



CENTER FOR
DATA INSIGHTS
AND INNOVATION
CALIFORNIA HEALTH &
HUMAN SERVICES AGENCY

STATE HEALTH INFORMATION GUIDANCE 4.1

SHARING HEALTH INFORMATION OF PEOPLE LIVING
WITH INTELLECTUAL AND/OR DEVELOPMENTAL
DISABILITIES IN CALIFORNIA

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Volume 4.1 – Change Log

Section	Page(s)	Change
Entire document	All	<ul style="list-style-type: none"> • AB172 – Human Services. (Chapter 696, October 8, 2021) – updated document to reflect new Center for Data Insights and Innovation (CDII) along with associated updates to statutory authority. Removed references to California Office for Health Information Integrity. • Updated for ADA compliance • Updated CDII web site information
Appendix 1 – SHIG Participants	52	Added list of SHIG Development Contributors for Volume 4.1 effort
Appendix 2 – Patient/Consumer Authorization or Consent	55	HIPAA Authorization Form Requirements was updated to reflect requirements as well as core elements for a valid HIPAA authorization.
Appendix 6 – Definitions	79	Patient’s Representative definition was updated to replace “treat” with “deal with” to eliminate any confusion with multiple meanings of the word “treat.”

Executive Summary

There are approximately 300,000+ people in California living with intellectual and/or developmental disabilities. Providing support services to persons living with intellectual and/or developmental disabilities requires coordination of care between health providers, social services agencies, independent service providers, home and community-based service programs and residential facilities, supported employment, and transportation providers. Sharing patient/consumer¹ information is critical to coordinating care and treatment which enables a patient/consumer to obtain tailored services and supports empowering them to live their best lives. In addition, Regional Centers (RC), Regional Center Vendors (RC vendors), State Operated Facilities (SOF), as well as divisions/programs within the California Department of Developmental Services (DDS) require specific medical information to adapt an Individualized Family Services Plan (IFSP), Individual Program Plan (IPP), or Individual Health Care Plan (IHCP) to assist their patients/consumers. Complex data privacy laws complicate the seamless coordination of care across the various service providers. In some cases, this causes service providers to shy away from sharing data or require complicated agreements between parties. The state created the State Health Information Guidance (SHIG) to help standardize and clarify federal and state law.

In SHIG Volume 4, the State provides guidance about how patient/consumer health and social services information can be shared in the day-to-day practice of providing integrated care and services to people living with intellectual and/or developmental disabilities. The SHIG Volume 4 clarifies existing federal and state laws that affect disclosure and sharing of patient/consumer health and social services information by providing scenario-based guidance written in simple, everyday business language.

The SHIG development process involved extensive input from non-profit, private, community-based, and government organizations involved in the delivery of services to people living with intellectual and/or developmental disabilities. During stakeholder sessions, participants offered ideas, identified common concerns and barriers to sharing patient/consumer health information, and provided insights about how organizations coordinate services. The SHIG scenarios are based on stakeholder feedback. In addition, the SHIG Advisory Committee provided periodic feedback on materials as the SHIG was developed.

The State believes appropriate exchange of patient/consumer health information can be achieved to effectively provide a patient/consumer with coordinated and integrated care and

¹ While the SHIG team understands that “consumer” is an outdated term to refer to individuals receiving services and that individuals may prefer to use other language, California law still uses this terminology. Because the SHIG is based on the law and interprets law, it uses the term “consumer” to align with California law and prevent confusion that may come from using language not reflected in existing law. The SHIG team looks forward to updating the SHIG when the law changes to reflect modern terminology.

services while still protecting the patient's/consumer's right to privacy. Based on this principle and relevant federal and state law, the clarifying guidance in this document is organized to move from general to more specific guidance in three (3) levels:

1. **General Guidance** identifies key federal and state laws regarding the disclosure of patient/consumer health information to help health, eligibility, enrollment, and program service providers determine whether and when they can share their patient's/consumer's information.
2. **Guidance by Category** provides help in the following seven (7) situational categories specific to serving people living with intellectual and/or developmental disabilities:
 1. Regional Center / Regional Center Vendor to Health Provider
 2. Regional Center / Regional Center Vendor to Parent (or family member)
 3. Regional Center / Regional Center Vendor to Caregiver
 4. Health Provider to Regional Center / Regional Center Vendor
 5. Behavioral Health Provider to Regional Center / Regional Center Vendor – Mental Health Information
 6. Behavioral Health Provider to Regional Center / Regional Center Vendor – Substance Use Disorder Information
 7. Health Provider to Health Provider
3. **Scenario-Based Guidance** provides answers and clarifications to stakeholder-identified questions through flow-chart graphics and narrative responses in seven (7) scenarios.

Federal and state laws regarding the privacy of patient/consumer health information clearly allow patient/consumer health information to be shared for many purposes when a patient/consumer or patient's/consumer's representative provides consent or authorization. Therefore, this guidance on the exchange of patient/consumer health information focuses on uses and disclosures that do not require a valid authorization from the patient/consumer or their authorized representative. However, there are times when patient/consumer health information can only be shared with written consent and the scenarios inform when that must occur.

While the guidance is designed to be helpful and authoritative, the SHIG is specifically not designed, nor does the State intend through its publication, to provide legal counsel applicable to all circumstances. This guidance is for informational purposes only and should not be considered as legal advice from the State. The State makes no warranties, expressed or implied, regarding errors or omissions and assumes no legal liability or responsibility for loss or damage resulting from the use of information contained within the SHIG. Readers are encouraged to consult an attorney prior to developing and implementing operational policies and procedures governing the use and disclosure of patient/consumer health information.

The SHIG is not intended as a comprehensive solution for all the associated legal, technological, operational, cultural, and financial issues associated with sharing patient/consumer health information. It is, however, intended to encourage the responsible and appropriate information sharing in California and promote a dialog among health and social services providers and interested stakeholders regarding what disclosures and sharing can be done within current federal and state laws. Health providers, patient/consumer advocates, RCs, RC vendors, SOFs, social services agencies, health plans and other payers, care coordinators, concerned individuals, county and local governments, community-based organizations, State agencies, and the Legislature must collaborate and communicate with one another to fully achieve this document's purpose. To protect patient/consumer rights while promoting whole-person care through improved care coordination and information sharing, this dialog must continue well beyond the SHIG's publication.

The State encourages readers to use the SHIG to take appropriate next steps for their organizations to improve coordination of services for people living with intellectual and/or developmental disabilities. Possible next steps for readers might include:

- Sharing the SHIG with appropriate staff and leaders within the readers' organizations and with staff and leaders in partner organizations
- Reviewing and possibly updating organization policies and procedures
- Identifying legislative changes that protect patient/consumer privacy while limiting obstacles for patient/consumer centric integrated care

While designed to be helpful, the SHIG clarifications will lead to improvements for the provision of services to people living with intellectual and/or developmental disabilities only if there is meaningful follow-up action.

CAUTION! This guidance is not intended for state entities as it does not address the California Information Practices Act. State departments and facilities, such as Department of Developmental Services (DDS) and State Operated Facilities (SOFs), must refer to the *Statewide Health Information Policy Manual (SHIPM²)* for guidance on sharing health information.

² The SHIPM is on the Center for Data Insights and Innovation (CDII) website: <https://www.cdii.ca.gov/compliance-and-policy/statewide-health-information-policy-manual-shipm/>

Navigating SHIG

This section helps orient the reader to the State Health Information Guidance (SHIG) document. It explains the imbedded hyperlinks, the structure of the guidance, and the approach to legal citations and references.

Definitions, Acronyms and Hyperlinks

Beginning with this section and throughout the rest of the SHIG, key words and phrases (which may include acronyms) are underlined in blue font the first time they are used in a section or scenario. As an example, note the formatting of [health information](#). Words and phrases formatted in this way are hyperlinks to definitions presented in [Appendix 6 - Definitions](#). All forms of a word are included under one definition (e.g., disclosure, disclose, and disclosures would all be listed under “[disclose](#)” in Definitions). If the reader is using an electronic version of the document, a click on the link will take the reader to the appropriate SHIG definition.

Acronyms and the phrase each acronym represents are in [Appendix 7 - Acronyms](#).

In addition to words and phrases, the titles of specific sections of the SHIG (or of reference documents included in the appendices) may also have the same formatting and are hyperlinks. A click on the link when using an electronic version of the SHIG will take the reader to the section of the document referenced. As examples, refer to the links to [Appendix 6 - Definitions](#) and [Appendix 7 - Acronyms](#) here and in the paragraph above.

Lastly, the [Table of Contents](#) is also a navigation tool. In electronic versions of the SHIG, the reader may click on a section defined in the Table of Contents and be taken to the beginning of the section selected.

Structure of Guidance

The guidance in this document is organized to move from general to more specific guidance:

- [General Guidance](#) – This is the most general information on overall information [privacy](#) laws and policies.
- **Guidance by Category** – Each guidance by category section presents a general introduction about the category. The introduction may include who is involved in the information sharing, an overview of the services provided, or examples of information sharing situations. This guidance is presented in seven (7) categories:
 - Regional Center / Regional Center Vendor to Health Provider
 - Regional Center / Regional Center Vendor to Parent (or family member)
 - Regional Center / Regional Center Vendor to Caregiver
 - Health Provider to Regional Center / Regional Center Vendor

- Behavioral Health Provider to Regional Center / Regional Center Vendor – Mental Health Information
- Behavioral Health Provider to Regional Center / Regional Center Vendor – Substance Use Disorder Information
- Health Provider to Health Provider
- **Scenario-Based Guidance** – This is guidance that addresses specific questions for each of the scenarios within a category. Each scenario answers a specific question raised by SHIG stakeholders. It uses illustrations to answer common questions regarding disclosure of [patient/consumer](#) health information.

The scenarios focus on the criteria for sharing information without a patient/consumer or their representative’s written consent or [authorization](#). However, even when written consent is not required by law, providers are encouraged to discuss with a patient/consumer why some forms of sharing are in their patient’s/consumer’s best interest. Engaging patients/consumers in informed disclosure decisions are often strongly beneficial to their health and wellbeing.

Each scenario has four (4) parts:

- a brief description of the scenario
- a graphic illustrating the State’s guidance for the scenario
- a narrative describing the State’s guidance specific to the scenario
- a list of relevant legal citations and references

Note: The guidance in this document can be used for the disclosure of individual patient health information as well as aggregate health data.

Legal Caveat

The State Health Information Guidance (SHIG) provides the State of California's (State's) non-mandatory guidance regarding [disclosure](#) of [patient/consumer health information](#) related to providing services to people living with [intellectual and/or developmental disabilities](#). The SHIG clarifies existing federal and state laws that affect disclosure and sharing of patient/consumer health information within the State by providing scenario-based guidance in everyday language.

While the guidance is designed to be helpful and authoritative, the SHIG is specifically not designed, nor does the State intend through its publication, to provide legal counsel. This is for informational purposes only and should not be construed as legal advice by the State. The State and the California Center for Data Insight and Innovation (CDII) makes no warranties, expressed or implied, regarding errors or omissions and assumes no legal liability or responsibility for any loss or damage resulting from the use of information contained within. Readers are encouraged to consult an attorney prior to developing and implementing operational policies and procedures governing the use and disclosure of patient/consumer health information.

The SHIG provides non-binding clarification to help readers working together to better understand relevant sections of federal and state [privacy](#) laws including, but not limited to, the:

- Health Insurance Portability and Accountability Act (HIPAA)
- Developmental Disabilities Assistance and Bill of Rights
- 42 Code of Federal Regulations (C.F.R.) Part 2
- Confidentiality of Medical Information Act (CMIA)
- California Consumer Privacy Act (CCPA)
- Lanterman Developmental Disabilities Services Act (Lanterman)
- Lanterman-Petris-Short Act (LPS)
- California Health and Safety Code

The SHIG does not address local, city, or county laws or ordinances. In addition, the SHIG only address regulations and laws listed above.

Purpose of SHIG Volume 4

Volume 4 of the State Health Information Guidance (SHIG) combines general guidance and real-life scenarios to clarify federal and state laws related to sharing of [patient/consumer health information](#) to provide coordinated services to people living with [intellectual and/or developmental disabilities](#) as part of whole-person care. The SHIG offers authoritative guidance to provide legal clarification for sharing information while protecting [privacy](#). Removing obstacles may result in improved coordination of care to help people living with intellectual and/or developmental disabilities achieve better health outcomes. However, [treatment](#) and coordination of care requires patient/consumer health information to be shared in an appropriate, secure, and timely manner between different types of service providers.

This SHIG provides non-mandatory, authoritative guidance from the State of California on the uses, [disclosures](#), and protection of patient/consumer health information. This guidance document is not designed to address all sharing challenges that providers currently experience but does address those issues stakeholders told us were their highest priority. The SHIG Volume 4 aims to clarify federal and state laws and regulations for a non-legal audience and to help inform health and social service providers about the when, why, and how patient/consumer health information may be shared among whole-person care partners.

Federal and state laws and regulations regarding the privacy of patient/consumer health information clearly allow this information to be shared for a wide variety of purposes when a patient/consumer or their representative provides valid written consent or [authorization](#). Therefore, the SHIG focuses on exchanges of patient/consumer health information that do not require an authorization from the patient/consumer or their representative. However, there are times when patient/consumer health information can only be shared with authorization and the scenarios inform when that must occur.

The intended audience of the SHIG is [health providers](#); [Regional Centers \(RCs\)](#); [RC Vendors](#), enrollment and eligibility application assistors; [health plans](#) and other payers; contractors; patient/consumer and privacy advocacy organizations; county and local governments; [community-based organizations](#); and other interested parties.

CAUTION! The SHIG is not intended for State departments covered by the Health Insurance Portability and Accountability Act (HIPAA). State entities that are [covered entities](#) or [business associates](#) (BA) refer to the *Statewide Health Information Policy Manual (SHIPM³)* for guidance.

General guidance and real-life scenarios are employed in the SHIG as a means to clarify applicable privacy laws in the context of common obstacles and opportunities currently

³ The SHIPM is on the CDII website: <https://www.cdii.ca.gov/compliance-and-policy/statewide-health-information-policy-manual-shipm/>

experienced by providers. Both general guidance and scenarios are used to clarify the State's interpretation of privacy protections in lay language for a general and broad audience of stakeholders.

This guidance document is not a restatement of current laws. Instead, the SHIG is designed to clarify existing federal and state laws that impact disclosure and sharing of patient/consumer health information within California by providing scenario-based guidance in everyday language.

Background of SHIG Volume 4

The State Health Information Guidance (SHIG) project was initially developed by the former California Health and Human Services Agency's (CalHHS) Office of Health Information Integrity (CalOHII). CalOHII is now the CalHHS Center for Data Insights and Innovation (CDII).

Part of CDII's mission is to assist State of California departments to protect and secure access to the [health information](#) in their care. CDII's statutory authority is to interpret and clarify federal and state laws – which led to the creation of the *Statewide Health Information Policy Manual (SHIPM)*. The SHIPM provides mandatory guidance for State departments covered by the Health Insurance Portability and Accountability Act (HIPAA). The SHIPM, originally published in 2015, is updated annually and in use today.

Leveraging this experience, CDII created the first State Health Information Guidance (SHIG) volume as non-binding guidance to interpret and clarify federal and state law for non-State departments. The first SHIG published was *Sharing Behavioral Health Information in California*⁴ (originally published in January 2018).

