A Consumer's Guide to The Lanterman Act

State of California

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A complete version of the Lanterman Developmental Disabilities Services Act, and other information about DDS programs, services and videotapes, is available online at the DDS Internet Home Page: www.dds.ca.gov

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Introduction

Chapters

I am IMPORTANT

I KNOW what I want

I will WORK HARD to get what I want

I am RESPONSIBLE for the choices I make

Adapted from a pledge of the Santa Barbara Council for Self-Advocacy

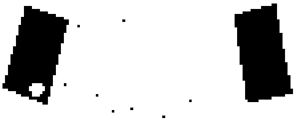
This is part of a pledge from a self-advocacy group. A self-advocacy group is a group of people with disabilities who get together to help each other figure out ways to live the lives they want. This pledge helps people speak up and do the things that are important in their lives. SPEAKING UP is very important to make the Lanterman Act work for you.

WHAT IS THIS BOOK ABOUT?

This book is about the Lanterman Developmental Disabilities Services Act (people also call it the Lanterman Act, for short) which was passed in 1969. This is the California law that says people with developmental disabilities and their families have a right to get the services and supports they need to live like people who don't have disabilities.

This book will help you:

- Learn about what the Lanterman Act promises you



- Be a partner with the regional center and other service providers when you make choices about your life

- Get ideas about how to get the services and supports you need

There are many words that lots of people don't like, like the word "mental retardation." Labels like this don't tell others about the person. We use this word and other labels in this book because those are the words written in the law. Labels are used to get services.

WHO IS THIS BOOK FOR?

This book was written for ADULTS with developmental disabilities who get services and supports from regional centers. In this book, the word “you” means an adult with a developmental disability. Parents, service coordinators, service providers, and other people may also read this book.

✔ To make sure this book has information YOU **should know**...

We met with groups of consumers in Los Angeles, San Diego, and Contra Costa to ask them what they thought consumers would want to know about the Lanterman Act. The names of these groups are in the back of the book.

✔ To make sure YOU **can understand** this book...

We asked consumers to help us write and read drafts of this book. Their names are in the back of the book.

✔ To make sure what YOU are reading is **correct and will help you**....

We asked self-advocacy leaders and people who support consumers to read all the drafts of this book. These people were members of the Statewide Advisory Group for the Project. Their names are also in the back of the book.

HOW TO READ THIS BOOK

The Lanterman Act says

The most important information in the book is in the box that says "The Lanterman Act says"

When you read a "Tip" it is an idea that consumers like **YOU**, came up with. You will not find "Tips" in the Lanterman Act, but they will help you use the information you just read.

Important words in color

"Important Words" are in **orange**. When you see a word written like **this**, it is an important word for you to learn and use.

1 What is the Lanterman Act?

The Lanterman Act says

you have a right to services and supports to help you live the most independent and productive life possible.

The Lanterman Act is a California law that promises services and supports to people with developmental disabilities and their families. Because it is a law, people who help you with services and supports must do what the Lanterman Act says.

The Lanterman Act tells you:

- What your rights are
- How the regional centers and service providers can help you
- What services and supports you can get
- How to use the Individualized Program Plan (IPP) to get the services you need
- What to do when someone says you can’t get what you need
- How you can make the system better

The Lanterman Act says **that you must have a developmental disability to get services from the regional center.**

A developmental disability is something that:

- You get before you are 18 years old
- Lasts all your life
- Makes it hard for you to do things, like walking, speaking, taking care of yourself, or working
- Is called cerebral palsy, mental retardation, autism, epilepsy, or anything that makes you need the same kind of support that someone with mental retardation needs

The regional center may test you to see if you are eligible.

Tip

1. **If you have a developmental disability, you can get regional center services no matter how old you are.**
2. **If the regional center says you cannot have regional center services, there are things you can do, called the "fair hearing" process. This is talked about in Chapter 6.**

The Lanterman Act says that you have a right to make choices about your life and make decisions about what services and supports you want and need.

