices in your own life,<sup>8</sup>
- have information that you can understand to help you make decisions, and<sup>9</sup>
- receive services and supports under the least restrictive conditions to help you maximize your potential.<sup>10</sup>

(See Supplement B for more about your rights.)

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<sup>6</sup> §§ 4512(a) and (l).

<sup>7</sup> § 4502.

<sup>8</sup> § 4202(j).

<sup>9</sup> § 4502.1.

<sup>10</sup> § 4502(a).

The law says the regional center is the local agency responsible for seeing that you get the services and supports you need. It also tells the Department of Developmental Services (DDS) to monitor the regional centers and make sure that the Act is implemented.<sup>11</sup>

The law requires the regional center to develop an Individual Program Plan (IPP) that must be based on your unique needs and living situation.<sup>12</sup> The IPP lists the services and supports that you and the regional center agree you need and choose. The regional center pays for some IPP services.

The regional center will assign you a service coordinator. This person will help you get the services listed on your IPP. (See Chapter 4 for more information about IPPs.)

The law gives you ways to enforce your rights, including your right to the services and supports you need and choose. For example, if you believe that the regional center was wrong to deny you services, you can ask for a fair hearing or appeal.<sup>13, 14</sup> and appeals. (See Chapter 12 for more about fair hearings and appeals.)

Another way to enforce your rights is through the complaint process – sometimes called a Section 4731 Complaint.<sup>15</sup> You can file a complaint if you think the regional center or an agency that provides services paid by the regional center violates your rights. For example, if you ask for an IPP meeting and the regional center refuses to schedule one, you can file a complaint. (See Chapter 12 for more about the Complaint process.)

You can also get access to independent advocacy services for advice or help. These agencies can help you understand and enforce your rights:

- The Office of Clients' Rights Advocacy (OCRA). Call 1-800-390-7032 or 916-575-1615 to find the Clients' Rights Advocate for your regional center. (Supplement Z is a list of Advocates to help consumers at each regional center and their contact information.)

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<sup>11</sup> § 4620.

<sup>12</sup> § 4646.

<sup>13</sup> When you ask the regional center to pay for something, such as additional respite services, you are really asking the regional center to change your IPP to include the service you are asking for.

<sup>14</sup> §§ 4700 et seq.

<sup>15</sup> A "Section 4731 Complaint" is named after the section in the Lanterman Act where information regarding the complaint process is located.

- Disability Rights California. Call Disability Rights California toll-free: 1-800-776-5746.
- Area Boards on Developmental Disabilities. (Supplement AA is a list of Area Board Offices with addresses and phone numbers.) Area Boards also have Clients' Rights Advocates and Volunteer Advocacy Coordinators for people who live in developmental centers. (Supplement BB is a list of Clients' Rights Advocates and Volunteer Advocacy Coordinators at all California Developmental Centers.)

## **5. What are regional centers?**

Regional centers are private, non-profit corporations. The regional center is your contact in your community for help getting the services and supports you want and need. With your help, the regional center develops an IPP for you and pays for some of the services in your IPP.

Every regional center client is assigned a service coordinator, also called a case manager or client program coordinator. Your service coordinator helps you get the services listed in your IPP, including services from other agencies, like Medi-Cal or the school district.<sup>16</sup> If any of the services listed in your IPP are not available elsewhere, the regional center will pay for the services.

There are 21 regional centers in California. Each one serves a different area of the state. The Department of Developmental Services, called DDS for short, is the state agency that monitors the regional centers and makes sure they implement the Lanterman Act.<sup>17</sup>

Supplement Y lists all the regional centers, with addresses and phone numbers.<sup>18</sup> (See Chapter 3 for more information about regional centers.)

## **6. Are regional centers the same thing as DDS?**

No. The Department of Developmental Services (DDS) is a state agency. Regional Centers are private, non-profit agencies under contract with DDS. Regional centers provide some services to people with developmental

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<sup>16</sup> § 4620.

<sup>17</sup> §§ 4416, 4434.

<sup>18</sup> To print a map of regional center locations, go to the Association of Regional Center Agencies web site: [www.arcenet.org/map.htm](http://www.arcenet.org/map.htm)

disabilities, and they make arrangements for others to provide needed services. DDS does not provide services directly.<sup>19</sup>

The Legislature says that DDS “has jurisdiction over the treatment of the laws relating to the care, custody, and treatment of developmentally disabled persons.” While “regional centers” provide developmentally disabled persons with “access to the facilities and services best suited to them through their lifetime.”