The Centers for Medicare and Medicaid Services (CMS), California Health Care Foundation (CHCF), Nourish California and Archstone Foundation provided CDII with grants to augment the SHIG to address information sharing with the State's vulnerable populations, including:

- people living with food or nutrition insecurity
- people living with [intellectual and/or developmental disabilities](#)
- older adults
- foster youth
- minors
- people living with Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS)

In July 2020, CDII launched the SHIG augmentation project to provide health information guidance related to each of these communities requiring care. Since the project's inception, CDII made a decision to publish one (1) SHIG volume for each population/topic.

SHIG Volume 4 – Sharing Health Information of People Living with Intellectual and/or Developmental Disabilities in California provides clarification of federal and state law targeting the sharing of [patient/consumer](#) health information to support the coordination of [treatment](#)/care and services to people living with intellectual and/or developmental disabilities. Serving these individuals relies on seamless information sharing between all members of the services/treatment/care community. This includes public, private, community-based, and non-

⁴ Refer to <https://www.cdii.ca.gov/compliance-and-policy/state-health-information-guidance-shig/>

profit organizations such as [health providers](#); [health plans](#) and other payers; [Regional Centers](#); independent service providers; county and local governments; social service agencies; and other related services. Like the original SHIG, this augmentation will illustrate a path to comply with federal and state [privacy](#) law while ensuring that each individual living with intellectual and/or developmental disabilities receive services and supports. The goal of this document is to address stakeholder challenges in interpreting federal and state privacy laws protecting patient/consumer health information.

The process to develop SHIG Volume 4 tapped on the experience, expertise, and knowledge of multiple committed stakeholders who identified and prioritized the most critical issues that became the basis for the scenarios in this volume. The project began in July 2020 with outreach to various and diverse stakeholders – CDII conducted surveys and interviews to collect initial insights. From this information, the team held two (2) stakeholder sessions – the goal was to capture the current barriers to information sharing and gather insights on issues preventing coordinated care and services. Below are themes heard from the stakeholders:

- Inconsistent information sharing process
 - Unilateral and bi-directional data sharing challenges
 - Lack of clarity on what data can be shared
 - Receipt of invalid Release of Information forms
- Patient/consumer (individual living with intellectual and/or developmental disabilities) [capacity](#) challenges when providing consent
 - Patient/consumer may be unable to give informed consent and no one else has the right to on their behalf
 - Knowing if the patient/consumer is [conserved](#); conservatorship documentation is not readily available
 - Understanding how the power of attorney limits the ability to [disclose](#) information
 - Aging parents who are the legal guardians or [caregivers](#) of a patient/consumer may die or lose capacity themselves
 - Consent forms are difficult to track and the patient/consumer has a right to revoke consent
 - Patient/consumer and their family may refuse to share information
- Regulatory/legal challenges – HIPAA, federal regulations on the service providers
 - Burden of HIPAA and other privacy compliance for small organizations
 - Need to clarify information sharing under the Lanterman Developmental Disabilities Services Act (Lanterman) (e.g., the Act does not clarify information sharing between members of multi-disciplinary teams)
- Technology challenges
 - Lack of interoperable technology

- Varied processes for determining eligibility
 - County variations
 - Programmatic variations (e.g., number of individual plans developed for improvement purposes) – ties to federal and state regulations and laws
 - Need for a clearly understandable universal [authorization](#)

During our closing session, stakeholder input informed the selection and priority of scenarios for SHIG Volume 4.

Additionally, a subset of stakeholders participated in the SHIG Advisory Committee. This group reviewed all SHIG content as it was developed, sharing their input and expertise to help shape the final SHIG document.

Refer to the [Appendix 1 - SHIG Participants](#) for a list of all individuals and organizations.

Conclusion

One of the main objectives of the SHIG is to promote better care integration and better health and wellness outcomes while protecting privacy. Through feedback received via its “grass roots” stakeholder engagement method, CDII believes the greatest value provided by the SHIG is its clarification of federal and state laws by translating the complex laws into non-legal and non-technical language for a general audience. The intention is that this clarity will empower health and other service providers to appropriately exchange patient/consumer health and social services information, ultimately leading to improved healthcare and wellness outcomes for people living with disabilities.

General Guidance

The State of California believes appropriate exchange of [patient/consumer health information](#) can effectively provide a patient/consumer with coordinated and integrated whole person care while still protecting the patient's/consumer's right to [privacy](#). Many [health providers](#) may choose to not share patient/consumer health information with community service partners due to the complexity and lack of clarity of federal and state laws as well as the fear of non-compliance. This creates gaps in appropriate services for individuals with health needs, including people living with [intellectual and/or developmental disabilities](#).

Note: The guidance in this document can be used for individual patient/consumer health information as well as aggregate health data.

This section provides guidance on patient/consumer health information sharing to encourage the appropriate exchange of patient/consumer health information between the communities of service providers. This section begins with an overview of the many programs and services that help people living with intellectual and/or developmental disabilities achieve their best health and independence. Next, we provide guidance on information sharing including how, when, and how much information can be shared. Finally, this section provides a summary of federal and state laws regarding uses and [disclosures](#) of health information.

Individuals Living with Intellectual and/or Developmental Disabilities Overview

The California Department of Developmental Services (DDS) manages [State Operated Facilities](#) (SOF) and contracts with [Regional Centers](#) (RC) and [Regional Center Vendors](#) (RC vendors) to provide and/or coordinate services for people living with an [intellectual and/or developmental disability](#). RCs provide diagnosis and [eligibility assessment](#) and help plan, access, coordinate, and monitor the services provided. RCs contract with vendors who also provide direct services and supports to patients/consumers. SOFs provide various types of [health provider](#) services for those individuals with an intellectual and/or developmental disability who are judicially committed for criminal competency training, temporarily in acute crisis, or in need of mobile crisis stability services.

The RCs also coordinate an early start program for infants and toddlers if a developmental delay exists or there is a high risk of a developmental disability.

Adults eligible for RC, RC vendor or SOF services must have a qualifying disability that begins before the person's 18th birthday that is also expected to continue indefinitely. Some adults have a dual diagnosis of lifelong intellectual and/or developmental disabilities along with co-occurring mental illness and/or challenging behaviors. Eligibility for services is established through diagnosis and assessment performed by a RC or RC vendor staff. Physical and

[behavioral health](#) providers, as well as other involved stakeholders, often refer a [patient/consumer](#) to a RC or RC vendor for eligibility assessment to determine whether they have a qualifying intellectual and/or developmental disability.

Once eligibility is determined, RC or RC vendor staff help the individual or consumer develop an [Individualized Family Services Plan](#) (IFSP) or [Individual Program Plan](#) (IPP), or SOF staff help the individual or consumer develop an [Individual Health Care Plan](#) (IHCP) for services including, but not limited to:

- Information and referral
- Assessment and diagnosis
- Physician or dentist documentation of visits
- Physician orders for services or medication
- Genetic counseling
- Planning, placement, and monitoring for 24-hour out-of-home care

The effective delivery of services for people living with intellectual and/or developmental disabilities requires coordination of care. DDS collaborates with a community of service providers to deliver whole person care for people living with intellectual and/or developmental disabilities.

Coordination of patient/consumer care for people living with an intellectual and/or developmental disability involves planning and organizing [treatment](#) activities, services, and supports. Sharing [health information](#) between health providers for a patient's/consumer's care is necessary to achieve improved health outcomes and effective care. To integrate and coordinate treatment and other care, patient/consumer health information must be securely and appropriately shared by and between health providers (e.g., physical health providers, behavioral health providers) as well as various delivery system providers (e.g., RCs, RC vendors, SOFs). Health providers [disclose](#) specific information (including health information) about their patient/consumer using RC or RC vendor designated release of information forms; referral form content and format varies between these organizations.

To promote clarity in this guidance people living with an intellectual and/or developmental disability are referred to or identified using different terminology based on the legal or regulatory terms covering the service (indicated as role in the table below).

Role	Refer to person receiving services as...
Regional Center / Regional Center Vendor / State-Operated Facility	Consumer ⁵
Health Providers	Patient

For guidance on health information disclosure, state departments or facilities, such as SOF and DDS, should refer to the *Statewide Health Information Policy Manual (SHIPM)*. This SHIG Volume 4 provides guidance for RC health information sharing; the remainder of this document will focus on RC health information sharing scenarios.

Generally Applicable Guidance

Authorizations for Release of Health Information

Health care and social service providers are encouraged to take the lead in coordinating [authorizations](#) for their patients/consumers when they make referrals. A copy of the completed and signed authorization form should be forwarded, whenever feasible by the provider as part of a referral. This is a great assistance to the patients/consumers, such as older adults and people living with disabilities, for whom downloading, printing, and forwarding/mailing copies of authorization forms may be burdensome and a barrier to seeking [treatment](#) or services.

Many providers believe that authorizations that serve multiple purposes are illegal – this is not true. There is a difference between a [compound authorization](#) and an authorization combining multiple releases of [health information](#).

A compound authorization mixes an authorization for the use and [disclosure](#) of [protected health information](#) (PHI) with another health services document – typically related to consent to receive treatment or assign payment of benefits to the provider. The Health Insurance Portability and Accountability Act (HIPAA) prohibits compound authorizations. The authorization for the use and disclosure of PHI must be voluntary.

On the other hand, a [covered entity](#) can combine (or consolidate) authorizations for the use and disclosure of PHI for multiple purposes or to multiple entities into a single authorization. The key to a [combined authorization](#) is that the authorization focuses on uses and disclosures

⁵ While the SHIG team understands that “consumer” is an outdated term to refer to individuals receiving services and that individuals may prefer to use other language, California law still uses this terminology. Because the SHIG is based on the law and interprets law, it uses the term “consumer” to align with California law and prevent confusion that may come from using language not reflected in existing law. The SHIG team looks forward to updating the SHIG when the law changes to reflect modern terminology.

of information and does not include any other legal permissions. This allows the [patient/consumer](#) to sign one (1) authorization form for all disclosures from a specific provider. Other items to keep in mind when consolidating the authorization for use and disclosure of PHI:

- It can list specific persons, providers and/or categories of providers to whom the patient's/consumer's provider can release the PHI.
- After the patient/consumer signs the authorization, adding a new category of treatment, a new purpose for disclosure, modified expiration date and/or a new provider (not listed in the original authorization) will require a new authorization.
- An authorization for the use or disclosure of psychotherapy notes **may not be combined** with an authorization for the use or disclosure of other types of PHI.

Federal and state statutes and regulations regarding the [privacy](#) of health information clearly allow health information to be shared when a patient/consumer or [patient/consumer's representative](#) provides a valid authorization. Therefore, the scenarios presented in this health information guidance will focus on activities involving uses and disclosures of health information that do not require an authorization, whenever possible. Refer to [Appendix 2 - Patient/Consumer Authorization or Consent](#) for the specific documentation requirements for authorized disclosure.

Minimum Necessary

When health information is requested, used, or disclosed, steps must be taken to limit the information to only what is relevant and necessary to accomplish the intended purpose. HIPAA requires disclosure of health information to be limited to the [minimum necessary](#) in many circumstances. While the minimum necessary requirement only applies to HIPAA regulated health information, other laws operate in a similar way to limit disclosures. The minimum necessary requirement in HIPAA does not apply to the following:

- Treatment and care coordination
- Disclosures made to the patient/consumer who is the subject of the information
- Uses or disclosures made pursuant to a valid patient/consumer authorization
- Disclosures to the Secretary of the U.S. Department of Health and Human Services
- Uses or disclosures required by federal or state law

[45 C.F.R. §§ 164.502(b), 164.506; Cal. Civ. Code § 56.10(c)(1).]

Re-Disclosure of 42 C.F.R. Part 2, Lanterman Developmental Disabilities Services Act, and Lanterman-Petris-Short Act Patient/Consumer Information

Health and substance use disorder (SUD) [patient-identifying information](#) regulated by 42 C.F.R. Part 2 is specially protected and, once received, may only be re-disclosed under specific conditions. Patient/consumer information regulated by 42 C.F.R. Part 2 that identifies a patient/consumer directly or indirectly as having been diagnosed, treated, or referred for treatment for a SUD requires each disclosure be made with written consent from the patient/consumer or [patient's/consumer's representative](#) unless disclosure meets an exception in the law. In addition, the person or persons who receive the SUD patient-identifying information cannot further disclose the information unless the further disclosure is expressly permitted by an authorization or as otherwise permitted by 42 C.F.R. Part 2.

While Lanterman Developmental Disabilities Services Act (Lanterman) and Lanterman-Petris-Short Act (LPS) are silent on re-disclosure, the privacy protections contained within Lanterman and LPS continue with the information once the information has been disclosed. Further disclosure of Lanterman or LPS regulated information may only be disclosed as allowed by law or with a patient/consumer authorization.

[42 C.F.R. § 2.32; Cal. Welf. & Inst. Code §§ 4514, 5328; State Department of Public Health v. Superior Court (2015) 60 Cal.4th 940, 954.]

Summary of Primary Laws

The [disclosure](#) of protected [patient/consumer health information](#) is governed by a number of federal and state laws specifically pertaining to disclosure of these types of information for adults living with [intellectual and/or developmental disabilities](#).

The primary federal statutes and regulations affecting the uses and disclosures of health information for adults living with intellectual and/or developmental disabilities include:

- 42 U.S.C. § 15001 et seq. – Developmental Disabilities Assistance and Bill of Rights
- 42 C.F.R. Part 2 – Confidentiality of Substance Use Disorder Patient Records
- 45 C.F.R. Parts 160 and 164 – Health Insurance Portability and Accountability Act (HIPAA)

The primary State of California statutes and regulations pertaining to the uses and disclosures of health information for adults living with intellectual and/or developmental disabilities include:

- Civil Code § 56 et seq. – Confidentiality of Medical Information Act (CMIA)
- Civil Code § 1798.100 et seq. – California Consumer Privacy Act (CCPA)
- Health and Safety Code § 11845.5

- Welfare and Institutions Code § 4514 et seq. – Lanterman Developmental Disabilities Services Act (Lanterman)
- Welfare and Institutions Code § 5328 et seq. – Lanterman-Petris-Short Act (LPS)

Following is the State’s summary of these regulations and laws related to the access, use, and disclosure of health information for an individual living with intellectual and/or developmental disabilities. The [Guidance for Specific Scenarios](#) section provides additional details and examples.

The SHIG does not address local, city, or county laws or ordinances.

Federal

Developmental Disabilities Assistance and Bill of Rights (42 U.S.C. § 15001 et seq.)

The Developmental Disabilities Assistance and Bill of Rights provides grants to states and public non-profits to support people living with intellectual and/or developmental disabilities and their families with health care, child care, employment, civil rights protections, education, transportation, and family support. These supports and services empower people in their independent living and employment. The Developmental Disabilities Assistance and Bill of Rights Act also establishes the State Councils on Developmental Disabilities, Protection and Advocacy Systems, University Centers for Excellence in Developmental Disabilities, Projects of National Significance, and Family Support Programs.

42 C.F.R. Part 2

42 C.F.R. Part 2 applies to federally assisted substance use disorder (SUD) [treatment](#) programs that are federally assisted, such as through grants, tax benefits, or license to prescribe certain medications to treat a SUD. These regulations apply to information that would identify a patient/consumer as having a SUD and allow very limited disclosures of information without a patient/consumer [authorization](#).

Health Insurance Portability and Accountability Act Privacy & Security Rule (45 C.F.R. § 164.500 et seq.)

The HIPAA Privacy Rule establishes national standards to protect patients’ medical records and other patient-identifying information and applies to [health plans](#), healthcare clearinghouses, and those [health providers](#) that conduct certain healthcare transactions electronically. The Privacy Rule requires appropriate safeguards to protect the [privacy](#) of patient-identifying health information, and sets limits and conditions on the uses and disclosures of such information without patient authorization. Generally, exceptions are allowed for treatment, payment, and healthcare operations. The Privacy Rule also gives patients-rights over their health information,

including rights to access and to request corrections. HIPAA applies to each scenario within this document.

