

California Department of Developmental Services



Know Your Privacy Rights

Having the right to privacy means you decide what you want to share about yourself, and with whom you share it. You do not have to share what is personal, tell your private thoughts to anyone, or share your private things. You have a right to be alone or to be around people that you choose. It is also important to remember that you have the right to keep your personal health information private.

The federal government gives California money to provide home and community-based services (HCBS) through a waiver program. To continue getting this federal money, California must follow certain rules. One of the rules is that service providers must respect your right to privacy.

You get to choose where you want to live based on your needs and preferences, and where resources are available.

- You have a right to privacy in your home
- You have the right to physically access your home
- You have the right to control your schedule and activities, and to keep your mail private
- You have the right to access food anytime you want to
- You have the right to have visitors or phone calls at anytime and keep conversations private

Source: <u>Final Rule Requirements (ca.gov)</u>; <u>Code</u> of Federal Regulations, Title 42 §441.301(c)(4); <u>A</u> <u>Consumer's Guide to the Lanterman Act; Your Rights Under HIPAA (HHS.gov)</u>





Wellness and Safety Bulletins are produced by the Department of Developmental Services to alert individuals, families, and others about specific risks to our community. Please provide feedback on this bulletin and what we can do better through this survey: <u>Bulletin Survey</u>.

Your Private Room

If you live in a home owned or managed by a service provider, you must have a door to your bedroom.

If you share a bedroom with someone, you have the right to choose who you share the bedroom with.

You must have the option to lock your bedroom door if you want to. The only other people who can have a key to your bedroom is anyone who shares the room with you, or staff that you have given permission to have a key.



Nobody, including your family members, should enter your private room unless you give them clear permission to enter. One exception is if there is, or might be, an emergency.

Your bedroom may not be used as a way to get to another room, bathroom, or toilet.

Your room should never be used as anything other than your bedroom. This includes using it as a storage space, living room, or dining room.

Source: <u>California Code of Regulations (westlaw.com</u>); <u>Final Rule Requirements (ca.gov)</u>; <u>Code of Federal</u> <u>Regulations, Title 42 §441.301(c)(4)</u>





Can someone ever limit my right to privacy?

If someone wants to limit your right to privacy:



It has to be for a specific reason, justified and documented, and you must be informed

You have the right to exercise informed consent before any limitation to your privacy occurs

You must get your privacy back when the reasons it was taken away no longer exist

Nobody can ever limit your privacy as a way of punishment

If someone limits your right to privacy, let someone you trust know!

There are a few times your right to privacy can be denied if there is a specific assessed need. Examples of when your right to privacy might be denied include, but are not limited to:



When privacy puts you at risk of injury or death

Your privacy would seriously affect the rights of other people

Your privacy would cause serious property damage

There is no alternative to protect you, others, or the property

Source: California Code of Regulations (westlaw.com)

Working With Your Planning Team

California law says that any limits to your right to privacy must be discussed with you and your planning team. You and your planning team should discuss and document how to keep you safe when you want to use your right to privacy.

Source: California Code of Regulations (westlaw.com)



What to Do if You Feel Like Your Right to Privacy has Been Violated

If you feel your privacy has not been respected, talk about your concerns with your planning team. If you can't reach agreement with your team, Section 4731 of California's Welfare and Institutions Code allows you, or someone acting for you, to make a complaint against a regional center, developmental center, or provider if you think they have violated your right to privacy.

Source: Your Rights: HCBS Fact Sheet for Individuals and Families (ca.gov); Consumer Rights, Appeals & Complaints : CA Department of Developmental Services



Tell someone if you feel as though your privacy is not being respected. You can tell a friend, a relative, your service coordinator, your clients' rights advocate, or someone at your area board.

Resources

- Home and Community-Based Services (HCBS) Final Rule CA Department of Developmental Services : CA Department of Developmental Services
- Your Rights: HCBS Fact Sheet for Individuals and Families (ca.gov)
- Final Rule Requirements (ca.gov)
- <u>A Consumer's Guide to the Lanterman Act English (ca.gov)</u>