## **7. What are “services and supports”?**

Services and supports are the types of help you choose and need to reduce the effects of your developmental disability and to allow you to live a full and productive life in the community. Services and supports help you learn new skills, improve your functioning, and lead an independent, productive, and normal life.<sup>20</sup>

For example, you may need occupational therapy to help you swallow so you can be less dependent on your feeding tube for nourishment. Or, you may need training to use the local bus system.

The regional centers and other agencies provide services and supports based on your Individual Program Plan (IPP). Regional centers pay for some services and help you get services and supports from other agencies. Even if a service or support is not specifically listed in the Lanterman Act, you can receive it if you prove that you need it.

See Supplement C or section 4512(b) of the Lanterman Act for a list of services and supports. To learn more about services and supports, see Chapters 6, 7, 8, and 13 of this manual.

## **8. Who provides services and supports?**

Most of the services and supports talked about in this manual are paid for by the Department of Developmental Services (DDS) through the regional centers.

Some services and supports are provided by other agencies, like

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<sup>19</sup> ARC v. DDS (1985) 38 Cal.3d 384, 388-389 (citations and footnotes omitted).

<sup>20</sup> § 4512(b).

- School districts,
- Department of Rehabilitation,
- Medi-Cal or Medicare,
- California Children’s Services (CCS),
- In-Home Supportive Services (IHSS) and other agencies. Services and supports that are available to the public through publicly funded agencies are called “generic” services.<sup>21</sup> You may need the regional center to coordinate services or provide advocacy to help you get “generic” services. See chapters 4 and 5 of this manual to learn about the regional centers’ coordination and advocacy obligations.

“Natural” supports are the types of help you get for free from family, friends, neighbors, and others in your community. Services paid for by the regional center – like independent living or supported living services – can help you develop, strengthen, or expand your natural supports. (See Chapter 6, Question 15.)

**9. Does the State look at the system to see if more services and supports are needed?**

Yes. Every five years, the State Council on Developmental Disabilities must assess the kinds and amounts of services and supports needed that are not currently available. The “needs assessment” must report on the need for new, expanded, or converted community services and supports. Their assessment must examine how any gaps in availability of services impact consumers in certain groups, for example, people with a certain disability, age, ethnicity, challenges, and geographical location. It must also highlight alternative and innovative service delivery models to address consumer needs. The needs assessment must be updated every year.

The State Council’s needs assessment is based on information provided by all regional centers, and may also include information from other sources, including:

- Public hearings,
- National Core Indicators assessments (required under §4571)<sup>22</sup>,

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<sup>21</sup> § 4644(b).

<sup>22</sup> § Required that effective January 1, 2010 a new Quality Assurance System be developed to collect information regarding consumer and family satisfaction, provision of services, and personal outcomes. DDS

- Annual reports on community-based vendor services (required under § 4637.5),
- Regional center reports on alternative service delivery submitted to DDS as required by § 4669.2, and
- Annual reports on self-directed services as required by § 4685.7.
- These assessment and reports are included in the Council's state plan, and sent to DDS and the Legislature. In addition, the State Council consults with DDS and makes recommendations to the Department of Finance about the amount of funding to be included in the Governor's Budget for program development, based on the needs assessment.<sup>23</sup> These documents are available to the public.

A special fund, called the Developmental Disabilities Program Development Fund, provides some of the resources needed to start new programs, and to expand or convert existing programs. Money for the fund comes from fees collected from families whose children are placed outside the home. The fund supports programs that promote integrated residential, work, instructional, social, civic, volunteer, and recreational services and supports that increase opportunities for self-determination and maximum independence of persons with developmental disabilities.<sup>24</sup> This is consistent with the approved priorities for program development in the State Council State Plan. This fund is financed from fees collected from families whose children are placed outside the home.

## **10. Does the regional center provide “preventive services”?**

Yes. You can qualify for preventative services under the state law (Lanterman Act, § 4644) or under federal law (Individuals with Disabilities Education Act (IDEA), Part C). The state law says that parents with a high risk of having a child with developmental disabilities can receive services to help prevent developmental disabilities.<sup>25</sup> This includes prenatal services (during pregnancy) and perinatal services (around the time of birth), as well as genetic

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awarded this contract to Human Services Research Institute (HSRI). HSRI will administer the National Core Indicators (NCI) assessment to regional center consumers, This will enabled the data in California to be compared against similar date collected in other states.

<sup>23</sup> § 4677

<sup>24</sup> § 4677(a).