The Lanterman Act talks a lot about YOU as an important and valuable person. It talks about how YOU should make choices and decisions about YOUR LIFE. It tells regional centers and service providers how to help and support YOU to meet your goals.

The law says that you have the right to make choices about:

- Where to live
- Where to go to school
- Where to work
- How you want to belong to your community
- Whom to live with and have relationships with
- What services and supports you want and need

2

Your Rights Under The Lanterman Act

The Lanterman Act says you have the same rights as any other person.

For a long time, people with disabilities were not treated like other people. The Lanterman Act pays special attention to your rights.

Rights are things the law says you have.

The Lanterman Act says you have a right to dignity and humane care.

When you depend on other people for some things, sometimes they can treat you like you don't know what you're doing. The Lanterman Act says that people should treat you with **dignity**. When people treat you with **dignity**, they respect you, they treat you as if you are a valuable and important person.

Humane care is what most people get without asking for it. It means:

- Having a safe and comfortable place to live
- Having enough food to eat
- Living in a community with people who care about you

Tip

If you feel you live in a place that is not safe, are not getting enough to eat, or you are not being treated with dignity, tell someone. Tell a friend, a relative, talk to your service coordinator, clients' rights advocate, or someone at your area board.

The Lanterman Act says you have a right to privacy.

Privacy is deciding for yourself what you want to share and whom you want to share it with.

A "right to privacy" means:

- You do NOT have to share what is personal

- You do NOT have to tell private thoughts to anyone

- You do NOT have to share your private things
- You have a right to be alone or with a friend

Tip **If people aren't respecting your privacy, tell someone. Tell a friend, a relative, your service coordinator, your clients' rights advocate, or someone at your area board.**

The Lanterman Act says you have a right to participate in an appropriate program of public education.

For a long time, people used to think that if you had a disability, you couldn't learn anything. So, people with disabilities didn't go to school or college.

The Lanterman Act says you have the right to go to school or college like people without disabilities. Other state and federal laws say this too.

If you are under 22 years old, the public schools must provide you with a free education that is right for you. Once you are over 22 years old, you can get more education if you want it.

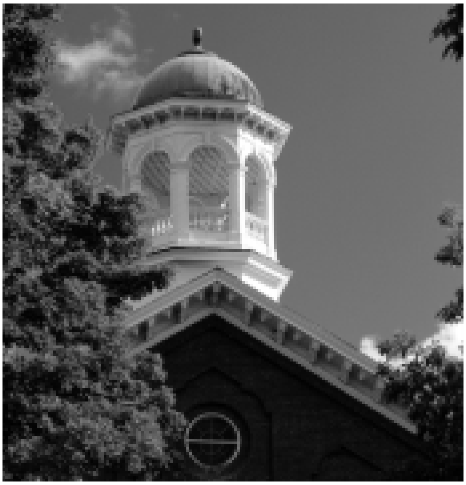
The Lanterman Act says you have a right to prompt medical care and treatment.

Staying as healthy as possible is important for everyone. You may need others to help you get medical help. If you need help getting good **medical care**, the Lanterman Act says you have a right to services and supports to help you:

- Find a good doctor
- Get to the doctor or hospital
- Sign up for MediCal
- Make sure you and the people who help you at home know when you should see the doctor, go to the hospital, or call 911

The Lanterman Act says you have a right to religious freedom and practice.

Many people belong to a religious community. This can mean some people going to a church, temple, mosque, or a meeting place, to be with people who believe the same things and worship the same way.



Just like people without disabilities, the Lanterman Act says you have the right to believe what you want about religion or faith. You have the right to practice your religion the way you choose.

Other people CANNOT:

- Tell you what to believe
- Punish you for what you believe
- Stop you from becoming a member of or practicing a religion of your choice

The Lanterman Act says you have a right to social interaction and participation in community activities.

Many people like to have friends including boyfriends and girlfriends. Many people like to go out in the community.