State of California Statutes

California Confidentiality of Medical Information Act (Cal. Civ. Code § 56 et seq.)

This law protects the privacy of medical information by limiting disclosures by health providers, health plans, and contractors. Disclosure of limited health information including location, general condition, or death may be released to family members, other relatives, domestic partners, close personal friends or other persons identified by the patient.

Note: If you are a health provider, you will be subject to CMIA only if you are not subject to the Lanterman Developmental Disabilities Services Act (Lanterman) or Lanterman-Petris-Short Act (LPS). If the Lanterman or LPS applies, then CMIA does not apply.

California Consumer Privacy Act (Cal. Civ. Code § 1798.100 et seq.)

This law protects the privacy of consumers' personal information collected by for-profit businesses that meet certain threshold requirements. Businesses regulated by the CCPA collect and buy, sell, or share personal information for profit. Health providers and information covered by HIPAA or the CMIA are exempted from the California Consumer Privacy Act (CCPA) requirements. In addition, non-profit organizations are exempted from the CCPA. All scenarios in the State Health Information Guidance (SHIG) assume that the CCPA does not apply.

California Health and Safety Code (Cal. Health and Safety Code § 11845.5)

This State of California statute specially protects health information that would identify a patient/consumer as having a substance use disorder (SUD) maintained by entities that are licensed by the California Department of Health Care Services (DHCS) to provide SUD treatment. Information and records may be disclosed only as provided in this law. The Confidentiality of Medical Information Act (CMIA) does not regulate these SUD information and records.

Lanterman Developmental Disabilities Services Act (Cal. Welf. & Inst. Code § 4514 et seq.)

Information and records obtained in the course of providing services regulated by Lanterman to people living with intellectual and/or developmental disabilities are confidential and specially protected. Lanterman regulated entities include, but may not be limited to:

- California Department of Developmental Services (DDS)
- [State Operated Facilities](#)
- [Regional Center](#)

- [Regional Center Vendors](#)
- [Intermediate Care Facilities](#)
- County [Psychiatric Health Facilities](#) (PHF) when providing services regulated by Lanterman
- Contractors of DDS and Regional Centers

In general, information and records may be disclosed as provided by Lanterman. If a health facility is not regulated by Lanterman, it is likely regulated by CMIA. In rare instances, both LPS and Lanterman can apply – such as when an individual is receiving services for both an intellectual and/or developmental disability and mental health in a county PHF.

Lanterman-Petris-Short Act (Cal. Welf. & Inst. Code § 5328)

Information and records obtained in the course of providing mental health services to involuntarily committed individuals living with [intellectual and/or developmental disabilities](#) are [confidential](#) and specially protected under the Lanterman-Petris-Short Act (LPS). [Patient/consumer health information](#) obtained by county or city mental health departments, State of California (State) hospitals, [state-operated facilities](#), [regional centers](#), and [regional center vendors](#) when providing involuntary mental health crisis services (under contract with the California Department of Developmental Services (DDS)), or other public or private entities (such as community mental health clinics) is also protected under LPS.

Note: If LPS applies, CMIA does not.

CAUTION! In rare instances, both LPS and Lanterman can apply – such as when an individual is receiving services regulated by Lanterman and LPS in a county [Psychiatric Health Facility](#) (PHF).

Guidance for Specific Scenarios

Guidance for specific scenarios is based on scenario descriptions and assumptions. Readers should thoroughly review them, as the laws discussed in the guidance for an individual scenario will vary based on the specifics of the scenario's description and assumptions.

Each scenario contains the following subsections:

- Description – provides a brief description of the scenario, the question to be addressed by the scenario and assumptions made when developing the guidance
- Graphic(s) – presents one or more decision flow diagrams illustrating the State's guidance for the scenario
- Scenario Guidance – provides a narrative describing the State's guidance specific to the scenario
- Citations and Related Guidance – presents a list of the relevant legal citations and references used in developing the guidance

CAUTION! For [community-based organizations](#) providing multiple services, refer to the scenario applicable to the service/role you are providing when sharing [health information](#).

Developmental Disabilities Scenarios

Scenario 1 – Regional Center / Regional Center Vendor to Health Provider

Description

A [Regional Center](#) (RC) or a [Regional Center Vendor](#) (RC vendor) needs to share [developmental service records](#) information with a [health provider](#) for diagnosis, [treatment](#), and coordination of care for people living with an [intellectual and/or developmental disability](#), for example:

- Notification of the patient's/consumer's admittance into a care facility
- Information on the [patient/consumer](#) assessment and treatment needs
- Reporting on patient/consumer progress meeting health improvement goals

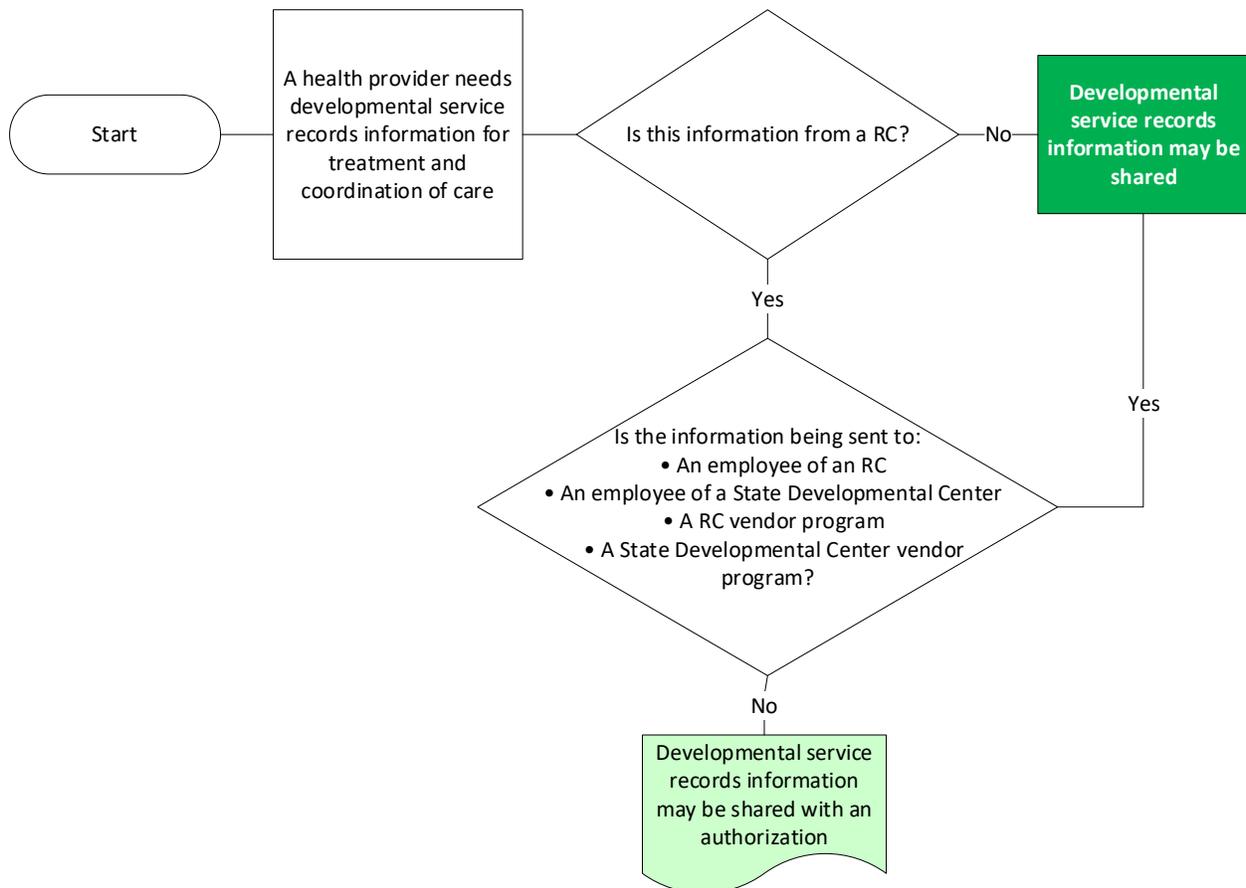
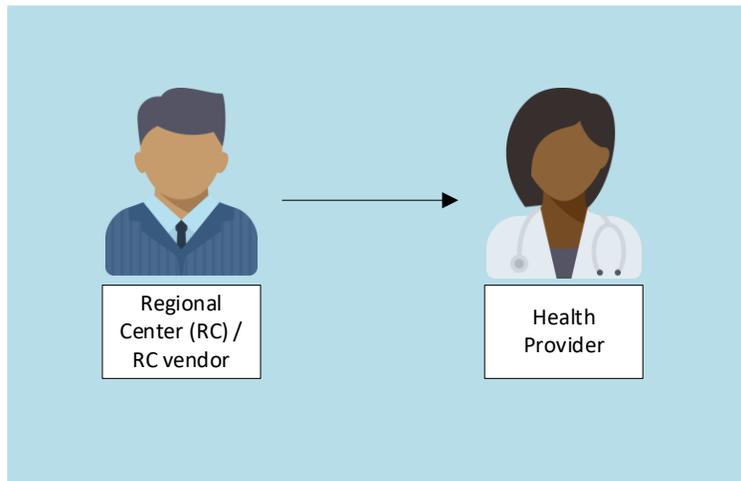
The development service records information that may be [disclosed](#) by a RC or RC vendor to a health provider that is regulated by the Lanterman Developmental Disabilities Services Act (Lanterman) and the Health Insurance Portability and Accountability Act (HIPAA).

What developmental service records information can a RC or RC vendor share with a health provider?

Important Scenario Guidance Assumptions:

- There is no patient/consumer or [patient's/consumer's representative authorization](#)
- There is no medical [emergency](#)
- There is no court order
- Organizations participating in this information exchange are not subject to California Consumer Privacy Act

Graphic – Regional Center / Regional Center Vendor to Health Provider



Scenario Guidance – Regional Center / Regional Center Vendor to Health Provider

In general, the RC or RC vendor may disclose developmental service records information to the health provider for the purpose of providing intake, assessment, and services or appropriate referrals, including for treatment and care coordination. For example, once a patient's/consumer's [Individual Program Plan](#) (IPP) is drafted, the RC or RC vendor may track and report status to the health provider on patient progress to accomplish plan goals related to health provider services. Health providers often need this information to help the patient/consumer meet their IPP medical and health goals.

However, patient/consumer authorization must be obtained when the information is shared from a RC to:

- a health provider who is not employed by a RC;
- a health provider who is not employed by a [State Developmental Center](#);
- a health care program that is not administered by a RC vendor; or
- a health care program that is not administered by a State Developmental Center.

Note that patient/consumer authorization is not required when information is shared from a RC health provider to a health provider who is providing health care as part of a program by a RC, RC vendor, or State Developmental Center. This requirement does not apply to RC vendors.

[45 C.F.R. § 164.506; Cal. Welf. & Inst. Code § 4514(a).]

For RC or RC vendor staff to health provider circumstances/situations not covered by this scenario, a valid patient/consumer or patient's/consumer's representative authorization may be needed to share the patient's/consumer's information.

[45 C.F.R. § 164.508; Cal. Welf. & Inst. Code § 4515.]

CAUTION! RC vendors that are a [Psychiatric Health Facilities](#) (PHF) must also comply with Lanterman-Petris-Short Act (LPS), refer to [Scenario 5 – Behavioral Health Provider to Regional Center / Regional Center Vendor – Mental Health Information](#).

Citations and Related Guidance

- 45 C.F.R. § 164.506.
- 45 C.F.R. § 164.508.
- Cal. Welf. & Inst. Code § 4514(a).
- Cal. Welf. & Inst. Code § 4515.

Scenario 2 – Regional Center / Regional Center Vendor to Parent (or family member)

Description

A [Regional Center](#) (RC) or a [Regional Center Vendor](#) (RC vendor) would like to share [patient/consumer health information](#) for a person living with an [intellectual and/or developmental disability](#) with a [parent](#) or family member. Parents or family members may need [developmental service records](#) information to better understand a patient's/consumer's health needs, for example:

- Notification of the patient's/consumer's presence in a facility
- Information on the patient/consumer diagnosis and [treatment](#)
- Medications prescribed and any medication side effects
- Reporting on patient/consumer progress meeting health improvement goals
- Notification of transfer or the patient's/consumer's death

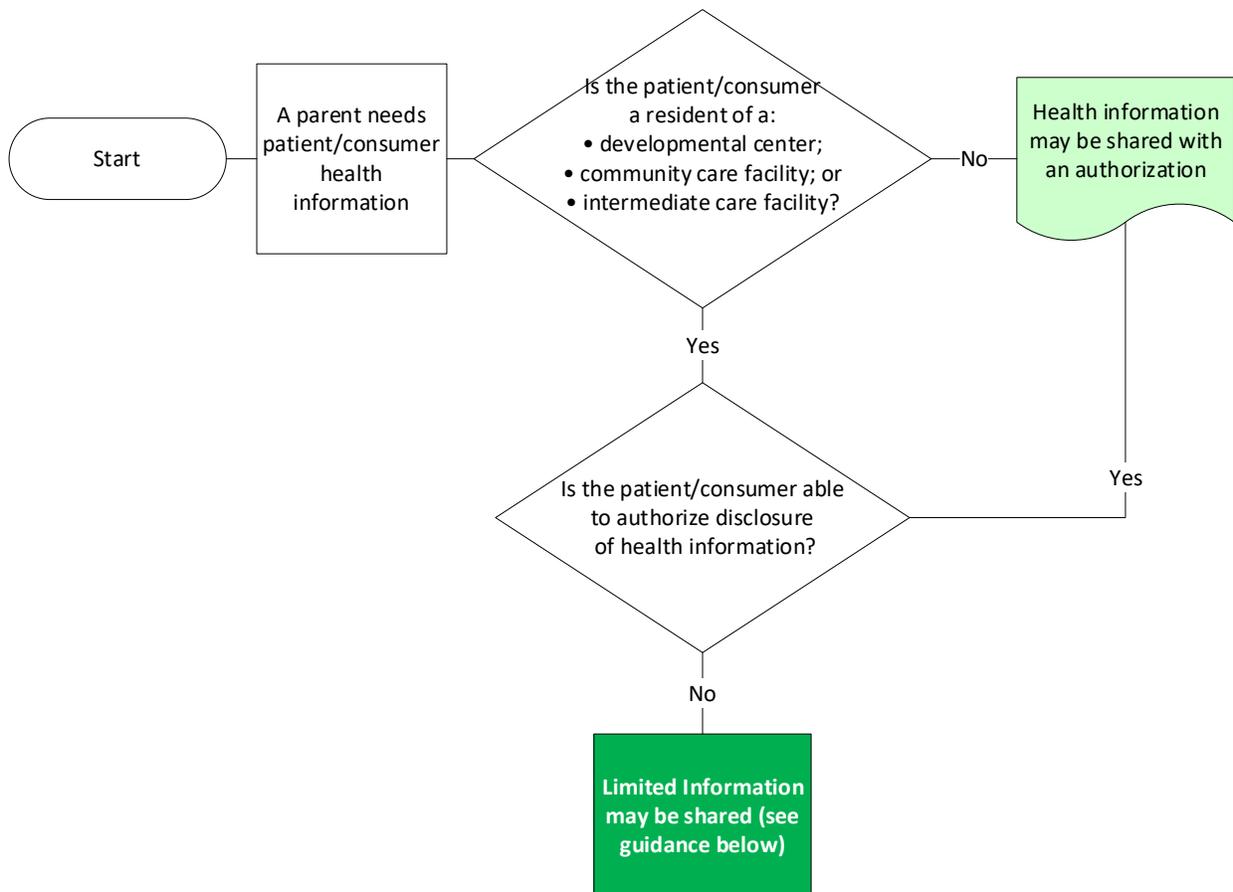
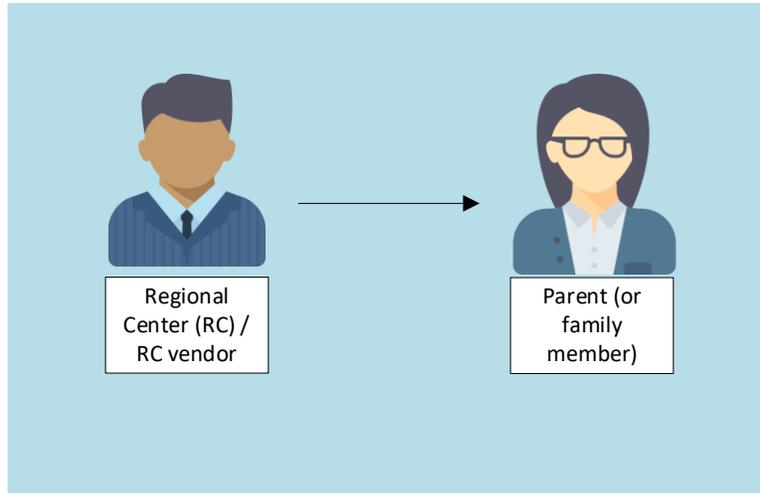
Health information sharing with a parent or family member is regulated by the Health Insurance Portability and Accountability Act (HIPAA) and the Lanterman Developmental Disabilities Services Act (Lanterman).

