

RIGHTS UNDER THE LANTERMAN ACT

How To Stay Out Of An Institution

Chapter 9

This chapter explains:

- Your right to be part of the community
- How to get out and stay out of institutions



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Chapter 9: How to Stay Out of an Institution

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Chapter 9

How to Stay Out of an Institution

This chapter explains:

- *Your right to live in your community,*
- *How to stay out of an institution, and*
- *How to get out of an institution.*

We explain what the law says about your right to live in and be part of your community. This information is based on a state law called the Lanterman Act. You may have to refer to the law to get the services you need. We give you the exact section of this state law where the information is found. When you see § 4512(a), for example, it means that information comes from the Lanterman Act, section (§) 4512, part a.

If you want to read the Lanterman Act, go to:

<http://www.dds.ca.gov/Statutes/LantermanAct.cfm>

1. Do I **have to** live in an institution?

No. The Lanterman Act gives you the right to get the services and supports you need to stay in your community. You also have the right to get these services and supports “in the least restrictive environment” (LRE, for short).¹

According to the California Supreme Court, the main purposes of the Lanterman Act are to:

- Keep people with developmental disabilities out of institutions as much as possible, and avoid separating them from their families and community,
- Allow people with disabilities to live like people their age without disabilities, and
- Help people with disabilities live more independently and productively in their community.²

¹ § 4502(a). All references in this manual are to the Lanterman Act unless it says otherwise. The § symbol means “section.”

One of the rights that all people with developmental disabilities have under the Lanterman Act is a right to receive services and supports “in the least restrictive environment” (or LRE³). The U.S. Supreme Court⁴ said it is an illegal form of discrimination based on disability to make you live in an institution if you do not need to. The Americans with Disabilities Act (ADA) is another law that gives you similar rights. These rights are sometimes called an “integration mandate.” It is against both the Lanterman Act and the ADA to only provide services in a segregated and isolated setting.

2. Can I get services to help me be part of the community?

Yes. Everyone has the right to live in and get services in the least restrictive, most integrated setting, based on their needs and choices. Community integration services can help you to become more integrated with your community.

You can get community integration services no matter where you live. For example, if you live in a residential facility with 6 other people, you might want a more integrated setting with more supports. A better choice for you could be supported living, a family teaching home⁵, or living at home with your family.

3. How can I move out of an institution and into the community?

You must change your IPP. The IPP process determines the services and supports you need and allows you to identify those that you want. It is also a way to make sure you can be integrated into your community. (*See Chapter 4 for more on the IPP process, and Chapter 7 for more on living arrangements.*)

If you live in a developmental center or other institution, you should have an assessment and an IPP that is based on your particular needs and preferences. Your IPP must look at what is keeping you from living in the community, and what you would need to be able to return to your community.

Sometimes, housing or supplemental services and supports are not available. But if the services and supports that you need to live in the community are listed in your IPP, your team must find or develop those services for you.

² *Assoc. for Retarded Citizens-Calif. v. Dept. of Developmental Services*, 38 Cal.3d 384, 388 (1985).

³ § 4502(a).

⁴ 527 U.S. 581 (1999).

⁵ § 4689.1(c).

4. What is deflection?

Deflection is the process of identifying and setting up the services and supports you need to stay out of an institution. There are special laws about deflection from developmental centers.⁶ Deflection services can keep you out of an institution by:

- Helping you stay in your current placement. For example, you could get mental health services and behavior intervention services to keep you in your living arrangement if you are going through a crisis.
- Helping you find a different placement if you cannot stay in your current placement. (See *Question 7*.)
- For children, the regional center may have to try new and creative ways to meet the family's needs, and keep the family together.⁷

Deflection sometimes means that you need more of the services that you are getting now. These are called supplemental services. For example, your IPP team may agree that you need more support staff.⁸

If crisis services do not work, you can get crisis intervention services in your community. If there is no way for you to stay in the community, the regional center must make every effort to get you back to the living arrangement you choose, with all the supports you need, as soon as possible.⁹

5. How do I know what deflection services are available?

Every regional center is supposed to have an agreement with county mental health agencies. These agreements, called *memoranda of understanding* (MOUs, for short), include crisis intervention plans for people who are regional center *and* county mental health agency consumers.