The Lanterman Act says that YOU have a right to:

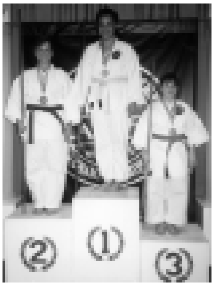
- Choose the people you spend time with
- Spend time with people you like and who like you
- Choose where you want to go in your free time
- Go to places where you can work, do business, buy things, help other people, learn things, meet and be with other people

Tip

If you need help making friends, having relationships, getting a job, or being part of your community, talk to your service coordinator.

The Lanterman Act says you have a right to physical exercise and recreation.

Exercise is how you keep your body strong and healthy. Walking, biking, running, swimming, going to the gym are types of physical exercise.



Recreational activities are things that you do to relax and have fun. Riding horses, playing music, biking, and swimming are examples of recreational activities.

Tip **If you need help getting exercise or doing things for fun or relaxation, talk to your service coordinator.**

The Lanterman Act says you have a right to be free from harm.

You may know someone who has been locked up, or told not to leave their room or house, or even tied to their bed or wheelchair. You also may know someone who has been hit, pushed, burned, or made afraid by what people tell them. You might know someone who was given lots of medication to make them quiet or sleep all the time. You also might know someone with a disability who wasn't helped to eat, go to the bathroom, or stay clean. **This is Wrong!**

The Lanterman Act says you have a right to be safe and treated with dignity. No one can:

- Scare you, tie you down, or hurt you
- Stop you from talking or going somewhere important
- Refuse to help you when you need it
- Give you a medicine you don't need

Tip

If you feel you are being hurt in any way, tell someone. Tell a friend, a relative, your service coordinator, your clients' rights advocate, or someone at your area board.

The Lanterman Act says you have a right to be free from hazardous procedures.

Doctors and other professionals sometimes do things to help figure out why you are having problems and to help you. These are called "procedures." Some procedures may hurt, but they are necessary. Procedures are supposed to help you; not change who you are.

Procedures which hurt you unnecessarily or harm other parts of your body or your mind are called "hazardous procedures." An example of a hazardous procedure is using electric shock to get you to change your behavior.

The Lanterman Act says you have a right to REFUSE hazardous procedures. People cannot do things to you that harm you:

NO!

- NOT in a hospital
- NOT where you live
- NOT where you work
- NOT in a program

Tip

If you are having procedures which scare you, tell someone. Tell a friend, a relative, your service coordinator, your clients' rights advocate, or someone at your area board.

The Lanterman Act says you have a right to get services and supports in the least restrictive environment.

Least restrictive environment means you have a right to get your services and supports in places close to your home community, including places where people without disabilities get services and supports, if that is appropriate.

This means your services and supports should be near your home, with people from your community.

Tip

1. **If you want your services to be closer to your community, tell someone. Tell a friend, a relative, your service coordinator, your clients' rights advocate, or someone at your area board.**
2. **When needed, regional centers should get services started closer to your community if there aren't any you can use. This is talked about in Chapter 3.**

3 The Regional Center

The Lanterman Act says **the regional center is the place to go to get the services and supports you need to live, work, learn, and have fun in your community.**

People who wrote the Lanterman Act set up organizations called REGIONAL CENTERS to help people with developmental disabilities (people like YOU) get the help they need. The Lanterman Act has the rules about how the regional centers can help you.

The law says regional centers must:

- Give you information you can understand to make good choices about the services you want
- Help you find and get the services you need
- Make sure the services and supports in your community can meet your needs

Tip

Remember, it's YOUR life. The regional center is there to help you get the life you want. Learn how to speak up for yourself. Join a self-advocacy group or get self-advocacy training.