<sup>25</sup> § 4644(a).

testing. The regional centers will help eligible future parents to get this type of services from generic agencies.<sup>26</sup>

Under the Lanterman Act, “at-risk” babies can also get services to prevent developmental disabilities, or to reduce the severity of their disability. The regional center can follow a child’s development in the early years of life and help the parents get the services the child needs to prevent a developmental disability, including specialized medical services.<sup>27</sup>

Most services for children under age three are covered by Part C of the federal IDEA.<sup>28</sup> (See Chapter 6, Question 7.) However, eligibility for Part C changed effective July 28, 2009. Infants and toddlers who are at a high risk of having a developmental disability are no longer eligible for Part C services. They will now be served under a new prevention program. The prevention program changed substantially in 2011. Effective July 1, 2011, no new children will be referred to the regional centers administered program. New at risk infants and toddlers will participate in the Prevention Resource and Referral Program (PRRS) administered through the Family Resource Centers. Eligibility for Part C for infants and toddlers with a developmental delay has also changed. It is now as follows:

For children aged 0-23 months, a significant delay is a 33% delay in one or more areas.

For children aged 24 -36 months, a significant delay is 50% in one area or 33% in two or more areas.

The areas of delay are unchanged and are: cognitive development, physical and motor development, communication development, social or emotional development, or adaptive development.

If you have children under three, read Chapter 12 of Special Education Rights and Responsibilities. It covers Part C services, and is available from Disability Rights California. Ask for Disability Rights California Publication 5040.01.

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<sup>26</sup> A generic agency is any agency which receives public funds and has a legal responsibility to provide services to all members of the general public. § 4644(b).

<sup>27</sup> § 4642

<sup>28</sup> 20 U.S.C. §§ 1431 et seq.

## **11. Does the regional center provide emergency and crisis intervention services?**

Yes. Emergency and crisis intervention services include things like mental health services and behavior modification services that you need to stay in your living arrangement.<sup>29</sup>

Crisis intervention services should be considered first so as not to disrupt your living arrangement.

Many regional centers have crisis intervention teams that go to your home in a time of crisis. They can provide behavioral or nursing support in a time of crisis, or when there are sudden behavioral problems.<sup>30</sup> Regional centers can also provide extra staff in your group home.

## **12. What happens if crisis intervention services do not work?**

If crisis intervention services in your home are not successful, the regional center must arrange for emergency housing in your community.<sup>31</sup> Every regional center offers emergency housing, but the type of emergency housing they have and how much is available varies in different areas. Sometimes there are a few crisis beds located in a small Community Care Facility (CCF). Other times a regional center can pay for a motel room and provide supports there for a short time.

If your placement in the community is at risk of failing, and you might be sent to a developmental center, the regional center must immediately inform you, your parents, legal guardian or conservator, and DDS.<sup>32</sup>

DDS has designated the Regional Resource Development Projects (RRDP)<sup>33</sup> to handle these situations. An RRDP will do an assessment. If the assessment shows that you need emergency services, the regional center must provide them. You will have an IPP meeting with the RRDP representative as soon as possible. The team will review the emergency services and determine the services and supports you need to stay in your community.<sup>34</sup>

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<sup>29</sup> § 4648(a)(10).

<sup>30</sup> § 4648(a)(9)(C).

<sup>31</sup> § 4648(a)(10).

<sup>32</sup> § 4418.7(a).

<sup>33</sup> For a list of RRDPs statewide, see Supplement CC.

<sup>34</sup> § 4418.7(b).

Redwood Place is a residential facility in the Bay Area that provides intensive support and rehabilitation to clients who otherwise would go to a state hospital or 24-hour care facility. (See Chapter 9 for more about how to prevent institutionalization.)

When there are no other options, you may be sent to a county psychiatric hospital. (See Chapter 10, Question 8 about the regional center's responsibilities if you are in a psychiatric unit.)

If you must move to another community, the regional center must make every effort to return you to your chosen living arrangement, with all the supports you need, as soon as possible.<sup>35</sup>

### **13. What happens when children need emergency services?**

There are several crisis homes for children in California that provide intensive behavioral supports. They are two-person facilities that help children manage their behavior so that they can return home or remain in a community setting.

Children usually are referred to these homes by the Regional Resource Development Projects (RRDP).

### **14. What is Medi-Cal?**

Medi-Cal pays for health care services for low-income people and people with disabilities. Many regional center consumers are eligible for Medi-Cal. The Medi-Cal program must follow federal and state laws and regulations.