The crisis intervention plan may include:

- response systems for after-hours emergencies,
- guidelines for notifying other agencies, and

⁶ See § 4418.7(a)-(c).

⁷ § 4685(c)(2).

⁸ § 4648(a)(9)(C).

⁹ § 4648(a)(10).

- follow-up protocols.¹⁰

You may also need emergency housing options, such as:

- crisis group homes,
- crisis beds in a regular group home,
- crisis foster homes, and
- motel, hotel or psychiatric facility beds.¹¹

To learn more about the services available at your regional center, you can ask your regional center for a copy of their MOU.

You can also contact DDS and ask for their annual report to the Legislature about crisis intervention services and emergency housing options offered by each regional center. DDS can also give you information about whether these options are for children or adults, and if they are accessible to people with physical disabilities.¹²

6. What is a developmental center?

A developmental center (DC) is a state institution for people with developmental disabilities. It is the most restrictive and segregated living situation. There are parts of DCs that are locked facilities. There are seven DCs in California.¹³ (Many other states have closed their large institutions.)

DCs are for people with medical or behavioral needs that cannot be met anywhere else. Some DC residents have severe disabilities. Some have a developmental disability and a psychiatric or mental disability. It is important to note, however, that there are people living successfully in the community with disabilities of the same nature and severity as virtually anyone in a DC. Thus, there are many people in DCs who *could* live in the community if they had the right services and supports. In fact, a growing number of states have done away with large state institutions all together.

¹⁰ § 4696.1(b)(2).

¹¹ § 4696.1(f).

¹² § 4696.1(f).

¹³ As of October, 2008. The seven developmental centers are: Agnews, Canyon Springs, Fairview, Lanterman, Porterville, Sierra Vista and Sonoma. Agnews DC is in the process of being shut down. According to DDS, as of September 24, 2008, there were 106 people still living at Agnews.

7. What happens if I am having problems living in the community?

You may need a different living situation in the community. If you need help to find or create a better living situation so you can stay out of an institution, your local RRDP (regional resource development program) should help you. If you are at risk of being placed in a DC, your regional center must notify the RRDP.

RRDPs are agencies that work with regional centers, DCs, and consumers to help you move or stay out of a DC. The RRDP looks at your situation, visits you (if appropriate) and figures out what is keeping you from integrating into the community. Then, they recommend the supports that would help you stay in your community. You should have an IPP meeting with a RRDP representative who can help figure out how to meet your needs in emergency situations, and in general.¹⁴

To learn about how successful your RRDP and regional center have been at keeping people out of a DC, contact DDS.¹⁵

Important! If someone threatens to send you to a DC, call the RRDP and ask for an assessment.¹⁶

8. What is the Community Placement Plan (CPP)?

The Community Placement Plan (CPP)¹⁷ is a yearly list made by each regional center. The CPP lists:

- Each person who the regional center plans to move out of a developmental center that year.¹⁸ It also lists the resources, services, and supports that each of those people needs.
- The people who will be evaluated that year to move out of a DC the following year.
- The types of services and supports needed to keep people from moving into a DC.

¹⁴ §§ 4418.7(a) & (b).

¹⁵ § 4418.7(d).

¹⁶ See Supplement CC for a list of RRDPs with contact information.

¹⁷ § 4418.25.

¹⁸ The state fiscal year is from July 1 to June 30.

Every year, the regional centers get additional funding to do assessments, plan programs, and provide resources, services, and supports to the people on the CPP list. Regional centers decide how many people to include in the CCP each year. Unfortunately, most regional centers list a small number of people compared to the number of people in DCs. So, many people in DCs who *could* live in the community now must wait for many years before they get the chance.