The Lanterman Act says **the regional center will help you find and get the services and supports you need and want.**

To make sure you get the help you need, the regional center gives you a **service coordinator**. Your service coordinator will:

- Help you get ready for your Individual Program Plan (IPP) meeting

- Help you get the services and supports in your IPP

- Help you if you are having problems

The service coordinator is usually someone who works for the regional center. But your service coordinator can also be:

- A family member

- A friend

- Even YOU

Tip

1. **Your service coordinator has an important job. Make sure this person listens to you.**

2. **If you are not satisfied with your service coordinator, the law says you can ask for a different one.**

The Lanterman Act says each regional center will get services and supports for you that are "cost-effective."

What does "cost-effectiveness" mean?

The law says regional centers and other agencies must work hard to find services which meet your needs for the least amount of money. This sometimes means regional centers will find other agencies to provide services to you.

Regional Centers do not always have to pay for your services, but regional centers must find and get you services that meet your needs. Chapter 4 talks about this more.

Tip

1. **If you feel your needs are not being met, talk to your service coordinator.**
2. **If you talk to your service coordinator and you are still not satisfied, talk to your clients' rights advocate.**

The Lanterman Act says that the regional center must give you information that you can understand.

About Communication:

To make good choices and decisions about your Individual Program Plan (IPP), you must get information and tell people what you want. There are many different ways to do this.

- Some people use signs or communication tools
- Some people point to what they want or nod "yes" and "no"

- Some people use a facilitator or an interpreter

An interpreter is someone who speaks your language and English.

A facilitator is someone who helps you read things, explains things to you, and helps you decide what you want.

If you do not speak with words, the law says that regional center staff and your service providers must find out from you what you want and need.

Tip

If you need help with communication and speaking up:

- Have someone you trust (like a friend, family member, or service provider) go to your IPP meeting with you and explain what you want
- Ask for an interpreter or facilitator to help you communicate at your IPP
- Ask for some extra meetings to find out what you need to know and to explain what you want
- Bring this book with you and point to the tip that you want

4 Services and Supports

The Lanterman Act says your services and supports should help you:

- Be independent
- Be productive
- Be a member of your community
- Live in places where you are safe, healthy, and know what to expect

Tip

You should have a say in the services and support you get. If people don't listen to you, tell someone. Tell a friend, a relative, your service coordinator, your clients' rights advocate, or someone at your area board.

Your Services and Supports

Here are some of the services and supports the regional center can help you find and get.

What Do You Want? What Do You Need?

Adaptive Equipment

Do you need things that can help you become more independent?

Advocacy Training

Do you need to learn more about your rights to speak up for yourself?

Crisis Services

Do you need a plan in case you have an emergency?

Living Services

Do you like where you live?

Do you need help in your home?

Do you need a roommate?

Does your home need to be fixed, so you can be more independent?

Community Life

Do you want to do more things in your community?

Do you want to have more fun?

Do you want to make new friends?

Do you need help getting places?

Parent Training

Do you have children?
Do you need to learn more about taking care of them?

Sexuality

Do you have questions about sex?

Do you need help with your relationships?

Working

Do you want to work?

Do you need help getting a job?

Tip

1. **Write the services and supports you need in your Individual Program Plan (IPP), with the help of your IPP team.**

2. **It's OK to ask for things you need that aren't on this list.**

5 The IPP–How You Get Services & Support

The Lanterman Act says **the IPP is an agreement between you and the regional center that lists the services and supports you need.**

The regional center must help you develop an Individual Program Plan (IPP). Your IPP is an agreement between you and the regional center. Your IPP is very important because it lists your goals and the services and supports that the regional center will help you get.

Your **needs and choices** are important to your IPP team.

The Law says the regional center must follow certain rules when writing your IPP.

The Lanterman Act says that your IPP must be written by an IPP team. YOU can invite people who know and support you to be on your team.

Your IPP Team/Who is on it?

- You are the most important member
- People who know you and care about you
- Someone from the regional center who can promise to get you the services you want and need

Tip **Invite people who know you well and care about you to be on your IPP team. Invite people who listen to you.**

Your IPP Meeting/What Happens There?