What developmental service records information can a RC or RC vendor share with a patient's/consumer's parent or family member?

Important Scenario Guidance Assumptions:

- There is no patient/consumer or [patient's/consumer's representative authorization](#)
- The patient/consumer is 18 years of age or older
- The patient/consumer has [capacity](#)
- The patient/consumer is not a dependent ward or conservatee
- There is no medical [emergency](#)
- There is no court order
- Organizations participating in this information exchange are not subject to California Consumer Privacy Act

Graphic – Regional Center / Regional Center Vendor to Parent (or family member)



Scenario Guidance – Regional Center / Regional Center Vendor to Parent (or family member)

While HIPAA might allow the sharing of some health information to a parent or family member without an authorization, Lanterman is more restrictive than HIPAA.

Lanterman allows developmental service records information to be shared as follows:

- If the patient is a resident of an RC contracted facility (e.g., [community care facility](#) or [intermediate care facility](#)) and is unable to authorize disclosure of developmental service records information, the parent or family members may only be notified of the presence of the resident in the facility, their release from the facility, or their death.

CAUTION! This exception only applies to the patient’s/consumer’s parents, spouse, child, or sibling.

[45 C.F.R. § 164.510; Cal. Welf. & Inst. Code § 4514.5.]

- The patient’s/consumer’s developmental service records information otherwise may be shared with the parent or family members with a valid patient/consumer or patient’s/consumer’s authorization.

[45 C.F.R. § 164.508; Cal. Welf. & Inst. Code § 4514.]

Note: Lanterman applies to all RCs and RC vendors so the Confidentiality of Medical Information Act (CMIA) does not apply.

[Cal. Civ. Code § 56.30.]

For RC or RC vendor staff sharing developmental service records information with parents or family member circumstances/situations not covered by this scenario, a valid patient/consumer authorization from the patient/consumer may be needed to share the patient’s/consumer’s developmental service records information.

[45 C.F.R. § 164.508; Cal. Welf. & Inst. Code § 4515.]

CAUTION! RC vendors that are a [Psychiatric Health Facilities](#) (PHF) must also comply with Lanterman-Petris-Short Act (LPS), refer to [Scenario 5 – Behavioral Health Provider to Regional Center / Regional Center Vendor – Mental Health Information](#).

Citations and Related Guidance

- 45 C.F.R. § 164.508.
- 45 C.F.R. § 164.510.
- Cal. Civ. Code § 56.30.
- Cal. Welf. & Inst. Code § 4514.
- Cal. Welf. & Inst. Code § 4514.5.
- Cal. Welf. & Inst. Code § 4515.

Scenario 3 – Regional Center / Regional Center Vendor to Caregiver

Description

A [Regional Center](#) (RC) or a [Regional Center Vendor](#) (RC vendor) would like to notify a [caregiver](#) of a [patient's/consumer's](#) location and general condition or provide [health information](#) the caregiver needs to successfully care for the person living with an [intellectual and/or development disability](#), for example:

- Sharing the name and location of a [health provider](#)
- Sharing the date and time for a health provider appointment
- Sharing whether the patient/consumer attended a health appointment
- Sharing changes in patient/consumer medication administration

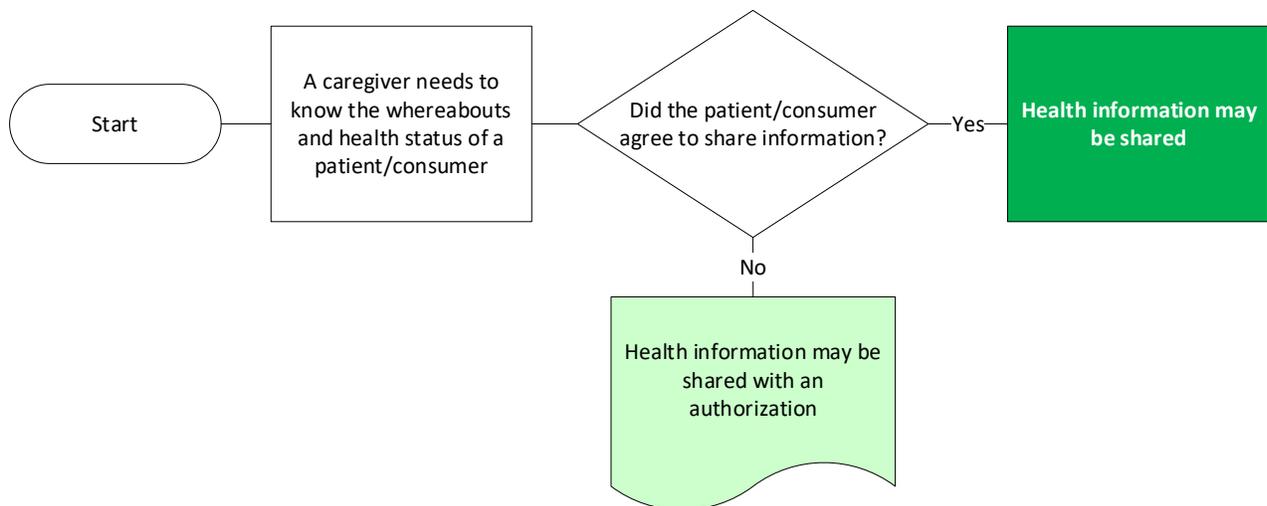
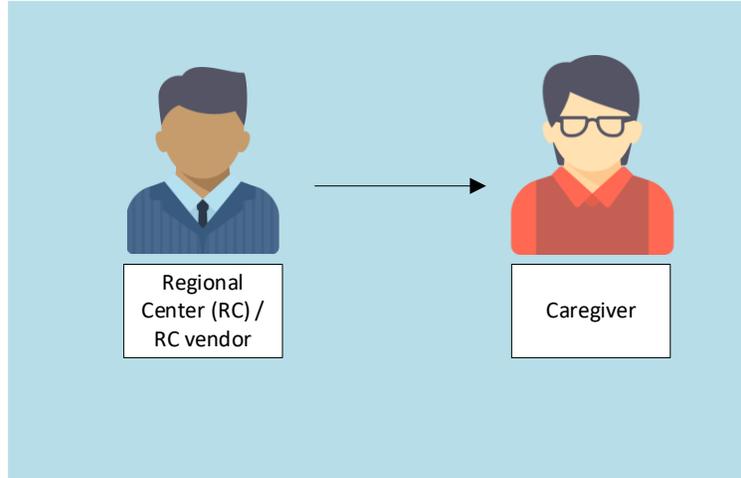
[Developmental service records](#) information sharing with a caregiver by an RC or RC vendor is regulated by the Health Insurance Portability and Accountability Act (HIPAA) and the Lanterman Developmental Disabilities Services Act (Lanterman).

What developmental service records information can a RC or RC vendor share with a patient's/consumer's caregiver?

Important Scenario Guidance Assumptions:

- There is no patient/consumer or [patient's/consumer's representative authorization](#)
- The patient/consumer is 18 years of age or older
- The patient/consumer has [capacity](#)
- The patient/consumer is not a dependent ward or conservatee
- There is no medical [emergency](#)
- There is no court order
- Organizations participating in this information exchange are not subject to California Consumer Privacy Act

Graphic – Regional Center / Regional Center Vendor to Caregiver



Scenario Guidance – Regional Center / Regional Center Vendor to Caregiver

A caregiver for a person living with an intellectual and/or developmental disability may include a family member, a professional or volunteer caregiver, or a friend. An authorized patient's/consumer's representative has legal authority to make healthcare decisions for another person. For the purposes of this scenario, caregiver is defined as someone who is not an authorized patient's/consumer's representative and so does not have any legal authority over a patient's/consumer's healthcare and [disclosure](#) of health information.

While HIPAA allows a health provider to disclose health information to a caregiver that relates to their involvement with the patient's/consumer's healthcare, Lanterman does not.

Lanterman requires a valid patient/consumer or patient's/consumer's representative authorization for any information sharing with caregivers.

[45 C.F.R. § 164.508; Cal. Welf. & Inst. Code §§ 4514(b), 4515.]

CAUTION! RC vendors that are a [Psychiatric Health Facilities](#) (PHF) must also comply with Lanterman-Petris-Short Act (LPS).

Citations and Related Guidance

- 45 C.F.R. § 164.508.
- Cal. Welf. & Inst. Code §4514(b).
- Cal. Welf. & Inst. Code § 4515.

Scenario 4 – Health Provider to Regional Center / Regional Center Vendor

Description

A [health provider](#) (e.g., physician, nurse practitioner, registered nurse) may share [health information](#) about their [patient/consumer](#) living with an [intellectual and/or developmental disability](#) with a [Regional Center](#) (RC) or [Regional Center Vendor](#) (RC vendor), so that RC or RC vendor staff can provide [treatment](#) and care coordination. Healthcare initial treatment and any changes are documented within the patient’s/consumer’s [Individual Program Plan](#) (IPP) at a RC. Health information sharing may include:

- A referral of the patient/consumer to the RC for [eligibility assessment](#)
- A referral of the patient/consumer to the RC for diagnosis, treatment and care coordination services
- To coordinate treatment provided by RC vendor staff
- To monitor patient/consumer progress and health outcomes or identify any new health conditions, to provide input on an IPP, or for medication management

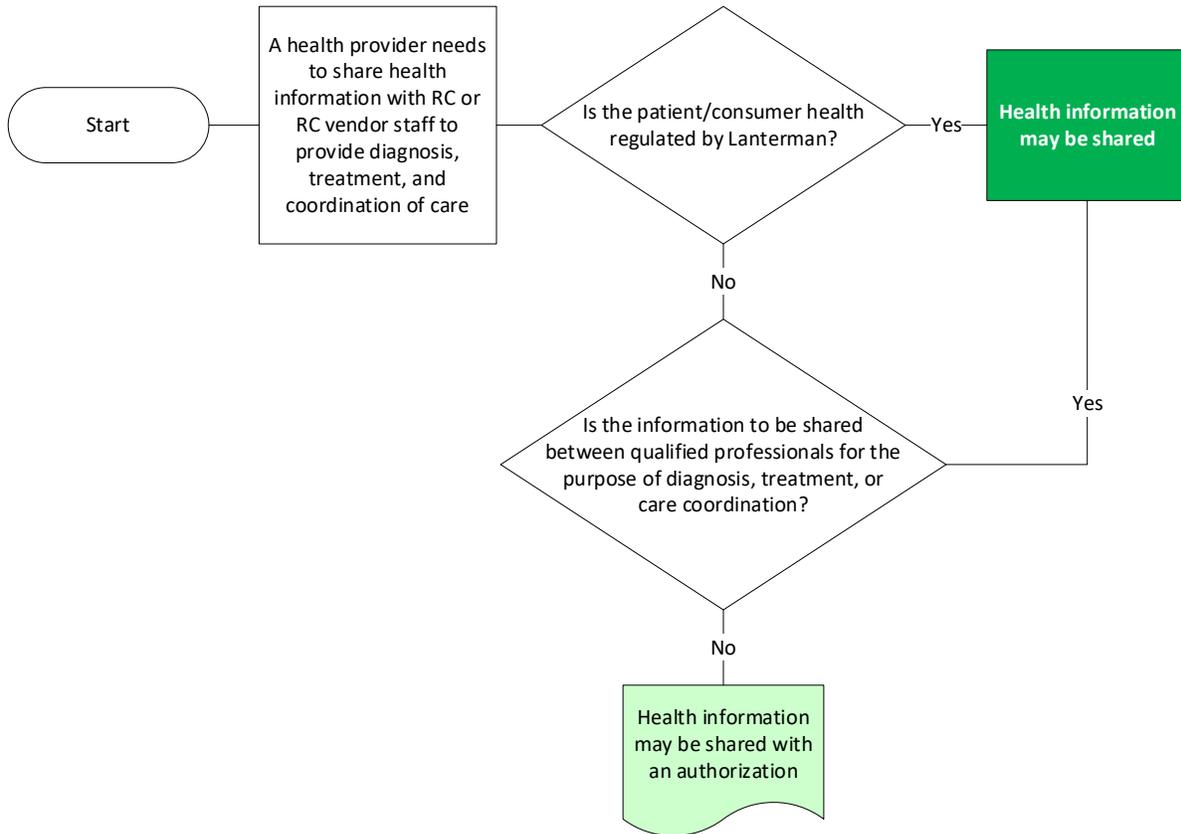
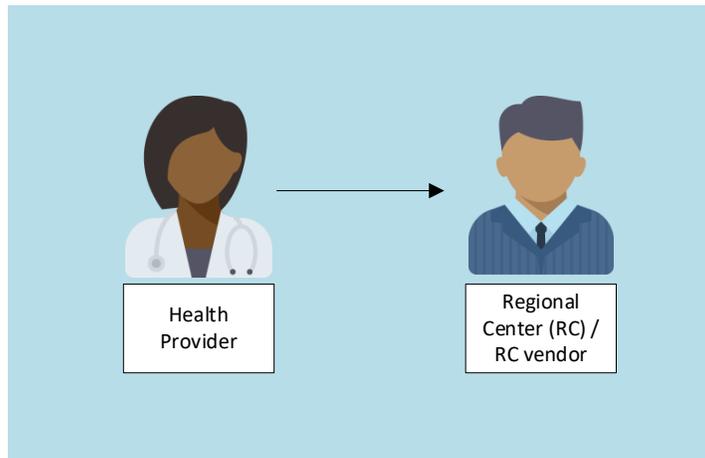
Health information sharing from a health provider to a RC or RC vendor is regulated by the Health Insurance Portability and Accountability Act (HIPAA), the Confidentiality of Medical Information Act (CMIA), and/or the Lanterman Developmental Disabilities Services Act (Lanterman).

What patient/consumer health information can a health provider share with a RC or RC vendor?