To learn about how well your regional center performs under the CPP, contact DDS.¹⁹

9. Can I move out of a developmental center if I am not in the CPP?

Yes. You still have rights under the Lanterman Act, including the right to assessments, person-centered planning, and the right to live in the least restrictive, most integrated setting.

If you are not on the CPP list, you will not get additional funding to help you move to a community setting. But, you have the right to get the services and supports listed in your IPP that would allow you to live in the most integrated setting possible. You can also get the services you need to move out of a DC or to keep from being placed in a DC.

Sometimes, you may have to go to court to enforce your right to not live in a DC.

10. Am I ready to move out of a developmental center?

This is a trick question. It does not matter if you are *ready* or whether the services you need are currently available. What matters is that you have the *right* to get the services and supports you need and want, and to live in an integrated community setting as much as possible.

Your IPP team should not ask if you are *ready*. They should ask:

- What services and supports will meet your needs and wants in a community setting and allow you to participate in community activities?
- If the resources you need are not available, your IPP team should also ask:

¹⁹ § 4418.25(c).

- What is keeping you from living in the community now?
- What steps do we need to take to allow you to live in the community?
- What services and supports do we need to find or develop so you can live in the community safely and appropriately?

11. What if I cannot express what I want?

If you cannot use words to say what you want, your IPP team can look at your actions and your general likes and dislikes. If your disability is so severe that your IPP team cannot figure out what you want, they can assume²⁰ that:

- You would make the same choices as most people.
- You do not want to live in an institution if there is a safe alternative.
- You want and deserve to be included and integrated into the community, not isolated and segregated.
- You want to be free, not confined.

12. Can I get help to transition from a DC to the community?

Yes. Your regional center, DC, and RRDP must work together to make sure your transition into the community is smooth. They will coordinate your assessment, IPP development, and transition and deflection services.

If the RRDP identifies you for possible placement in the community (even if you are not on the CPP list), they must give you services. Ask the RRDP to be involved at the **beginning** of your assessment and IPP process.²¹ The RRDP can help your IPP team identify the services and supports you need to succeed in the community.

The RRDP must give you information you understand to help you make decisions about community living, services, and supports. They can also give this information to your family, conservator, or legal representative. They may be able to take you to visit different community living arrangements.²²

²⁰ The fundamental values underlying such laws as the Lanterman Act and the Americans with Disabilities Act require the presumption that even those who cannot express their preferences would prefer and deserve to live in the least restrictive environment.

²¹ § 4418.3.

²² § 4418.3(d).

You must have a transition conference at least 15 days before you leave the DC. You can go to the meeting with your parents, conservator, or legal representative. There will also be someone from the regional center, the DC, and a representative from the main services and supports identified in your IPP.²³

13. What happens after I move out of the DC?

After you move, the RRDP provides follow-up services to make sure your transition into the community is smooth. The RRDP must:

- Meet with you and visit you during your first year. You should have regularly scheduled visits, and you can ask for extra visits if you need them.
- Meet with your service providers during the first year.
- Participate in your IPP.
- Identify any problems that need to be solved.
- Arrange for you to get DC services, for example, medication review, crisis services, and behavior consultation.

For the first 90 days after you move, the regional center must schedule face-to-face meetings with you at least once every 30 days. The regional center uses these meetings to make sure that they are following your IPP, that you are getting the services you need, and that you are happy with your living arrangement. After that, you will have reviews as often as your IPP recommends.²⁴

If you want, you have the right to return to the DC within the first year.²⁵

14. Can I be sent to a developmental center?

Yes. Some people live in DCs against their will (called involuntarily²⁶). If you are placed in a DC involuntarily, you will have a hearing that follows strict

²³ § 4418.3(e).

²⁴ §§ 4418.3(f), (g) & (h).

²⁵ § 4508.

²⁶ § 6000(a).

legal rules. Because living in a DC severely impacts your freedom, you have the same rights as someone accused of a crime, including the right to:

- a lawyer,
- a jury trial, and
- proof beyond a reasonable doubt that you need to live in a DC and cannot live in a less restrictive environment.²⁷

After the hearing, the judge makes an order saying whether or not you have to live in a DC. In order for you to be placed in a DC, the judge has to make a commitment order.