- The time to "talk" with your team about what you want and need
- You meet at a time and place that you choose, including your home

- Important decisions about your life are made here
- A very important meeting—be prepared
- A very important meeting—don't miss it!

You should have an IPP meeting at least every three years. If things change in your life, you can ask your service coordinator to set one up sooner.

Tip

1. **Your regional center cannot change what is in your IPP without having a meeting with you. That is the law.**
2. **If you need an interpreter or a facilitator (a helper), the regional center has to get this for you.**
3. **If you have trouble writing or get nervous and forget things at your meeting, you can have someone help you make a tape recording of the things you want and bring the tape to play at your meeting. (from** *Your IPP, It's Not Just A Piece of Paper***)**

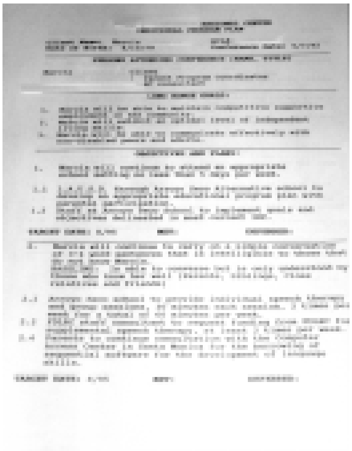
Your IPP:

What Do You Want? **What Do You Need?**

Adaptive Equipment
Do you need things that can help you become more independent?

Advocacy Training
Do you need to learn more about your rights to speak up for yourself?

Crisis Services
Do you need a plan in case you have an emergency.



- Lists your goals
- Lists the services and supports the regional center will get for you
- Based on what you need
- Based on what you want
- A very important piece of paper

Your regional center coordinator will write up what your IPP team agreed on at your IPP meeting.

Tip

Your IPP should be written so you understand it. If it's not, ask your service coordinator to re-write it.

Signing your IPP:

Your services cannot start until you and the regional center agree on what is in your IPP. When you sign your IPP, you are saying that you agree with what is in your IPP.

If you don't agree with everything that is in your IPP, you don't have to sign it. BUT, you can agree to part of it. Write down what you agree with and what you don't agree with. Once you do this, the services you and the regional center agreed on can start.

Tip

1. **Make sure you get a copy of your IPP. The regional center can send copies of your IPP to people who came to your meeting, if you want them to have a copy.**

2. **Go over your IPP with people who care about you. Make sure it has what you wanted in it.**

3. **If it's in your IPP, the regional center must get the services or supports for you.**

After your IPP Meeting

It is your service coordinator's job to find and get the services and supports written on your IPP. You can call another meeting if:

- You don't get the services written on your IPP
- You don't like the services you get
- Your needs change

Tip

1. **You and your service coordinator will be partners in making sure that the goals and objectives in your IPP happen. Get to know your service coordinator. If your service coordinator is not helping you make your IPP happen, the law says you can ask for another service coordinator.**

2. **See the back of this book for the names of some very good guides to the IPP meeting that have more information about the IPP.**

6 Disagreements with the Regional Center

The Lanterman Act says you have the right to ask questions and talk about the decisions the regional center makes about you and your life.

There will be times when you don't agree with the regional center's decision. When this happens, the Lanterman Act gives you steps you can take so you and the regional center can try to solve the problem.

Like most laws, you have to follow certain steps carefully, and the law gives you a certain number of days for you and the regional center to come up with a better plan.

REMEMBER, if you do not agree with a regional center decision, you must tell them IN WRITING.

Tip **If you have trouble writing, the regional center must help you write your complaint.**

Disagreements with the Regional Center

If you do not agree with something the regional center does, there are 3 things you can do to come up with a new plan.

Meeting

Meet with the regional center director or the director's representative to try to solve the problem.

Mediation

You can meet with a mediator who talks to you and the regional center and tries to help the two of you agree.

Fair Hearing

You can have a hearing with people from the regional center and a judge.
The judge makes the final decision.