For more information about Medi-Cal, see Medi-Cal System Overview, Disability Rights California Publication 5360.01, at: [www.disabilityrightsca.org/issues/health\\_pubs.html](http://www.disabilityrightsca.org/issues/health_pubs.html)

### **15. Will Medi-Cal pay for any of my regional center services?**

Probably yes. If you are a Medi-Cal beneficiary, Medi-Cal will probably pay for at least part of the services, equipment, and case management that you receive from the regional center.

If your IPP includes services or equipment that is not usually covered by Medi-Cal, such as respite care or supported living services, Medi-Cal may pay for

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<sup>35</sup> § 4648(a)(10).

them through the Home and Community-Based Services Waiver for regional center consumers. (See Chapter 13.)

## **16. What regional center services are covered through the Home and Community-Based Services Waiver?**

Some regional center consumers are eligible to receive Medi-Cal services through the Developmental Disability Home and Community-Based Services Waiver, or “DD Waiver”. The following services are available through this waiver: (not an exhaustive list)

1. Case Management
2. Homemaker
3. Home Health Aide Services
4. Respite Care
5. Habilitation
6. Environmental Accessibility Adaptations
7. Skilled Nursing
8. Transportation
9. Specialized Medical Equipment and Supplies
10. Chore Services
11. Personal Emergency Response Systems (PERS)
12. Family Training
13. Adult Residential Care
14. Other waiver services which are cost-effective and necessary to prevent institutionalization:
  - Vehicle Adaptations
  - Crisis intervention
  - Mobile Crisis Intervention
  - Crisis Intervention Facility Services
  - Nutritional Consultation
  - Behavior Intervention Services including the development, analysis and tracking of programs
  - Specialized Therapeutic Services

(See Chapter 13, for more information on the DD Waiver.)

## **17. Will Medi-Cal pay for all regional center services?**

No. Some regional center services are not covered by Medi-Cal. And, some regional center consumers are not eligible for Medi-Cal because their income is too high, because of their immigration status, or some other reason.

The services that you need should be listed in your IPP. Whether or not Medi-Cal pays for your services should not affect what services are listed as needed in your IPP. However, due to recent changes in the Lanterman Act, regional centers are reducing or eliminating some services. If you are on the DD Waiver and your regional center tries to reduce or eliminate a service listed above, you should contact Disability Rights California or the Office of Clients' Rights Advocacy. (See Chapter 13.)

**18. Do I have to be a U.S. citizen or legal resident to get Medi-Cal?**

No. You do not have to be a U.S. citizen to get Medi-Cal. Many immigrants are eligible for “full-scope” Medi-Cal that covers all services that Medi-Cal usually covers. Some immigrants are not eligible for full-scope Medi-Cal. But they may be eligible for limited Medi-Cal services, such as emergency medical services, pregnancy services, and some nursing facility services.

To see a chart about Medi-Cal eligibility requirements, visit:  
[www.nilc.org/ce/ceindex.htm#calbens](http://www.nilc.org/ce/ceindex.htm#calbens)

If you qualify for regional center services but do not qualify for Medi-Cal, the regional center must pay for the services and equipment you need and that are listed in your IPP without using Medi-Cal funding.

**19. Do I have to be poor to qualify for Medi-Cal?**

There are income requirements for Medi-Cal. There are special income rules for children and adults with disabilities.

For more information about income requirements, see Medi-Cal System Overview, Disability Rights California Publication 5360.01, at:  
[www.disabilityrightsca.org/issues/health\\_pubs.html](http://www.disabilityrightsca.org/issues/health_pubs.html)

There are special rules that allow some people to qualify for Medi-Cal even if their family income is not very low. This is called “institutional deeming.” For more information about institutional deeming, see Chapter 13, Questions 9-14.

**20. Do I have to be a U.S. citizen or legal resident to receive services from a regional center?**

No. Your immigration status does not matter for regional center eligibility. The Lanterman Act only says that you have to be a California resident.<sup>36</sup> In general, you are a California resident if you live in California and plan to stay here. You can only live in one place at a time. It does not matter if you leave California temporarily, as long as you plan to return. For an unmarried child under 18, the residence is normally the same as his or her parents’.

If you are in California on a temporary visa, it is very difficult to prove that you are a California resident. The temporary visa says that you are in the U.S. and California temporarily, so it is hard to claim that you are here permanently. Some regional centers will believe you if you say that you plan to stay here even though you have a temporary visa. Talk to an immigration attorney before you do this. It could affect your immigration status.

**21. Do I have to be poor to qualify for regional center services?**

No. The regional center gives you the services and supports you need because of your developmental disability. It does not matter what your income is. In some situations however, parents may have to pay small fees. See Questions 23-38 below.