Important Scenario Guidance Assumptions:

- There is no patient/consumer or [patient’s/consumer’s representative authorization](#)
- There is no medical [emergency](#)
- There is no court order
- Organizations participating in this information exchange are not subject to California Consumer Privacy Act

Graphic – Health Provider to Regional Center / Regional Center Vendor



Scenario Guidance – Health Provider to Regional Center / Regional Center Vendor

HIPAA and CMIA permit health providers, who are not regulated by Lanterman, to [disclose](#) patient/consumer health information to an RC or RC vendor for diagnosis, treatment, or care coordination.

[45 C.F.R. § 164.506; Cal. Civ. Code § 56.10(c)(1).]

Lanterman allows sharing of health information between [qualified professional persons](#), to provide intake, assessment, health services or appropriate referrals.

[45 C.F.R. § 164.506; Cal. Welf. & Inst. Code § 4514(a).]

Note: If Lanterman regulates the information, CMIA does not.

[Cal. Civ. Code § 56.30.]

For health provider sharing health information with RC or RC vendor staff circumstances/situations not covered by this scenario, a valid patient/consumer or patient's/consumer's representative authorization may be needed to share the patient's/consumer's information.

[45 C.F.R. § 164.508; Cal. Civ. Code § 56.11; Cal. Welf. & Inst. Code § 4515.]

Citations and Related Guidance

- 45 C.F.R. § 164.506.
- 45 C.F.R. § 164.508.
- Cal. Civ. Code § 56.10(c)(1).
- Cal. Civ. Code § 56.11.
- Cal. Civ. Code § 56.30.
- Cal. Welf. & Inst. Code § 4514(a).
- Cal. Welf. & Inst. Code § 4515.

Scenario 5 – Behavioral Health Provider to Regional Center / Regional Center Vendor – Mental Health Information

Description

Some individuals have a dual diagnosis of [intellectual and/or developmental disabilities](#) and mental illness. [Behavioral health](#) providers may refer a [patient/consumer](#) to a [Regional Center](#) (RC) or [Regional Center Vendor](#) (RC vendor) for [eligibility assessment](#). Behavioral health providers might be asked by a RC or RC vendor for [health information](#) for [treatment](#) purposes.

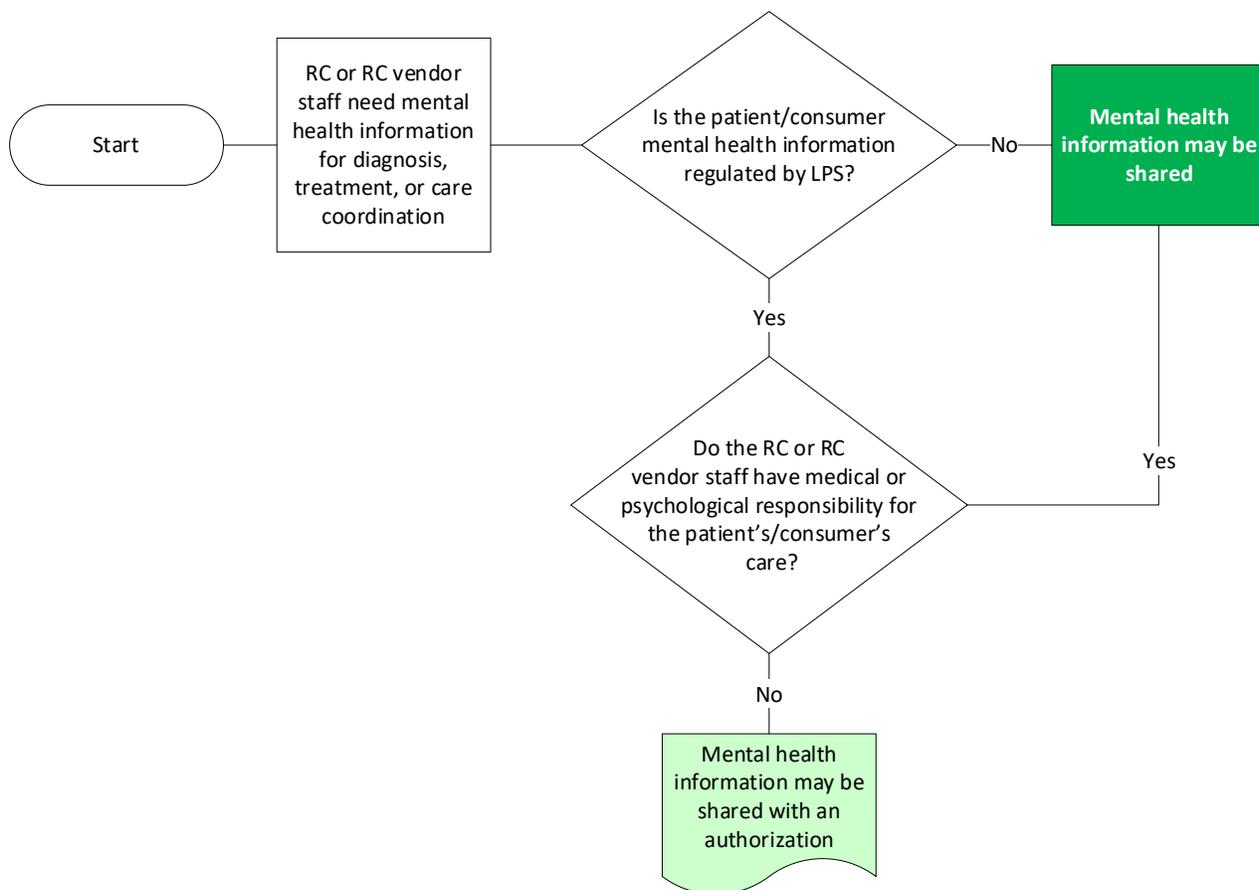
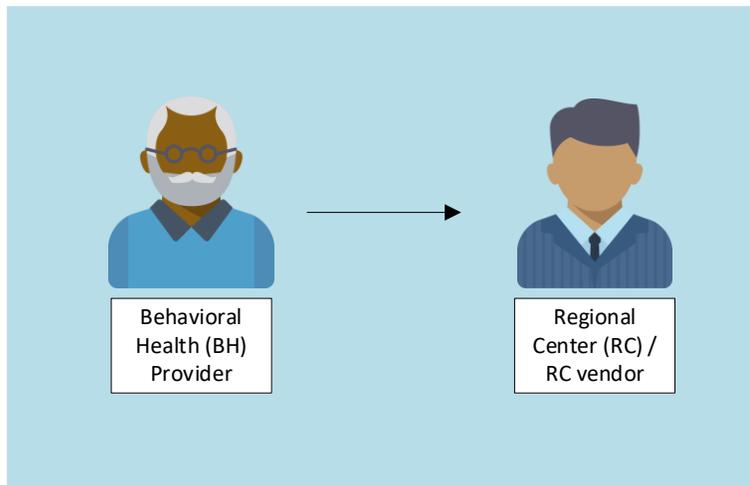
Health information that may be [disclosed](#) by a behavioral health provider to a RC or RC vendor depends on whether the health information is regulated by the Health Insurance Portability and Accountability Act (HIPAA), the Lanterman Developmental Disabilities Act (Lanterman), the Lanterman-Petris-Short Act (LPS), or the Confidentiality of Medical Information Act (CMIA).

What patient/consumer [mental health information](#) can a behavioral health provider share with a RC or RC vendor?

Important Scenario Guidance Assumptions:

- There is no patient/consumer or [patient's/consumer's representative authorization](#)
- There is no medical [emergency](#)
- There is no court order
- Organizations participating in this information exchange are not subject to California Consumer Privacy Act
- The receiving entity at the RC or RC vendor is a [health provider](#)

Graphic – Behavioral Health Provider to Regional Center / Regional Center Vendor – Mental Health Information



Scenario Guidance – Behavioral Health Provider to Regional Center / Regional Center Vendor – Mental Health Information

A behavioral health provider may need to share [mental health information](#) with RC or RC vendor staff for diagnosis, treatment, or care coordination purposes. LPS regulates mental health information when obtained in the course of providing services to involuntarily admitted patients/consumers of behavioral health services.

Note: When LPS applies, the Confidentiality of Medical Information Act (CMIA) does not. *[Cal. Civ. Code § 56.30.]*

CAUTION! In some cases, both LPS and Lanterman can apply. This is likely to occur if there is a patient/consumer residing in a county [Psychiatric Health Facility](#) (PHF) who is receiving both intellectual and/or developmental disability and mental health services. In these cases, the health provider must meet an exception under both LPS and Lanterman to share the health information.

When the patient/consumer health information is regulated by LPS and HIPAA, the behavioral health provider may disclose mental health information as follows:

- The RC or RC vendor are [qualified professional persons](#) providing diagnosis, treatment, or care coordination services in the same facility as the mental health provider. *[45 C.F.R. § 164.506; Cal. Welf. & Inst. Code § 5328(a)(1).]*
- The RC or RC vendor have responsibility for the patient’s/consumer’s medical or psychological care. The information may include prescribed psychotropic medications, diagnosis and treatment information, and programs/services utilized (such as discharge plans for the physical health provider). If the RC or RC vendor does not have medical or psychological responsibilities for the patient/consumer, then LPS-regulated mental health information can be shared with a valid patient/consumer or patient’s/consumer’s representative authorization. *[45 C.F.R. § 164.506; Cal. Welf. & Inst. Code § 5328(a)(1).]*

If the health provider is not subject to LPS, then CMIA applies. Generally, CMIA does not treat [behavioral health information](#) for people living with an intellectual and/or developmental disability any differently than other medical information. A behavioral health provider may disclose patient/consumer behavioral health information to other healthcare professionals for purposes of diagnosis or treatment of the patient/consumer. *[45 C.F.R. § 164.506; Cal. Civil Code §§ 56.10(c)(1), 56.104.]*

For health provider sharing health information with RC or RC vendor staff circumstances/situations not covered by this scenario, a valid patient/consumer authorization may be needed to share the patient's/consumer's information.

[45 C.F.R. § 164.508; Cal. Civ. Code § 56.11.]

Behavioral health providers should refer to *SHIG Volume 1 – Sharing Behavioral Health Information in California*⁶ for additional guidance regarding the sharing of mental health or substance use disorder [patient-identifying information](#), as there are generally more stringent [privacy](#) protections.

Note: For health information sharing guidance for non-behavioral health providers, refer to the [Scenario 7 - Health Provider to Health Provider](#).

Citations and Related Guidance

- 45 C.F.R. §164.506.
- 45 C.F.R § 164.508.
- Cal. Civ. Code § 56.10(c)(1).
- Cal. Civ. Code § 56.11.
- Cal. Civ. Code § 56.30.
- Cal. Civ. Code § 56.104.
- Cal. Welf. & Inst. Code § 5328(a)(1).

⁶ SHIG Volume 1 – Sharing Behavioral Health Information in California can be found at: <https://www.cdii.ca.gov/compliance-and-policy/state-health-information-guidance-shig/>

Scenario 6 – Behavioral Health Provider to Regional Center / Regional Center Vendor – Substance Use Disorder Information

Description

[Regional Centers](#) (RCs) and [Regional Center Vendors](#) (RC vendors) often serve individuals with [behavioral health](#) substance use disorders (SUD) in addition to an [intellectual and/or developmental disability](#) and need [patient/consumer health information](#) to coordinate services and supports and for [treatment](#) purposes. For example, to support discharge planning or multi-disciplinary coordination of care, an RC or RC vendor may request a behavioral [health provider](#) (e.g., medical social worker, addiction specialist, physician providing Medication Assisted Treatment) to share patient/consumer health information.

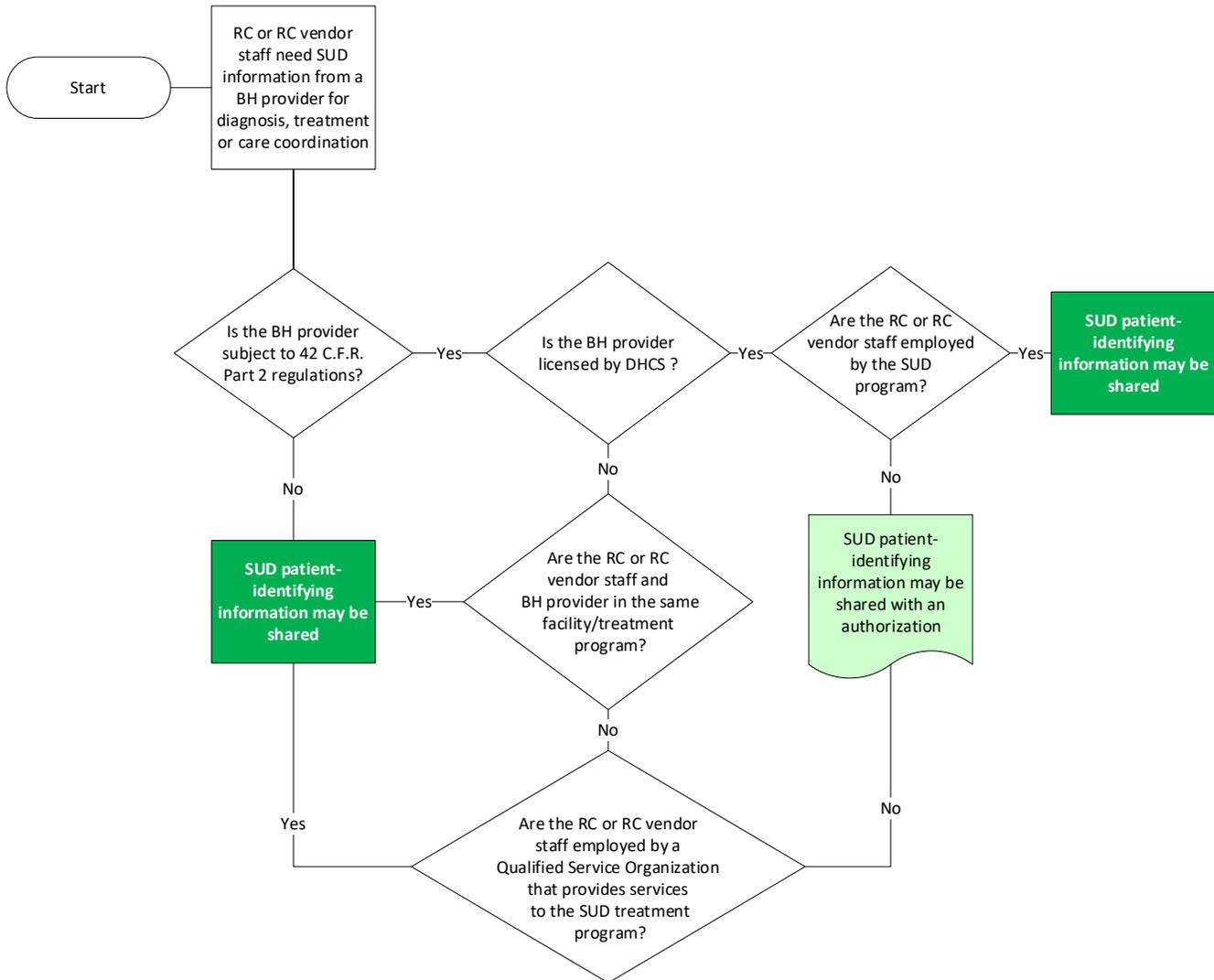
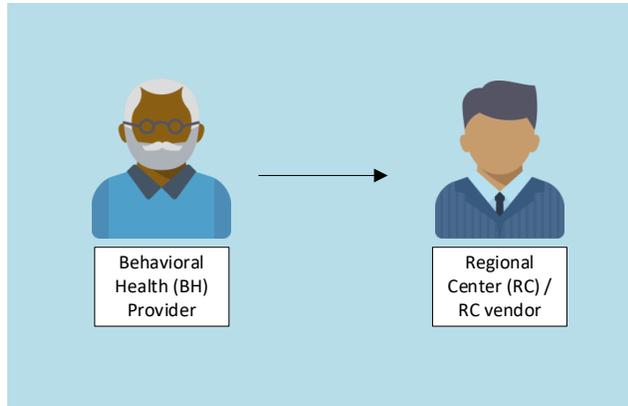
SUD [behavioral health information](#) that may be [disclosed](#) by a behavioral health provider to a RC or RC vendor depends on whether the health information is regulated by the Health Insurance Portability and Accountability Act (HIPAA), 42 C.F.R. Part 2, California Health and Safety Code section 11845.5, or the Confidentiality of Medical Information Act (CMIA).