Remember

The law says you have the right to make choices about your life and to get the services and supports you need to be a member of your community.

When you don’t agree with a decision that will affect your life, speak up.

Tip

If you need help deciding what to do, talk to a friend, a relative, your service coordinator, your clients’ rights advocate, or someone at your area board.

7 Giving Your Opinion (Advocacy)

The Lanterman Act says **that people with developmental disabilities must have a say in the way the service system works.**

There are many ways you can have a say in how the service system works. Here are a few ways:

Become A Member of the Regional Center Board of Directors

The people who are in charge of the regional centers are called the Board of Directors. The Lanterman Act says that half of the regional center Board of Directors must be adults with developmental disabilities (consumers) and parents of children with developmental disabilities. The law says there should be as many consumers as there are parents on the Board of Directors.

All regional center board members are volunteers who want to make sure the regional center does a good job helping people with developmental disabilities. You can apply to become a board member.

Tip **If you want to become a regional center board member, ask your service coordinator how to apply.**

The Lanterman Act says **the regional center must provide training and support to help board members participate in board meetings.**

Being a board member is a big responsibility. To make sure you participate in board meetings, the law says that regional centers must provide you with training and support as a board member. Training might mean learning how to read budgets, or learning about new laws and what it means for you.

Support might mean getting your materials in BIG PRINT, having someone go over the material with you before the meeting (facilitation), and having someone at the meeting with you to help you with board decisions and business.

Tip

1. **If you are on a board or committee and you need training or support, ask for it.**
2. **If you need your board materials in special print or in a special form, ask for it.**
3. **If you need more time to read and understand your board materials, ask to have your materials two weeks in advance.**
4. **If you need facilitation, ask for it.**

Join a committee or board for other agencies in the developmental services system

There are other agencies that write plans, watch the regional centers and other service systems, provide services, and/or help consumers speak up, that have boards or committees that you might join, like the State Council on Developmental Disabilities, the Area Boards, Protection and Advocacy, and many regional center vendors. You can apply to become a member.

Tip

If you want to become a committee or board member of another agency, ask your service coordinator how to apply. Write it in your IPP to get support to do this.

Give your Opinion at Public Meetings

Most organizations have public meetings that anyone can attend. You can go to these meetings and speak up about things that are important to you.

Tip

If you want to get better at public speaking, write it in your IPP.

There is a lot in the Lanterman Act and we couldn’t put all of it in this book. If you want more information, you can:

- Ask someone to help you find out what you want to know
- Look at the books on the inside back cover
- Get a copy of the Lanterman Act from your Area Board, Regional Center, Protection and Advocacy, or DDS.

Acknowledgments

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Notes

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Resources & References

I.P.P. Books

"More than a Meeting; A Pocket Guide to the Person-Centered Individual Program Plan," 2000, California Department of Developmental Services, (916) 654-1956.

"Your I.P.P. - It's Not Just a Piece of Paper", Protection and Advocacy, Inc., (800) 776-5746.

Services

"Supported Employment", 2000, Protection and Advocacy, Inc., (800) 776-5746.

"Supported Living", 2000, Protection and Advocacy, Inc., (800) 776-5746.

"Finding a Place to Live, A Guide to Community Living Options for Adults with Developmental Disabilities and Their Families," 2000, Area Board X, Glendale, CA (818) 543-4631.

Self-Advocacy

"Your Rights," 2000, Protection and Advocacy, Inc., Sacramento, CA (800) 776-5746.

"Beginning Steps to Self Advocacy" video training package, 1996, USC University Affiliated Program, Los Angeles, CA (323) 669-2300. (All regional centers have a copy)

People First of Washington self-advocacy materials, Clarkston, WA (800) 758-1123.

Choice and Decision Making

A Guide to Training in Decision Making for People with Developmental Disabilities. S.T.O.G. (See, Think, OK?, Go). On the Internet: http://www.allenshea.com.

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