Very few adults live in DCs voluntarily. To go voluntarily, you have to waive your right to due process (including a court hearing). Parents can place their children (under 18) in a DC if the regional center refers them²⁸ and the DC is the least restrictive appropriate setting. This is rare. If a parent or guardian sends a child to a DC, the child is in the DC “voluntarily”.²⁹ (See Question 18.)

15. What are the different types of commitment orders?

The most common commitment orders are:

- **Welfare & Institutions Code, section 6500:** This is used to commit people with mental retardation who are found to be dangerous to themselves or others. The court must decide what is the least restrictive environment for the person to live.³⁰ The court must review the commitment every year.
- **Penal Code, section 1370.1:** This is used for people who are “incompetent to stand trial” (IST) on criminal charges because of a developmental disability.³¹ It is also called a forensic commitment. The commitment is for more than 3 years.

²⁷ *Id* at 93-94.

²⁸ § 4653.

²⁹ § 6000(b).

³⁰ § 6509.

³¹ For a more detailed description, see Disability Rights California’s publication *Forensic Mental Health Issues in Criminal Law: Statute & Case Summaries*, publication 5077.01. Also see Disability Rights California’s publication *Legal Bases for Obtaining Competency Training*

- **Penal Code, section 1026:** This is for people declared “not guilty by reason of insanity” (NGI). It lasts until “sanity has been restored” or until their sentence ends.
- **“In re Hop”:** This type of commitment is for people who do not meet the standards for other types of commitments. The procedures and standards for this commitment vary widely from county to county. Some counties do not use *In re Hop*.

We do not cover the complicated procedures for commitment orders here.³²

16. What is diversion?

If you have a developmental disability and are charged with a criminal offense, the court may let you get treatment and habilitation instead of going to jail.³³ This is called diversion.

Your diversion program can last up to 2 years. If you finish the program as instructed, the court dismisses the charges against you. If not, the court may reinstate the charges.

You are eligible for diversion if:

- Your crime is a misdemeanor (or is reduced to a misdemeanor).
- You have not been in a diversion program in the last two years.
- You have a “cognitive developmental disability,” such as mental retardation, autism, or a condition closely related to mental retardation or autism or that requires similar treatment.
- You are a regional center client (unless you have mental retardation).

17. What diversion services can I get?

Diversion services include:

Outside an Institutional Setting for Individuals with Developmental Disabilities (9/06). Find it at Disability Rights California’s web site: www.disabilityrightsca.org/issues/index.htm.

³² See the DDS publication *Admission and Community Re-entry Processes at State Residential Facilities: A Guide to Statutory Requirements, Judicial Findings (Case Law) and Administrative Procedures in California*. Find it online at: www.dds.cahwnet.gov/publications/pdf/Admission_CommunityReEntry.pdf.

³³ Penal Code §§ 1001.20 *et seq.*

- Diagnosis, evaluation, and treatment.
- Personal care, day care, in-home care, and special living arrangements.
- Physical, occupational, and speech therapy.
- Training, education, and sheltered employment.
- Mental health services, recreation, and counseling for you and your family.
- Other services to make sure you get your services, including protective services, other social and legal services, information and referral services, follow-along services, and transportation services.

18. Can my parent, guardian, or conservator put me in a developmental center?

If you are **under 18**, your parents or guardian can apply for you to live in a DC. But, the regional center must also refer you. The regional center should only refer you if the DC is the least restrictive setting that meets your needs. If you are over 14, you have more legal rights regarding placement in a DC than younger children.³⁴

If you are **over 18**, your parents cannot put you in a DC, even if your parents have the legal right to decide where you live. You cannot be placed in a DC without a court hearing that meets strict legal requirements.