What patient/consumer health information can a behavioral health provider share with a RC or RC vendor?

Important Scenario Guidance Assumptions:

- There is no patient/consumer or [patient's/consumer's representative authorization](#)
- There is no medical [emergency](#)
- There is no court order
- Organizations participating in this information exchange are not subject to California Consumer Privacy Act

Graphic – Behavioral Health Provider to Regional Center / Regional Center Vendor - Substance Use Disorder Information



Scenario Guidance – Behavioral Health Provider to Regional Center / Regional Center Vendor – Substance Use Disorder Information

Substance use disorder (SUD) [patient-identifying information](#) is specially protected under federal and state law. Federal and state law prohibits most disclosures of patient/consumer information that identify an individual as having a SUD, or as a participant in a covered SUD program. Without patient/consumer authorization, disclosure is strictly regulated for any patient/consumer health information that identifies an individual directly or indirectly as having a current or past drug or alcohol problem.

Despite the restrictions, a SUD treatment provider may disclose SUD patient-identifying information to RC staff without a patient/consumer authorization if any of the following criteria are met:

- When the patient/consumer health information is regulated by 42 C.F.R. Part 2 and Health and Safety Code section 11845.5, the RC or RC vendor may receive health information when they are a [qualified professional person](#) working *in the same facility or treatment program* as the SUD treatment provider. As long as the SUD patient-identifying information is shared within the same facility/treatment program for diagnosis, treatment, or care coordination, the sharing of SUD health information from a behavioral health provider is allowed.
[42 C.F.R. § 2.12(c)(3); 45 C.F.R. § 164.506; Cal. Health & Safety Code § 11845.5(c)(1).]
- If the SUD treatment facility is not licensed by Department of Health Care Services (DHCS), CMIA applies and health information may be shared with the RC or RC vendor staff who are employed by a [qualified service organization](#) (QSO) to arrange for medical assistance, or directly provide follow-up care to the SUD program’s patient/consumer. The QSO must have an appropriate written agreement in effect with the program as defined in the 42 C.F.R. Part 2 regulations. A QSO may not re-disclose SUD patient-identifying information without an authorization.
[42 C.F.R. § 2.12(c)(3); 45 C.F.R. § 164.506; Cal. Civil Code § 56.10(c)(1).]

For behavioral health provider to RC or RC vendor staff circumstances/situations not covered by this scenario, a valid patient/consumer authorization may be needed to share the patient’s/consumer’s information, unless otherwise permitted or required by law.

[42 C.F.R. § 2.31; 45 C.F.R. § 164.508; Cal. Civ. Code § 56.11; Cal. Health & Safety Code § 11845.5.]

Behavioral health providers should refer to *SHIG Volume 1 – Sharing Behavioral Health Information in California* for additional guidance regarding the sharing of mental health or substance use disorder patient-identifying information, as there are generally more stringent [privacy](#) protections.

Note: For health information sharing guidance for non-behavioral health providers, refer to the [Scenario 7 - Health Provider to Health Provider](#).

Citations and Related Guidance

- 42 C.F.R. § 2.12.
- 42 C.F.R § 2.31.
- 45 C.F.R. § 164.506.
- 45 C.F.R. § 164.508.
- Cal. Civ. Code § 56.10(c)(1).
- Cal. Civ. Code § 56.11.
- Cal. Health & Safety Code § 11845.5.

Scenario 7 – Health Provider to Health Provider

Description

To provide effective [treatment](#) and coordination of care for a [patient/consumer](#) living with [intellectual and/or developmental disabilities](#), a [health provider](#) needs patient/consumer [health information](#) from a second health provider.

Generally, a health provider may [disclose](#) health information to another health provider for treatment purposes – for example, this could include:

- Primary Care Physician needs test results regarding a patient/consumer from a laboratory, or wants to know what services their patient/consumer has received from a specialist
- Nurse Case Manager or Medical Social Worker needs health information from a physician about a patient/consumer for coordination of care

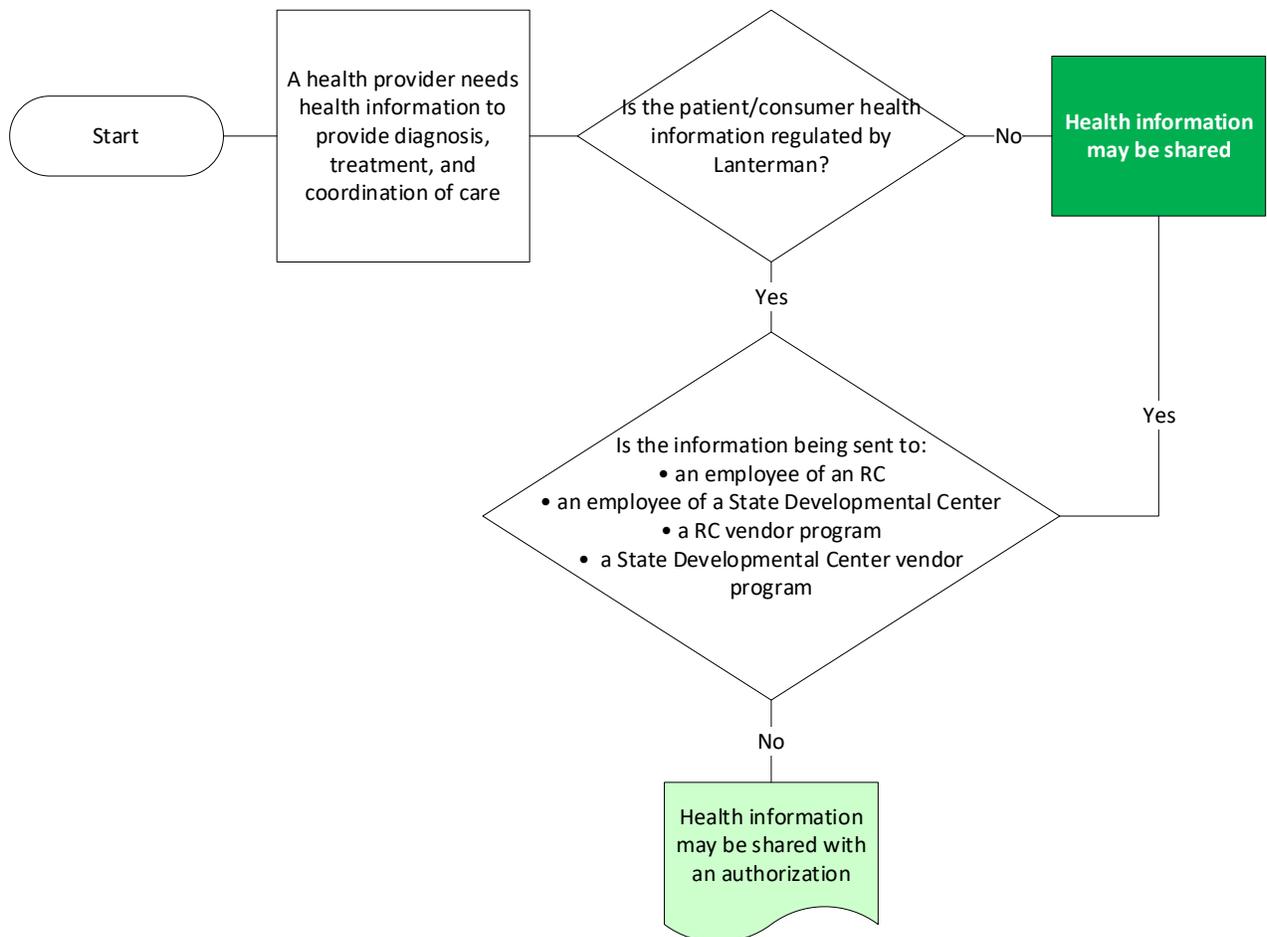
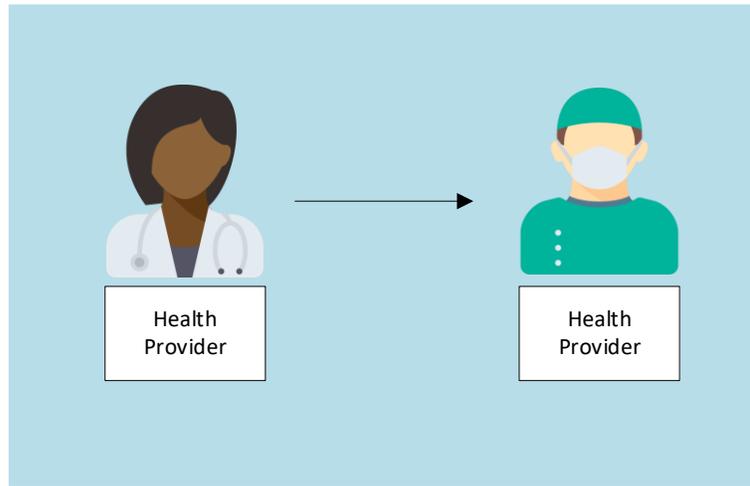
The extent that health information can be shared between health providers is regulated by the Health Insurance Portability and Accountability Act (HIPAA), the California Confidentiality of Medical Information Act (CMIA), and/or the Lanterman Developmental Disabilities Services Act (Lanterman).

What patient/consumer health information can a health provider share with another health provider?

Important Scenario Guidance Assumptions:

- There is no patient/consumer or [patient's/consumer's representative authorization](#)
- There is no medical [emergency](#)
- There is no court order
- Organizations participating in this information exchange are not subject to California Consumer Privacy Act

Graphic – Health Provider to Health Provider



Scenario Guidance – Health Provider to Health Provider

Health providers covered by HIPAA and/or CMIA may generally disclose patient/consumer health information to another health provider for diagnosis, treatment and care coordination (including referrals).

[45 C.F.R. § 164.506; Cal. Civ. Code § 56.10(c)(1).]

Health providers subject to Lanterman, may share health information for diagnosis, treatment, services, or referrals with other health providers. However, patient/consumer authorization must be obtained when the information is shared from a [Regional Center](#) (RC) to:

- a health provider who is not employed by a RC;
- a health provider who is not employed by a State Developmental Center;
- a health care program that is not administered by a RC vendor; or
- a health care program that is not administered by a State Developmental Center.

Note that patient/consumer authorization is not required when information is shared from a RC health provider to a health provider who is providing health care as part of a program by a RC, RC vendor, or State Developmental Center. Health providers subject to Lanterman include health providers working in a RC or RC vendor facility, health providers contracted to work with a RC or RC vendor, and county [psychiatric health facilities](#) (PHF) when providing developmental disability services.

[45 C.F.R. § 164.506; Cal. Welf. & Inst. Code § 4514(a).]

For health provider sharing health information with another health provider circumstances/situations not covered by this scenario, a valid patient/consumer authorization may be needed to share the patient's/consumer's health information.

[45 C.F.R. § 164.508; Cal. Civ. Code § 56.11; Cal. Welf. & Inst. Code § 4515.]

Note: For health information sharing guidance specific to behavioral health providers, refer to [Scenario 5 - Behavioral Health Provider to Regional Center / Regional Center Vendor – Mental Health Information](#), [Scenario 6 - Behavioral Health Provider to Regional Center / Regional Center Vendor – Substance Use Disorder Information](#) and/or *SHIG Volume 1 – Sharing Behavioral Health Information in California*.

Citations and Related Guidance

- 45 C.F.R. § 164.506.
- 45 C.F.R. § 164.508.
- Cal. Civ. Code § 56.10(c)(1).
- Cal. Civ. Code § 56.11.
- Cal. Welf. & Inst. Code § 4514(a).
- Cal. Welf. & Inst. Code § 4515.

Concluding Thoughts

In conclusion, the State of California recognizes the value of sharing health information when legally permissible and in the interests of the patient. Such sharing improves coordination of care and health outcomes that benefits the patient. In the current complex regulatory environment, the State recognizes it can be challenging for health providers; community-based organizations; public health departments; and other entities to understand when sharing patient health information as well as other personal information is permissible.

The State developed this State Health Information Guidance (SHIG) to help clarify conditions when health information may be shared without a signed release form and when disclosures are permitted with a signed release form.

As the California healthcare landscape continues to evolve and coordination of care for patients continues to rise, the State's intent is to support health providers by clarifying federal and state law. As a result, the State wishes to contribute to the dialogue taking place among stakeholders through this authoritative guidance so that patient-centric care solutions can continue to be developed.

Direct any questions or requests for additional information associated with this publication to:

California Center for Data Insights and Innovation (CDII)

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Sacramento, CA 95814

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Appendix 1 – SHIG Participants

SHIG Stakeholder Sessions – Participants

The following organizations participated in two (2) State Health Information Guidance (SHIG) Stakeholder Sessions held virtually in November 2020. The purpose of these sessions was to explain the project, discuss barriers to information exchange, and to solicit input on possible topics for the SHIG:

- ALTA California Regional Center
- California Department of Developmental Services
- California Department of Rehabilitation
- Orange County Health Care Agency
- East Los Angeles Regional Center
- Sacramento LGBT Community Center

SHIG Advisory Committee Members

Advisory Committee members reviewed SHIG materials as they were developed and provided input/insight on SHIG content. Advisory Committee members include the following individuals and organizations.

Name	Title	Organization Name
Robin Black	Legal Services Manager	ALTA California Regional Center
Cindy Chiu, M.S., C.R.C.	Assistant Deputy Director, Vocational Rehabilitation Policy & Resources Division	California Department of Rehabilitation
Leslie Morrison	Division Chief, Office of Quality Assurance and Risk Management	California Department of Developmental Services
Judy Perez	Supervisor, Family Services Unit	East Los Angeles Regional Center
Lois Richardson	Vice President, Legal Counsel	California Hospital Association
Dawn Smith	Division Manager, Children and Youth Behavioral Health	Orange County Health Care Agency
Lee Tien	Senior Staff Attorney	Electronic Frontier Foundation

SHIG Development Contributors

Under the direction of the Center for Data Insights and Innovation (CDII) and the SHIG Advisory Committee, the following individuals contributed significantly to the development of the SHIG publication.

SHIG Volume 4.1 – Publication in 2023

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CDII and the SHIG Advisory Committee greatly appreciate the services of individuals and organizations who also contributed to the development of the SHIG by consulting with the development team and/or reviewing sections of the document.

Name	Title	Organization Name
Carrie Kurtural	Privacy Officer and Attorney IV	California Department of Developmental Services
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Appendix 2 – Patient/Consumer Authorization or Consent

Although State of California statutes provide special protections for people living with [intellectual and/or developmental disabilities](#), they also provide flexibility for [disclosing](#) and sharing the [health information](#) with a [patient/consumer authorization](#). If a patient/consumer has the [capacity](#) to provide explicit or implicit consent or instruction, they generally have the right to authorize to whom his or her [behavioral health](#) and general medical information can be disclosed. A legally competent adult patient/consumer may provide permission for a provider or organization to share their personal health information, including developmental services information, [mental health information](#), and substance use disorder (SUD) [patient-identifying information](#), for a wide range of purposes, including [treatment](#), coordination of care and social services. [Health providers](#) are encouraged to discuss with patients/consumers why some forms of sharing might be in the patient's/consumer's best interests. Informed disclosure decisions by patients/consumers may be beneficial to the therapeutic relationship.