**22. Are my regional center records confidential?**

Yes. All regional center information and records about you are confidential.<sup>37</sup> This means that before anyone can see your information, the regional center needs permission from you, your conservator, or someone you have asked to represent you.

If you are under 18, your parents or legal guardian must give permission. There are only a few exceptions to this rule. Courts and law enforcement agencies can see your records under certain circumstances. Some licensing investigators can see your records if they need them to make sure the

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<sup>36</sup> Government Code § 244 lists rules to consider in determining where your residence is located.

<sup>37</sup> § 4514.

standards of care and services are being met in health facilities and community care facilities.<sup>38</sup>

You have the right to review and copy records in your regional center file.<sup>39</sup> If you ask to review your file, the regional center has three business days to show you the files.<sup>40</sup> You also can give someone else permission to see your file.

See Chapter 12, Question 16 for more about reviewing your file when you want to file a fair hearing appeal or complaint.

### **23. Do I have to pay for services?**

In general, no. The Lanterman Act does NOT say that you have to pay for services and supports in your IPP.

However, in some situations the Lanterman Act requires families to pay for some services in a child's IPP, including:

Out-of-Home Care for Children – Parents of children under age 18 who receive 24-hour-a-day, out-of-home care, may have to pay for some of that care, depending upon their ability to pay. The fee will be based on the current cost of caring for a child at home. The cost will be determined by using data from the United States Department of Agriculture's survey and adjusted by the Consumer Price Index.<sup>41</sup> The regional center will consider what the family has paid for medical expenses and other expenses, like how much it costs to travel to visit you, among other things.<sup>42</sup>

If you disagree with parental fee that has been assessed, you have appeal rights. The appeal process for parental fees is different than for services

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<sup>38</sup> §§ 4514(a)-(p).

<sup>39</sup> § 4725.

<sup>40</sup> § 4728.

<sup>41</sup> § 4782.

<sup>42</sup> § 4784. See also Cal. Code Regs., tit. 17 §§ 50201-50241. Disability Rights California believes there should be no parental fees when the child is a Medi-Cal recipient and is living in a Medi-Cal funded placement, such as a nursing facility, an intermediate care facility for people with developmental disabilities, a developmental center, or a community care facility funded under the HCBS Waiver. This is because state and federal Medicaid laws require that the payment made by the Medicaid program – Medi-Cal in California – is to be considered as payment in full. (Welf. & Inst. Code 14019.3(d); 42 C.F.R. §447.15.) Parental fees for children who need to live outside the family home to benefit from their education may also be unlawful. Federal special education law provides that “[i]f placement in a public or private residential program is necessary to provide special education and related services to a child with disabilities, the program, including non-medical care and room and board, must be at no cost to the parents of the child.” (34 C.F.R. §300.302.) If a residential placement is necessary for educational purposes, it must be provided at no cost to the parents.

received under the Lanterman Act. The appeal must be filed within 30 days of receipt of the parental fee confirmation letter, be in writing, be addressed to the Director of Developmental Services, and state the reason(s) for the appeal. The Director will issue a written decision within 30 days after receipt of all pertinent financial information.

Day Care – The law says parents must pay the same amount for day care as they would pay for a child without disabilities. The regional center pays for any costs beyond the cost of typical day care. If the family can show that they cannot afford to pay, the regional center can pay the entire cost of day care.<sup>43</sup> (See Chapter 6 for more about services to keep families together.)

Diapers – See Chapter 6, Question 17.

Annual Family Program Fee – Effective July 1, 2011, your family will have to pay an annual fee if:

- your child is eligible for regional center services under the Lanterman Act or Early Intervention Services Act,<sup>44</sup>
- your child is under 18 years of age,
- your child lives with you,
- your child or family receives services beyond needs assessment and service coordination,
- your child receives services beyond those for which a copay is being assessed under the Family Cost Participation Program (see below), and
- your child is not eligible for Medi-Cal, including through the Home and Community Based Services (HCBS) DD Waiver. (See Question 8 above.)

If the family's adjusted gross income is less than 4 times the federal poverty level, there will be no fee. If the family's adjusted gross income is between 4 and 8 times the federal poverty level, there will be a fee of \$150 per family per year.<sup>45</sup> If the family's adjusted gross income is over 8 times the poverty level, there will be a fee of \$200 per family per year.

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<sup>43</sup> § 4685(c)(6).

<sup>44</sup> The fee will apply to children age 0-2 years only if approval is given to the state by the federal government.

<sup>45</sup> § 4785(b).

These fees are per family, regardless of the number of regional center eligible children in the family. See Questions 33 – 38 below for more information about the Annual Family Program Fee.