Probate Code Conservatorship hearings do *not* meet these requirements.³⁵ Conservatorship hearings under the Lanterman-Petris-Short (LPS) Act *do* meet these standards. So, if your conservator was appointed under the Probate Code, he or she **cannot** place you in a DC. But your LPS conservator may be able to apply for you to go to a state facility to get treatment for your psychiatric disability.³⁶

19. Can my parent or conservator keep me from leaving a developmental center?

No. In the past, DDS would not place someone in the community if the family did not agree. The *Richard S.* case successfully challenged this policy in

³⁴ *In re Roger S.*, 19 Cal.3d 921 (1977).

³⁵ See, e.g., *In re Violet C.*, 213 Cal.App.3d 86 (1989).

³⁶ §§ 5350 *et seq.*

federal court.³⁷ The court said that family members can be involved in the IPP process if appropriate, but they cannot make the decision. That means your family's opinions can be considered, but they cannot keep you from moving into the community.

The *Richard S.* case settlement specifies the procedures that DDS must follow. If your IPP team recommends that you move to the community but someone on your IPP team disagrees:

- The team recommendation will be highlighted in your IPP.
- The disagreement will be highlighted in your IPP.
- Once the recommended community placement is located and the proposed transfer date is set, DDS will send written notice to the court at least 15 days before you move. The notice will include the objection.
- The person who objects can fill out a *Request for Hearing* form. DDS will send the form to the court with their notice.
- The court can then decide to hold a hearing. If not, you will move out as planned.

The Lanterman Act says that disagreements about being or staying in a DC must be settled through the fair hearing process. The court of appeals said that a conservator can ask for a fair hearing if they do not agree with your IPP team's recommendation to move you out of a DC.³⁸

20. How often does the court review my placement in a DC?

It depends on the type of commitment order. For example, if you were ordered to a DC because you are a danger to yourself and others (a Welfare & Institutions Code, section 6500 commitment), the order only lasts a year. After that, a new petition is filed to renew the placement. The new petition comes with the same due process rights and must meet the same legal standards as the original petition.

There are no laws that say when a court should review *In re Hop* commitments. You can argue that your *In re Hop* commitment should be

³⁷ *Richard S. et al. v. Dept. of Developmental Services et al. v. Bell et al.* (C.D. Calif. No. SA CV 97-219-GLT(ANx)).

³⁸ *In re Conservatorship of Whitley*, 155 Cal.App.4th 1447 (2007).

reviewed at least once a year, like a section 6500 commitment. Some counties already do this. But, some people are committed under *In re Hop* and never have another automatic court review.

There are people living in DCs who never had a court hearing. This might be because they lived in the DC before the *In re Hop* case (1981), or because they moved there as children and stayed after they turned 18. These DC placements are illegal.

21. Can I ask the court to review my placement if I live in a DC?

Yes. If you think your placement in the DC is illegal or inappropriate, ask the DC or regional center staff to release you. Or have someone else ask for you. Then you are entitled to a court hearing by *writ of habeas corpus*.³⁹

The DC or regional center staff person who you tell that you want to be released must fill out a *Request for Release* form.⁴⁰ (The Client's Rights' Advocate at the DC can help you with this process.⁴¹) The DC must send the form to the court and a copy to your parent or conservator with a letter saying that the court was notified. If the DC intentionally does not follow these requirements, it is a misdemeanor.

The court can make an order saying the DC must release you. Or there may be a hearing. You have a right to have a lawyer at the hearing. If you cannot afford a lawyer, the court will appoint a lawyer for you.

If the court says that you do not have a developmental disability, or that you can safely meet your own needs, the DC has 72 hours to release you. If you cannot meet your own needs, but have a responsible person or agency that can and will, you may be released subject to any conditions the court finds proper and consistent with the Lanterman Act.⁴² For example, the court can order the DC to release you and order the regional center to give you the services and supports you need. If the services are not available, the court

³⁹ §§ 4800-4801.

⁴⁰ § 4800(c).

⁴¹ See Supplement BB for a list of the Clients' Rights Advocates and Volunteer Advocacy Services Coordinator with contact information.

⁴² § 4801(c).

can order the regional center to find or develop the services and to make periodic reports to the court on its progress.