As defined by health information [privacy](#) laws, a provider generally has responsibility to act on a patient's/consumer's decision to authorize or not authorize disclosure of their health information. In some situations, questions may arise concerning whether the patient/consumer has the capacity to provide consent and if not, who is able to give informed consent for those individuals. Providers should seek legal counsel in such situations.

Depending upon the type of patient/consumer health information being released, written consent or authorization form requirements differ by law. The Health Insurance Portability and Accountability Act (HIPAA), Lanterman-Petris-Short Act (LPS), Health and Safety Code section 11845.5, Confidentiality of Medical Information Act (CMIA), the Lanterman Developmental Disabilities Services Act (Lanterman), and 42 C.F.R. Part 2 each define required (but not identical) elements of a consent form. The requirements for a compliant authorization form from each statute or regulation are described below. Keep in mind, valid authorizations must include HIPAA as well as the requirements associated with CMIA-, LPS-, Lanterman-, or SUD-regulated entities.

Authorizations or releases for the disclosure of health information require: that an individual have the opportunity to refuse to sign the authorization; notification to individuals that signing the authorization is not a condition of eligibility or treatment; and notification to individuals that their refusal to sign the form will not affect their eligibility or treatment. While not legally required, the State suggests including these statements on the forms themselves to document that these notifications took place.

Form Requirements

HIPAA Authorization Form Requirements

The core elements of a valid Health Insurance Portability and Accountability Act (HIPAA) authorization must include:

- Meaningful description of the information to be disclosed
- Name of the person or entity authorized to make the disclosure
- Name of the person/class of persons/entity who receives the information
- Description of the purpose of the disclosure
- Expiration date or an expiration event that relates to the individual
- Signature of the patient/consumer or [patient's/consumer's representative \(along with a description of each representative's authority to sign on behalf of the patient\)](#)

In addition, the authorization must include the following statements:

- The Notice of Privacy Practices provides instructions for me should I choose to revoke my authorization and includes limitations on my revocation.
- Treatment, payment, enrollment or eligibility for benefits will not be affected if the authorization is not signed
- If the organization or person I have authorized to receive the information is not a health plan or health care provider; the released information may no longer be protected by federal privacy regulations

[45 C.F.R. § 164.508(c).]

CMIA-Regulated Authorization Form Requirements

When a patient/consumer or patient's/consumer's representative authorization for a disclosure of mental health information is required for a Confidentiality of Medical Information Act (CMIA)-regulated entity, the form must include the Health Insurance Portability and Accountability Act (HIPAA) core elements (above) as well as the following (where different):

- No smaller than 14-point type
- Signed and dated by the patient/consumer or patient's/consumer's representative, or spouse, or beneficiary/personal representative of a deceased person
- Specific uses and limitations on the types of medical information to be disclosed
- Name or functions of providers of healthcare, healthcare service plan, contractor, or pharmaceutical company that may disclose information
- Name or functions of persons or entities authorized to receive medical information

- Specific uses and limitations on the use of the medical information by persons or entities authorized to receive the information
- Specific date after which the authorization is no longer valid
- Advises person signing of their right to receive a copy of the authorization

[Cal. Civ. Code § 56.11.]

The Lanterman Act Release Form Requirements

A release for authorization, signed by the individual living with an intellectual and/or developmental disability or patient's/consumer's representative is required for each separate use. When a patient/consumer or patient's/consumer's representative authorization for a disclosure of health information is required for a Lanterman-regulated entity, the form must include the Health Insurance Portability and Accountability Act (HIPAA) core elements (above) as well as the following (where different):

The release form must include:

- Name of the individual and/or other person who is authorizing the disclosure
- Purpose of the disclosure
- Information to be released
- Name of the agency or individual to whom information will be released
- Signed by the patient/consumer or patient's/consumer's representative

Any use of an authorization form must be noted in the record of the person living with intellectual and/or developmental disabilities. The individual who signs consent forms must be given a copy of the consent forms signed.

[Cal. Welf. & Inst. Code § 4515.]

LPS-Regulated Authorization Form Requirements

When a patient/consumer or patient's/consumer's representative authorization for a disclosure of health information is required for a LPS-regulated entity, the form must include the Health Insurance Portability and Accountability Act (HIPAA) core elements (above) as well as the following (where different), and is required for each separate use:

- Purpose of the disclosure
- Information to be released
- Name of the agency or individual to whom information will be released

- Name of the responsible individual at the mental health facility who has authorization to release the information requested
- Signed by the patient/consumer or patient's/consumer's representative

[Cal. Welf. & Inst. Code § 5328.7.]

Any use of an authorization form must be noted in the record of the person living with intellectual and/or developmental disabilities. The individual who signs consent forms must be given a copy of the consent forms signed.

[Cal. Welf. & Inst. Code § 4515.]

Substance Use Disorder (SUD) and Health & Safety Code Regulated Authorization Form Requirements

When a patient/consumer or patient's/consumer's representative authorization for a disclosure of substance use disorder (SUD) patient-identifying information is required for a 42 C.F.R. Part 2 regulated entity licensed by the California Department of Health Care Services (DHCS), the form must include the Health Insurance Portability and Accountability Act (HIPAA) core elements (above) as well as the following elements (where different):

- Name of the patient/consumer
- Specific name or entity making the disclosure
- Name of the person or entity who receives the information
- Purpose of the disclosure
- How much and what kind of information will be released, including an explicit description of the substance use disorder information that may be disclosed
- Indicate that the patient/consumer understands they may revoke the authorization at any time, orally or in writing, unless authorization has already been relied upon
- Date, event, or condition upon which the authorization expires, if not revoked earlier
- Date the authorization form was signed
- Signature of the patient/consumer or their representative

[42 C.F.R. §§ 2.31, 2.33; Cal. Health & Safety Code § 11845.5.]

Appendix 3 – Summary of Privacy Laws

Due to the complex nature of [privacy](#) laws, State Health Information Guidance (SHIG) users should review and consult the materials in this section with your legal counsel.

Federal

Health Insurance Portability and Accountability Act (HIPAA)

HIPAA describes privacy, [security](#), [patient/consumer](#) rights, and healthcare transactions requirements for healthcare entities. Sets restrictions on access, use, and [disclosure](#).

Item	Information
Citation(s)	45 C.F.R. Parts 160 and 164.
Who is Covered?	Covered Entities : 1) health plans ; 2) healthcare clearing houses; and 3) health providers conducting certain healthcare transactions electronically. Business Associates of a Covered Entity.
What information is covered?	Protected Health Information (PHI)*: all "individually identifiable health information " held or transmitted by a Covered Entity or its Business Associate, in any form or media, whether electronic, paper, or oral. *Exempts educational records covered by the Family Educational Rights and Family Act (FERPA).
Patient/Consumer breach notification requirement?	YES
Patient/Consumer access requirement?	YES
Patient/Consumer amend/correct requirement?	YES
Limitations on disclosure?	YES
Respond to a subpoena?	YES
Private right of action?	NO

Liability for violation	Fines levied by federal oversight (Health and Human Services, Office for Civil Rights).
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Substance Use Disorder (SUD)

42 C.F.R. Part 2 sets restrictions on access, use, and disclosure.

Item	Information
Citation(s)	42 C.F.R. Part 2.
Who is Covered?	Federally assisted substance use disorder (SUD) treatment programs that meet the definition of a Program.
What information is covered?	Information that would identify a patient/consumer as having a SUD and allow very limited disclosures of health information without patient/consumer authorization .
Patient/Consumer breach notification requirement?	NO
Patient/Consumer access requirement?	YES
Patient/Consumer amend/correct requirement?	NO
Limitations on disclosure?	YES
Respond to a subpoena?	NO
Private right of action?	YES
Liability for violation	<ul style="list-style-type: none"> • Entity Liability • Criminal Liability

State of California

Information Practices Act (IPA)

The IPA sets limitations on collection and retention of data. Describes individual rights requirements. Sets restrictions on access, use, and disclosure.

Item	Information
Citation(s)	Cal. Civ. Code § 1798 et seq.
Who is Covered?	State agencies, departments, offices, officers, etc.
What information is covered?	Personal Information: any information that is maintained by an agency that identifies or describes an individual.
Patient/Consumer breach notification requirement?	YES
Patient/Consumer access requirement?	YES
Patient/Consumer amend/correct requirement?	YES
Limitations on disclosure?	YES
Respond to a subpoena?	YES
Private right of action?	YES
Liability for violation	<ul style="list-style-type: none"> • Entity liability • Personal liability (potential job loss)

Confidentiality of Medical Information Act (CMIA)

The CMIA sets restrictions on access, use, and disclosure.

<i>Item</i>	<i>Information</i>
Citation(s)	Cal. Civ. Code § 56 et seq.
Who is Covered?	Health providers, health plans, and their contractors.
What information is covered?	Medical information ⁷
Patient/Consumer breach notification requirement?	Refer to Health Facilities and Data Breach
Patient/Consumer access requirement?	YES
Patient/Consumer amend/correct requirement?	NO
Limitations on disclosure?	YES
Respond to a subpoena?	YES
Private right of action?	YES
Liability for violation	Entity liability

⁷ Note, while CMIA covers privacy of most health information, it does not cover all. Health information covered by Cal. Welf. & Inst. Code sections 4514 and 5328 et seq., 42 C.F.R. Part 2, and Cal. Health & Safety Code section 11845.5 are not covered by CMIA.

California Consumer Privacy Act (CCPA)

The CCPA describes individual rights and sets restrictions on access, use, and disclosure.

Item	Information
Citation(s)	Cal. Civ. Code § 1798.100 et seq.
Who is Covered?	For-profit businesses* that collect personal information and meet certain threshold requirements for annual revenue or number of individuals of whom they receive, buy, sell, or share personal information. *Exempts health providers covered by the Health Insurance Portability and Accountability Act (HIPAA) or the Confidentiality of Medical Information Act (CMIA).
What information is covered?	Personal Information*: information that identifies, relates to, describes, is reasonably capable of being associated with, or could reasonably be linked, directly or indirectly, with a particular individual or household. *Exempts data covered by HIPAA or the CMIA.
Patient/Consumer breach notification requirement?	NO
Patient/Consumer access requirement?	YES
Patient/Consumer amend/correct requirement?	NO
Limitations on disclosure?	YES
Respond to a subpoena?	YES
Private right of action?	YES
Liability for violation	<ul style="list-style-type: none"> • Entity liability • Injunctive or declaratory relief

Patient Access to Health Records Act (PAHRA)

The PAHRA describes a [patient's/consumer's](#) right of access or denial of access to [health information](#).

<i>Item</i>	<i>Information</i>
Citation(s)	Cal. Health & Safety Code §§ 123100 – 123149.5.
Who is Covered?	Health providers
What information is covered?	Medical records
Patient/Consumer breach notification requirement?	NO
Patient/Consumer access requirement?	YES
Patient/Consumer amend/correct requirement?	NO; however, a patient/consumer has the right to add a written addendum to the record.
Limitations on disclosure?	NO
Respond to a subpoena?	
Private right of action?	YES
Liability for violation	Entity liability

Lanterman-Petris-Short Act (LPS) – Mental Health

LPS describes privacy requirements and sets restrictions on access, use, and disclosure.

<i>Item</i>	<i>Information</i>
Citation(s)	Cal. Welf. & Inst. Code § 5328 et seq.
Who is Covered?	Generally, county or city mental health departments, State hospitals, or other public or private entities (such as community mental health clinics).
What information is covered?	Information and records obtained in the course of providing services to involuntary, and some voluntary, patients/consumers of services are confidential and specially protected under the Lanterman-Petris-Short Act (LPS).
Patient/Consumer breach notification requirement?	NO
Patient/Consumer access requirement?	NO
Patient/Consumer amend/correct requirement?	NO
Limitations on disclosure?	YES
Respond to a subpoena?	NO
Private right of action?	YES
Liability for violation	<ul style="list-style-type: none"> • Entity liability • Personal liability

Lanterman Developmental Disabilities Services Act (Lanterman) – Intellectual and/or Developmental Disabilities

Lanterman sets restrictions on access, use, and disclosure.

Item	Information
Citation(s)	Cal. Welf. & Inst. Code § 4514.
Who is Covered?	California Department of Developmental Services (DDS), Regional Centers under contract with the DDS, Regional Center Vendors , and service providers.
What information is covered?	All information and records obtained in the course of providing intake, assessment, and services for persons living with intellectual and/or developmental disabilities .
Patient/Consumer breach notification requirement?	NO
Patient/Consumer access requirement?	NO
Patient/Consumer amend/correct requirement?	NO
Limitations on disclosure?	YES
Respond to a subpoena?	NO
Private right of action?	YES
Liability for violation	<ul style="list-style-type: none"> • Entity liability • Personal liability

California Substance Use Disorder Records – SUD

California SUD sets restrictions on access, use, and disclosure.

<i>Item</i>	<i>Information</i>
Citation(s)	Cal. Health & Safety Code § 11845.5.
Who is Covered?	Entities that are licensed by the California Department of Health Care Services (DHCS) in connection with substance use disorder (SUD) diagnosis and treatment.
What information is covered?	Information that would identify a patient/consumer as having a SUD and allow very limited disclosures of information without patient/consumer authorization.
Patient/Consumer breach notification requirement?	NO
Patient/Consumer access requirement?	NO
Patient/Consumer amend/correct requirement?	NO
Limitations on disclosure?	YES
Respond to a subpoena?	NO
Private right of action?	NO
Liability for violation	

Health Facilities and Data Breach

Breach reporting requirement to licensing entity.

<i>Item</i>	<i>Information</i>
Citation(s)	Cal. Health & Safety Code § 1280.15.
Who is Covered?	A clinic, health facility, home health agency, or hospice licensed pursuant to Cal. Health & Safety Code sections 1204, 1250, 1725, or 1745.
What information is covered?	Medical information
Patient/Consumer breach notification requirement?	YES
Patient/Consumer access requirement?	NO
Patient/Consumer amend/correct requirement?	NO
Limitations on disclosure?	NO
Respond to a subpoena?	
Private right of action?	NO
Liability for violation	Fines levied by State oversight (California Department of Public Health)

Appendix 4 – Who is Subject to 42 C.F.R. Part 2 - Confidentiality of SUD Patient Records

In order to be subject to 42 C.F.R. Part 2, an entity or provider must be both [federally assisted](#) and meet the definition of a ‘program.’ The provider is a ‘program’ if it promotes itself as offering substance use disorder (SUD) services and provides or makes referrals for SUD services.

For-profit programs and private practitioners who only accept private insurance or self-pay patients are not subject to 42 C.F.R. Part 2 regulations except when licensed by the State of California as described in the next paragraph.

In California under Section 10568(c) of Title 9 of the California Code of Regulations, all information and records obtained from or regarding residents in Residential or Drug Abuse Recovery and Treatment facilities licensed by the California Department of Health Care Services (DHCS) shall be confidential and maintained in compliance with 42 C.F.R. Part 2.

Federally Qualified Health Centers licensed by the DHCS as an Alcoholism or Drug Abuse Recovery or Treatment Facility are also subject to 42 C.F.R. Part 2.

Am I Federally Assisted?