Services under the Family Cost Participation Program – Your family will have to pay a co-payment for respite, daycare, and/or camping services listed in your IPP if:<sup>46</sup>

- your family income is more than 4 times the federal poverty level,<sup>47</sup>
- the children living at home are between 0 and 17 years old, and
- the children are not eligible for Medi-Cal, including through the Home and Community Based Services (HCBS) DD Waiver. (See Question 8 above.)

The amount of the co-pay will be based on the family income. See Questions 24-32 below for more information about the Family Cost Participation Program.

The regional center cannot ask you or your family to pay for other regional center services listed in your IPP. They cannot deny you a service you need because your family cannot pay for it.

## **24. What is the Family Cost Participation Program?**

The Legislature adopted The Family Cost Participation Program in 2004. This law only affects respite, day care and camping services.<sup>48</sup> It does not apply to all families.

For example, if your child qualifies for Medi-Cal, you do not have to pay for any part of services.<sup>49</sup> Even if your child qualified for Medi-Cal without considering your family income, (called “institutionally deemed”) you do not have to pay any share of cost.

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<sup>46</sup> § 4783, this parental fee program was implemented on January 1, 2005.

<sup>47</sup> In 2006, 4 times the federal poverty level for a family of four was \$6,668 a month. The regional center looks at your adjusted gross income for last year – that is, the amount you paid state or federal taxes on after deductions.

<sup>48</sup> § 4783(c).

<sup>49</sup> § 4783(a)(1)(E).

## 25. Who has to pay for part of respite, day care, or camping<sup>50</sup>?

Only families who meet all of these conditions will have to pay for part of respite, day care, and camping services:

- Your children are between 0 and 17 years old and live at home,
- Your children are not eligible for Medi-Cal,
- Your children receive respite, day care, and/or camping services,
- Your family's gross annual income is at least four times the "federal poverty level."<sup>51</sup> (See Question 28 below.)

If your family meets these conditions, you will have to pay a share of the cost on a sliding scale. "Sliding scale" means that families with less income pay less, sometimes as low as 5% of the cost. Families with higher income pay more, sometimes up to 80% of the cost.

## 26. How do I prove my income?

You must show the regional center one of the following documents that prove your gross annual income, such as:

- an IRS Form W-2,
- last year's state or federal income tax return,
- payroll stubs,
- other acceptable proof of other income.<sup>52</sup>
- After you sign your completed IPP, you have 10 days to give the regional center your income information. Then, the regional center has 10 days to tell you how much you will have to pay, also called your cost participation.<sup>53</sup> If you do not provide your complete income information, you will have to pay the maximum cost participation.<sup>54</sup>

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<sup>50</sup> In 2009, camping services were suspended. However, there are exceptions. See Chapter 8, question 60 for details.

<sup>51</sup> §§ 4783(a)(1)(A)-(E); 4783(b)(1).

<sup>52</sup> § 4783(g)(2).

<sup>53</sup> § 4783(g)(3).

<sup>54</sup> § 4783(g)(4).

**27. Does the regional center have to give me information about the cost participation program?**

Yes. The regional center has to give you a booklet called Family Cost Participation Program Guide, the first time you apply for services and at all IPP review meetings where you change day care, respite, or camping services.<sup>55</sup>

You can download the Family Cost Participation Program Guide and get more information about this program at: [www.dds.cahwnet.gov/fcpp/index.cfm](http://www.dds.cahwnet.gov/fcpp/index.cfm)

**28. How does the regional center decide how much I have to pay?**

How much you have to pay is based on a sliding scale. This means that families with lower incomes pay less, and families with higher incomes pay more. You only have to pay if your family's gross annual income is more than four times the Federal Poverty Level (FPL). The FPL is based on income and family size. It is part of the guidelines that the government uses to decide who is eligible for programs like Medi-Cal.

For example, in 2007, 100% of the FPL was:

\$13,690 annual income for a family of 2

\$17,170 annual income for a family of 3

\$20,650 annual income for a family of 4

To calculate the Family Cost of Participation (how much you have to pay), you multiply the FPL for the number of people in your family by 4. If your income is more than this amount, you would pay from 5% – 80% of the cost of the services. For example, if there are two people in your family, you would multiply the federal poverty level of \$13,690 by four. That amount is \$54,760. If your gross income is less than \$54,760 you will not pay for any services. If your gross income is more than \$54,760 you will pay 5%-80% of the cost of the services.