22. What can my IPP team do if the court sends me to a DC?

Your IPP team should consider why the court made this decision and start helping you address the issues that influenced the court so that you can move out as soon as possible.

The court relies heavily on reports from your DC and the regional center to determine if you need to stay in the DC. Your IPP also gives the court valuable information about the supports you need, what is keeping you from living in the community, and what you need to return to the community. Often the problem is simply that the housing or supplemental services and supports you need to live safely in the community are not available. Once the court knows what you need, it can decide if you need to live in a DC, or how to meet your needs in the least restrictive setting.

Your lawyer or advocate can ask for an order that does not specify how much time you have to be in the DC. Instead, they can ask for an order that says you can leave the DC when the services you need to return to the community are available. Your lawyer can also ask the court to monitor the progress of the regional center, RRDP, and DC in finding or developing the services and supports you need.

23. Can someone in the DC help me?

Yes. Area Boards provide clients' rights advocacy services to people in DCs.⁴³ There is a clients' rights advocate (CRA) in every DC.

The CRA can:

- Tell you about your legal rights, including your right to assessments and an IPP to identify the services and supports you need to return to the community,
- Help you with administrative and legal solutions, and
- Advocate for you when you live in a DC.

⁴³ § 4433.5.

The DC also has a Volunteer Advocacy Assistance Program. A volunteer advocate can help represent you at your IPP and when you want to move into the community.⁴⁴

See Supplement BB for a list of the Clients' Rights Advocates and Volunteer Advocacy Services Coordinators.

24. What are the *Coffelt* and the *Capitol People First* cases?

Many people with developmental disabilities are still in institutions when they do not need to be even though the Lanterman Act and other state and federal laws say that people should be allowed to live in the least restrictive environment. In 1990, Disability Rights California filed a class action lawsuit called *Coffelt v. DDS*. The lawsuit claimed that DDS and regional centers did not follow the law, and that there was a shortage of quality, stable, integrated community living arrangements. Because of this, people who could live in the community were being sent to DCs, and staying there.

The case settled in 1994. Thanks to the *Coffelt* Settlement agreement, more than 2,000 people were able to leave DCs in California from 1994-1999. The system was reformed under the settlement agreement, to make more services available, including:

- More emergency and crisis intervention services
- More integrated community living arrangements, such as foster homes for children, homes for children with special medical needs, and supported living arrangements for adults.⁴⁵

But after the 5 year *Coffelt* settlement agreement period, progress in reducing unnecessary institutionalization slowed virtually to a stand still. In 2001, Disability Rights California filed another lawsuit, called *Capitol People First v. DDS*, on behalf of people in DCs and other large institutions (such as nursing facilities, ICF-DDs, large community care facilities, and psychiatric hospitals) and people at risk of being sent to institutions. The lawsuit is about the rights of all people with developmental disabilities to get:

⁴⁴ § 4548(d).

⁴⁵ For more information about the *Coffelt* settlement, ask Disability Rights California for a copy of *Summary of Settlement Agreement: Coffelt, et al., v. DDS, et al.*, Publication 5089.01. You can also or download a copy of the publication from Disability Rights California's web site at: www.disabilityrightsca.org/pubs/508901.htm.

- adequate assessments,
- comprehensive person-centered planning, and
- access to the services and supports that will let them live in integrated, community-based placements whenever possible.

In 2007, the Court of Appeal for the First Appellate District handed a significant victory to the plaintiffs in the case.⁴⁶ The court held that the case may proceed as a class action on behalf of more than 7,000 individuals who receive services from regional centers and are either living in state or private institutions, or are at risk of institutionalization. After this court decision, the case was able to move forward as a class action lawsuit and the trial was set for March 2009.

This case has not been decided yet.⁴⁷

⁴⁶ CPF v. DDS, 155 Cal.App.4th 676

⁴⁷ For an overview of the *Capitol People First v. DDS* lawsuit, call Disability Rights California for Publication 5381.01. You can also download the publication from Disability Rights California's web site at: www.disabilityrightsca.org/pubs/538101.pdf.