

WELLNESS BULLETIN PRIVACY & SAFETY

California Department of Developmental Services





Is this bulletin useful?

Federal and State Privacy Requirements



Privacy is an important part of our lives. This bulletin provides you with information about the importance of privacy in the home, how to honor the privacy of the people that you support, and permissible exceptions.

California participates in the Home and Community-Based Services (HCBS) Program, which allows federal funding to be used to support individuals to live and work in their communities instead of in an institution or healthcare facility. Under the HCBS waiver, services must include opportunities for individuals to engage in community life, control their personal resources, receive services in the community, and seek employment and work in competitive integrated settings. To qualify for the waiver, states must agree to certain terms, including guaranteeing that service providers ensure an individual's rights to privacy, dignity and respect, and freedom from coercion and restraint.

Source: Lanterman Act and Related Laws (dds.ca.gov)



Rights in Residential Settings

Individuals select the setting in which they want to live from among available options. Individuals living in provider-owned or controlled residential settings have a right to privacy in their homes. The setting must be physically accessible to the individual. Individuals must have the freedom and support to control their own schedules and activities, have access to food at any time, and have privacy when answering the phone or opening mail. They also have the right to have visitors of their choosing at any time. Lastly, all individuals have a right to keep their personal health information private, including those living in residential settings.

Source: Final Rule Requirements (ca.gov); Your Rights Under HIPAA (HHS.gov)



Wellness and Safety Bulletins are produced by the Department of Developmental Services to alert direct service providers, regional center staff, and others about specific risks to our community. Please provide feedback on this bulletin and what we can do better through this survey: Bulletin Survey.

Private Room of an Individual



Within a provider-owned or controlled residential setting, individuals must be given a door to their bedroom that can be locked and the key to that door. They must be guaranteed the option to lock that door if they wish to do so. The only other people that may have access to the key are other residents that share the bedroom or staff that have been approved to have a key. Individuals sharing bedrooms or housing have the right to choose with whom they share that space.

Nobody, including family members and staff, should enter the private room of an individual unless given clear permission by the individual, in the event of an emergency, or if there is a reason to believe there is an emergency.

An individual's bedroom may not be used as a passageway to another room, bathroom, or toilet. Their room also never should be used for other purposes, such as a storage, living, or dining room.

Sources: <u>California Code of Regulations (westlaw.com);</u> <u>Code of Federal Regulations</u>; <u>Final Rule Requirements</u> (ca.gov)

Exceptions to Privacy Rights



Privacy is a right for everyone, with very limited exceptions and strict limits:

Limitations on the right to privacy must be related to a specific reason. Limitations should be justified and documented, and the individual must be informed.

Privacy must be restored once the risk is determined to no longer exist.

Limitation of privacy can never be used as a punishment.

The right to privacy can be limited or denied only if there is a specific assessed need. Examples may include, but are not limited to:



Privacy puts the individual at risk of injury; or

Privacy, if exercised by the individual, would seriously infringe on the rights of others; or

Privacy would cause serious property damage; and

There is no alternative to protecting the individual, others, or the property.



Engagement of Individual and Planning Team

Any limitation on an individual's right to privacy must be discussed with the individual and the planning team. In cases where respecting privacy will put the individual at risk of injury or death, the individual and their circle of support should be involved with the planning team to discuss prevention strategies, when possible. There may be emergency situations that do not allow for a planning team discussion in advance of the restriction but one should be planned and documented as soon as possible thereafter.

Source: <u>California Code of Regulations</u> (westlaw.com)



What to do if Someone Feels that Their Rights Have Been Violated



If an individual feels that their privacy has been violated, they should talk with their support team about their concern. This may include their planning team and regional center service coordinator.

Source: <u>Consumer Rights, Appeals & Complaints - CA Department of</u> <u>Developmental Services : CA Department of Developmental Services</u>

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)