To calculate the exact amount of your co-payment, you can look at page 4 of the DDS Family Cost Participation Program Guide chart at: [www.dds.ca.gov/fcpp/PDF/BestTranslations\\_Pamphlet.pdf](http://www.dds.ca.gov/fcpp/PDF/BestTranslations_Pamphlet.pdf)

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<sup>55</sup> § 4783(i).

**29. What if I have more than one child who gets regional center services?**

If you have more than one child who gets regional center services, the amount you have to pay will be reduced. For example, the co-payment for a family with two children who are regional center clients will be reduced by 25%. The co-payment for a family with 3 children will be reduced by 50%. A family with 5 or more children who are regional center clients will not have to pay anything at all.<sup>56</sup>

For example, if the regional center pays \$240 for 16 hours of respite for a family of 4, and if the family's gross annual income is \$82,600, the family's co-payment would be 5% of \$240, or \$12.00. If the family has 2 children who are regional center clients, the co-payment will be 25% less, or \$9.00.

**30. Does a family who earns 4 times the FPL always have to pay?**

No. The executive director of each regional center can adjust the family cost participation amount when families are experiencing "unavoidable and uninsured catastrophic loss" that temporarily limits their ability to pay and when there would be a "direct economic impact" if the cost were not lowered.

An "uninsured catastrophic loss" can be natural disasters, accidents, major injuries to immediate family members, or extraordinary medical expenses.<sup>57</sup> A "direct economic impact" means that if the director does not lower the cost, your family would go without basic necessities, like food, shelter, clothing, or medical care.<sup>58</sup>

**31. If the director of the regional center denies my request to adjust my cost participation, can I appeal?**

Yes. If you disagree with the executive director's decision, you can appeal. The regional center must give you a "notice of action" that says why your request was denied.<sup>59</sup> As of July 1, 2006 you have 15 days after you receive the written decision to appeal to the Director of the Department of Developmental Services.<sup>60</sup> (See Chapter 12 for more on appeals.)

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<sup>56</sup> § 4783(d).

<sup>57</sup> Cal. Code Regs., tit. 17 § 50265(a).

<sup>58</sup> Cal. Code Regs., tit. 17 § 50265(b).

<sup>59</sup> § 4783(k)(2).

<sup>60</sup> § 4783(k)(3).

### **32. What if the regional center made a mistake in calculating my cost participation?**

If you believe the regional center is charging you more than it should, or that they made a mistake when they calculated your cost participation amount, you have 30 days to appeal the decision.

First, send a letter to the regional center's executive director. If the regional center does not recalculate it to your satisfaction, you can appeal to the Director of the Department of Developmental Services. You must do this within 15 days of receiving the regional center's executive director's decision.<sup>61</sup>

### **33. What is the Annual Family Program Fee?**

DDS established a new program by which it will collect fees for children receiving regional center services. This program began July 1, 2011. Any family whose adjusted gross income is at or above 4 times the federal poverty rate and that meets the following criteria will be assessed an annual fee:

1. The child is eligible for regional center services under the Lanterman Act or Early Intervention Services Act,<sup>62</sup>
2. The child is under 18 years of age,
3. The child lives with his/her parents,
4. The child or family receives services beyond needs assessment and service coordination,
5. The child does not receive Medi-Cal including Medi-Cal waiver services, and
6. The child receives services beyond those for which a copay is being assessed under the Family Cost Participation Program (see questions 24- 32, above).<sup>63</sup>

If the family's adjusted gross income is less than 4 times the federal poverty level, there will be no fee. If the family's adjusted gross income is between 4 and 8 times the federal poverty level, there will be a fee of \$150 per family. <sup>64</sup>If

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<sup>61</sup> § 4783(k)(1).

<sup>62</sup> The fee will apply to children age 0-2 years only if approval is given to the state by the federal government.

<sup>63</sup> Welfare and Institutions Code Section 4785(a); includes respite, day car, or camping costs.

<sup>64</sup> Welfare and Institutions Code Section 4785(b)

the family's adjusted gross income is more than 8 times the federal poverty level, there will be a fee of \$200 per family.

General considerations:

1. These fees are per family, regardless of the number of regional center eligible children are in the family.
2. Total adjusted gross family income means all income from both parents (even if living separately unless a court order states otherwise), including the community property portion of a stepparent's income.
3. If a noncustodial parent's income cannot be obtained, then it shall not be included.

**34. How do I calculate if I have to pay the Annual Family Program Fee and if so, how much?**

If your family's adjusted gross income is less than 4 times (400%) the federal poverty level, there will be no fee. If your family's adjusted gross income is between 4 and 8 times (400 and 800%) the federal poverty level, there will be a fee of \$150 per family. <sup>65</sup>If the family's adjusted gross income is more than 8 times (800%) the federal poverty level, there will be a fee of \$200 per family. See the chart below for the amounts in 2011. Remember, the guidelines for the federal poverty level change every year.

**2011 HHS Poverty Guidelines <sup>66</sup>**

<b>Persons in Family</b>	<b>48 Contiguous States and D.C.</b>	<b>400%</b>	<b>800%</b>
1	\$10,890	\$43,560	\$87,120
2	\$14,710	\$58,840	\$117,680
3	\$18,530	\$74,120	\$148,240
4	\$22,350	\$89,400	\$178,800
5	\$26,170	\$104,680	\$209,390
6	\$29,990	\$119,960	\$239,920
7	\$33,810	\$135,240	\$270,480
8	\$37,630	\$150,520	\$301,040

<sup>65</sup> Welfare and Institutions Code Section 4785(b)

<sup>66</sup> SOURCE: Federal Register, Vol. 76, No. 13, January 20, 2011, pp. 3637-3638 at <http://aspe.hhs.gov/poverty/11poverty.shtml>

For each additional person, add \$3,820.

**35. Are there exemptions to the Annual Family Program Fee?**

Yes, a regional center may grant an exemption to the assessment of an annual family program fee if the parents demonstrate:

1. The exemption is necessary to maintain the child in the family home;
2. The existence of an extraordinary event that impacts the parents' ability to pay the fee or the parents' ability to meet the care and supervision needs of the child; or
3. The existence of a catastrophic loss that temporarily limits the ability of the parents to pay and creates a direct economic impact on the family. For purposes of this subdivision, catastrophic losses may include, but are not limited to: natural disasters, accidents involving or major injuries to an immediate family member and extraordinary medical expenses.<sup>67</sup>

**36. How is the Annual Family Program Fee going to be implemented?**

At the annual IPP meeting, the regional center should give each qualifying family a form and an envelope to mail the Annual Family Program Fee to the Department of Developmental Services (DDS). DDS will report on the fees collected to each regional center quarterly.

**37. What happens if I don't pay the Annual Family Program Fee?**

Non-payment of the Annual Family Program Fee cannot result in delayed or denied services for the child or family.<sup>68</sup> If fees are not paid, the regional center will send a letter requesting payment of the fees. If fees are still not paid DDS can pursue collections.<sup>69</sup>

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<sup>67</sup> Welfare and Institutions Code Section 4785(f)

<sup>68</sup> Welfare and Institutions Code Section 4785(g)

<sup>69</sup> Welfare and Institutions Code Section 4785 (d) and (e)

**38. Can I challenge the amount of the Annual Family Program Fee that was assessed for my family?**

Yes, the Lanterman Act states that if you are dissatisfied with a decision you can appeal that decision by filing a hearing request within 30 days after notification. See Chapter 12 for information about appeals.

**39. How can I learn more about my rights under the Lanterman Act?**

Disability Rights California has several publications that can help you. You can get them by calling Disability Rights California or OCRA. Or download them from Disability Rights California's web site:

[www.disabilityrightsca.org/issues/index.htm](http://www.disabilityrightsca.org/issues/index.htm)

- Your Rights, Disability Rights California Publication 5150.01.
- Your IPP, It's Not Just A Piece of Paper, Disability Rights California Publication 5038.01.

This was written by consumers to explain the Individual Program Plan (IPP) process and individual rights.

The Department of Developmental Services (DDS) also has information you can get from their web site or by calling them, including:

*A Consumer's Guide to the Lanterman Act*

You can download a copy at: [www.dds.cahwnet.gov/cac/pdf/la\\_guide.pdf](http://www.dds.cahwnet.gov/cac/pdf/la_guide.pdf)

*Picture Sticker Book* for use with the "Making My Own Choices" Booklet and "Satisfaction Guide"

For more information or copies of either of these, contact:

Department of Developmental Services  
Office of Human Rights and Advocacy Services  
1600 Ninth Street, Room 240, Sacramento, CA 95814  
Tel: (916) 654-1888

People First of California, Inc. has these helpful publications:

*PFCA Self-Determination and IPP Buddy System*

You can get it at: [www.peoplefirstca.org/self-determination.htm](http://www.peoplefirstca.org/self-determination.htm)

*The People First Community Services Inclusion Workbook*

You can get it at: [www.peoplefirstca.org/CommunityInclusion.htm](http://www.peoplefirstca.org/CommunityInclusion.htm)

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