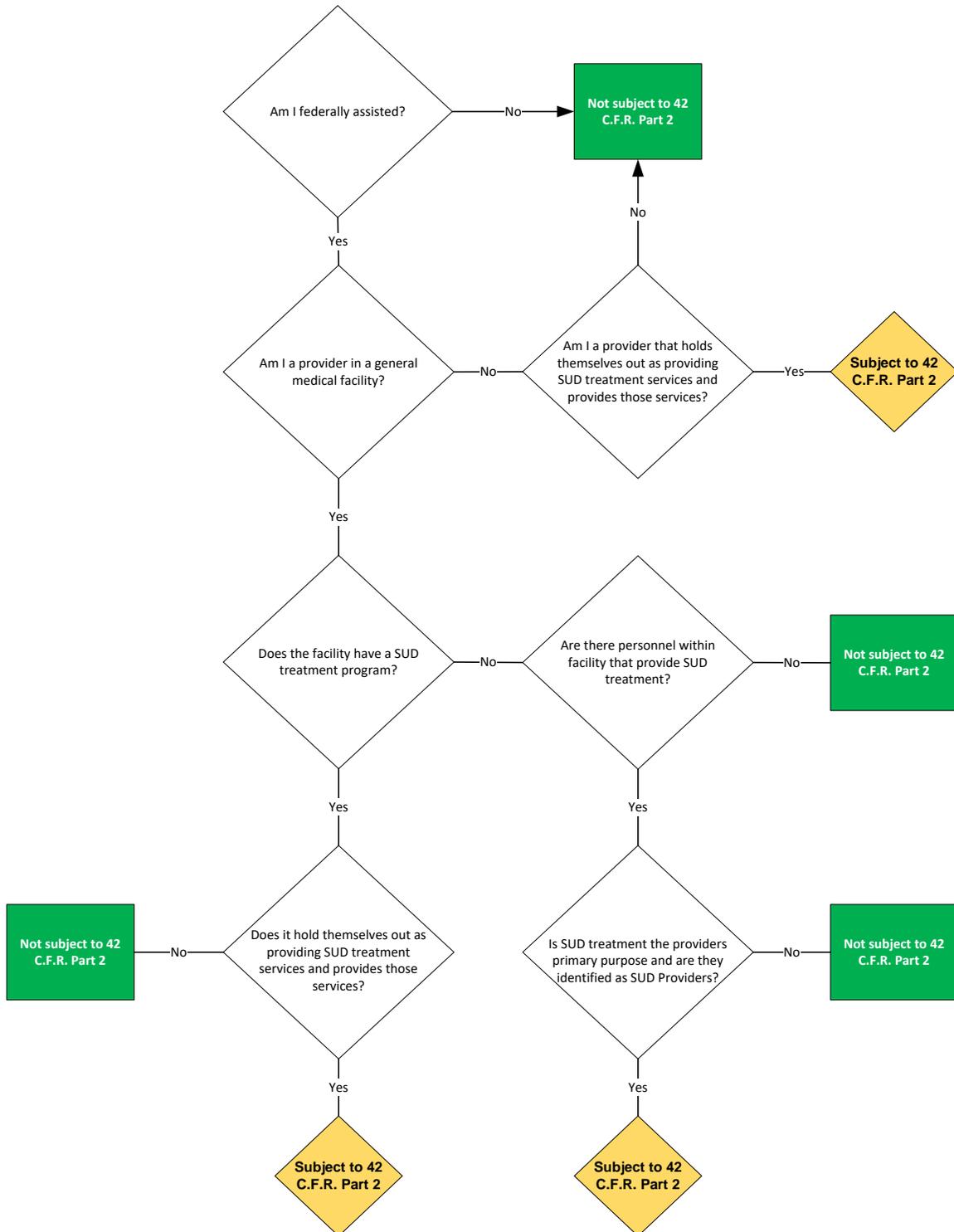
42 C.F.R. Part 2 regulations cover SUD [treatment](#) programs that are federally assisted in any of the following ways:

- The program is authorized to conduct business by any agency or department of the United States federal government.
- The program is licensed, certified, registered, or authorized by any department or agency of the United States including but not limited to:
 - Participating as a provider in the Medicare or Medicaid (Medi-Cal)⁸ program;
 - Authorized to conduct maintenance treatment or withdrawal management; or
 - Registered with the Drug Enforcement Agency to dispense a substance under the Controlled Substances Act to the extent the controlled substance is used in the treatment of a SUD.
- The program is supported by funds provided by any agency or department of the United States by being:
 - A recipient of federal financial assistance in any form, including financial assistance which does not directly pay for the SUD diagnosis, treatment, or referral for treatment; or
 - Conducted by a state or local government unit through revenue sharing or other forms of assistance, receives federal funds which could be but not necessarily spent for the SUD treatment program.
- The program is assisted by the Internal Revenue Service by being:
 - Allowed income tax deductions for contributions to the program; or
 - Granted tax exempt status.

[42 C.F.R. § 2.12(b).]

⁸ Medi-Cal is the State of California's Medicaid program.

Am I a 'Program' Under 42 C.F.R. Part 2



Appendix 5 – Additional Resources

The State Health Information Guidance (SHIG) volumes have been posted on the Center for Data Insights and Innovation (CDII) website⁹ as public resources. The online SHIG documents will be available for as long as the public and stakeholders find these documents useful.

Issues and Subjects Not Addressed in SHIG

The State Health Information Guidance (SHIG) Volume 4 only provides clarifications relating to [disclosure](#) and exchange of [health information](#) during specific [intellectual and/or developmental disability](#) information sharing scenarios. Additional health information sharing scenarios or [privacy](#) protection challenges outside of this use are not addressed. Fortunately, the SHIG is designed to be a virtual binder that can be expanded to include other topics. Should funding and resources become available, useful future topics for clarification could include, but are not limited to, any or all of the following:

- Information sharing when a [patient/consumer](#) may be unable to give informed consent due to [capacity](#) issues and no one else has the right to on their behalf
- Knowing if the patient/consumer is [conserved](#); conservatorship documentation is not readily available
- Understanding how the power of attorney limits the ability to disclose information
- Guidance on information sharing in circumstances when aging parents who are the legal guardians or [caregivers](#) of a patient/consumer may die or lose capacity themselves
- Patient/consumer and family refusal to share information
- Information sharing between members of multi-disciplinary teams
- Information sharing between Child and Family Teams
- Information sharing using a universal information sharing tool
- Technology or legacy information technology (IT) system updates
- Privacy and electronic records
- Electronic signatures

⁹ Refer to <https://www.cdii.ca.gov/compliance-and-policy/state-health-information-guidance-shig/>

Appendix 6 – Definitions

Term	Definition
Authorization	<p>A detailed document that gives an individual or organization permission to use and disclose health information for purposes specified in the authorization.</p> <p><i>[source: 7 C.F.R. § 246.26(d)(4); 7 C.F.R. § 272.1(c)(1)(iii); 42 C.F.R. §§ 2.31, 2.33; 45 C.F.R. § 164.508; Cal. Civ. Code § 56.11; Cal. Health & Safety Code § 11845.5(b); Cal. Welf. & Inst. Code § 4515, 5328.7.]</i></p>
Behavioral Health	<p>For purposes of the State Health Information Guidance (SHIG), behavioral health includes mental health and substance use disorder (SUD) information.</p> <p><i>[source: Created by the SHIG team.]</i></p>
Behavioral Health Information	<p>SUD patient-identifying information regulated by 42 C.F.R. Part 2 and/or California Health and Safety Code § 11845.5 and/or mental health information regulated by Lanterman-Petris-Short Act (LPS) or Confidentiality of Medical Information Act (CMIA).</p> <p><i>[source: 42 C.F.R. Part 2; Cal. Civ. Code § 56.30; Cal. Health & Safety Code § 11845.5; Cal. Welf. & Inst. Code § 5328.]</i></p>
Business Associate (BA)	<p>A person or entity that performs certain functions or activities that involve the use or disclosure of health information on behalf of, or provides services to, a covered entity. Business associates may include, but are not limited to:</p> <ul style="list-style-type: none"> • organizations that provide services (e.g., claims processing, clearing houses, data analysis, utilization review, quality assurance, billing, legal) on behalf of a covered entity where access to health information is required • a person or organization “that offers a personal health record to one or more individuals on behalf of a covered entity...” • “subcontractor that creates, receives, maintains, or transmits health information on behalf of the business associate...” <p>A member of the covered entity’s workforce is not a business associate.</p> <p><i>[source: 45 C.F.R. § 160.103 (paraphrased).]</i></p>

Term	Definition
Capacity	<p>The loss or deterioration of intellectual capacity (cognitive impairment) due to a medical condition such as Alzheimer’s disease, another form of dementia, or brain injury. These conditions can cause short- or long-term memory loss; language, concentration and attention issues; challenges with visual spatial abilities; impaired judgment or reasoning; or other functional limitations.</p> <p><i>[Cal. Welf. & Inst. Code § 14522.4(11).]</i></p>
Caregiver	<p>Anyone who provides care for another person. There are different types of caregivers that provide specific care, like family caregivers and respite caregivers. Caregivers can help relieve burdens and support individuals in need.</p> <p><i>[source: Created by the SHIG team.]</i></p>
Combined Authorization	<p>A single authorization may contain uses and disclosures for multiple purposes. The only limitations are that an authorization for the use or disclosure of psychotherapy notes may not be combined with an authorization for the use or disclosure of other types of health information and that an authorization that is a condition of treatment, payment, enrollment, or eligibility may not be combined with any other authorization.</p> <p>In [45 C.F.R.] § 164.508(b)(3), HIPAA permits covered entities to combine an authorization for the use or disclosure of health information created for purposes of research including treatment of individuals with certain other documents.</p> <p><i>[source: Office of the Assistant Secretary for Planning and Evaluation website]</i></p> <p>https://aspe.hhs.gov.</p>
Community-Based Organizations	<p>Any not-for-profit entity organized for the purpose of providing services or other assistance to economically or socially disadvantaged persons within its designated community,</p> <p><i>[source: Law Insider]</i></p> <p>https://www.lawinsider.com/dictionary/community-based-organization-cbo.</p>

Term	Definition
Community Care Facility	<p>A facility contracted by a Regional Center to provide 24-hour residential care to children and adults with intellectual and/or developmental disabilities who are in need of personal services, supervision, and/or assistance essential for self-protection or sustaining the activities of daily living.</p> <p><i>[source: North Bay Regional Center website https://nbrc.net.]</i></p>
Compound Authorization	<p>Combining an authorization for the use or disclosure of health information with any other document – this is prohibited by HIPAA.</p> <p><i>[source: Office of the Assistant Secretary for Planning and Evaluation website https://aspe.hhs.gov.]</i></p>
Conserved	<p>An individual 18 years of age or older may be conserved if they are deemed by the court to be incapable of caring for their own health and well-being due to a serious mental illness and/or substance use disorder.</p> <p><i>[source: Cal. Welf. & Inst. Code § 5451 (paraphrased).]</i></p>
Covered Entity	<p>The following individuals or organizations that directly handle health information:</p> <ul style="list-style-type: none"> • a health plan • a healthcare clearinghouse • a health provider who transmits any health information in electronic form in connection with a standard transaction covered by HIPAA <p><i>[source: 45 C.F.R. § 160.103.]</i></p>
Developmental Service Records	<p>All information and records obtained in the course of providing intake, assessment, and services covered under Division 4.1, Division 4.5, Division 6, or Division 7 of the Welfare and Institutions Code to persons with developmental disabilities.</p> <p><i>[source: CA Welfare and Institutions Code § 4514.]</i></p>
Disclose	<p>The release, transfer, dissemination, or to otherwise communicate all or any part of any record orally, in writing, or by electronic or any other means to any person or entity.</p> <p><i>[source: 45 C.F.R. § 160.103 (paraphrased).]</i></p>

Term	Definition
Eligibility Assessment	<p>Regional center staff assess whether people living with intellectual and/or developmental disabilities qualify for needed health services and supports. As part of the assessment, RC staff provide diagnoses and help plan, access, coordinate and monitor the services and supports that are needed because of an intellectual and/or developmental disability.</p> <p><i>[source: California DDS website https://www.dds.ca.gov/general/eligibility/ (paraphrased).]</i></p>
Emergency	<p>A condition or situation in which an individual has a need for immediate medical attention, or where the potential for such need is perceived by emergency medical personnel or a public safety agency.</p> <p><i>[source: Health & Safety Code § 1797.70.]</i></p>
Health Information	<p>Any name in combination with any other information related to the provision of healthcare that can lead a person to reasonably identify the patient/consumer.</p> <p>This definition incorporates and synthesizes federal and state definitions, including:</p> <ul style="list-style-type: none"> • Protected Health Information • Electronic Health Information • Personal Information • Medical Information • Confidential and Private Information <p>Special note: Health Information as used in the SHIG does not include information and records covered by other federal or state laws regarding substance use disorder treatment records, developmental service records, mental/behavioral health records, HIV/AIDS, genetic information.</p> <p><i>[source: Statewide Health Information Policy Manual (SHIPM).]</i></p>

Term	Definition
Health Plan	<p>An individual or group plan that provides, or pays the costs of, healthcare and includes the following, singly or in:</p> <ul style="list-style-type: none"> • a group plan, a health insurance issuer, a healthcare service plan • a Health Maintenance Organization • Part A, B or D of the Medicare program, or a supplemental policy thereof • Medicaid (Medi-Cal – State of California version of Medicaid) • a long-term care policy excluding a nursing home fixed indemnity policy • an employee welfare benefit plan • a healthcare program for uniformed services • a veterans’ healthcare program • an Indian Health Services program • the Federal Employees Health Benefits Program • an approved State child health plan • a Medicare Advantage program • a high risk pool established under State law to provide health insurance coverage or comparable coverage • any other individual or group plan or combination of individual or group plans that provides or pays for the cost of medical care <p><i>[source: 45 C.F.R. § 160.103; 42 U.S.C. 300gg-91(a)(2); Cal. Civ. Code § 56.05.]</i></p>
Health Provider	<p>Any person or organization that furnishes, bills, or is paid for healthcare in the normal course of business. Examples include, but are not limited to:</p> <ul style="list-style-type: none"> • doctors • clinics • psychologists • dentists • chiropractors • nursing homes • pharmacies <p><i>[source: 45 C.F.R. §§ 160.102, 160.103.]</i></p>

Term	Definition
Individualized Family Services Plan	<p>Regional center or Regional Center vendor staff work with the family to develop a written plan that lays out the supports and services children three (3) and under need early intervention services.</p> <p><i>[source: 17 C.C.R. § 52102.]</i></p>
Individual Health Care Plan	<p>The State Operated Facility staff collaborate with an Individual Health Care Team to develop an Individual Health Care Plan (IHCP) for adults living with intellectual and/or developmental disabilities residing in an Adult Residential Facility for Persons with Special Health Care Needs (ARFPSHN).</p> <p><i>[source: Cal. Welf. & Inst. Code § 4648.55.]</i></p>
Individual Program Plan	<p>The Regional Center staff collaborates with a planning team to develop an Individual Program Plan (IPP) for services for adults living with intellectual and/or developmental disabilities who are receiving services via a Regional Center.</p> <p><i>[source: Cal. Welf. & Inst. Code § 4646.]</i></p>
Intellectual and/or Developmental Disability	<p>A disability that originates before an individual attains 18 years of age, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual. As defined by the Director of Developmental Services, in consultation with the Superintendent of Public Instruction, this term shall include intellectual disability, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to intellectual disability or to require treatment similar to that required for individuals with an intellectual disability, but shall not include other handicapping conditions that are solely physical in nature.</p> <p><i>[source: Cal. Welf. & Inst. Code §4512(a) (paraphrased).]</i></p>
Intermediate Care Facility	<p>Intermediate Care Facilities are health facilities licensed by the Licensing and Certification Division of the California Department of Public Health to provide 24-hour-per-day residential services to Regional Center patients/consumers with intellectual and/or developmental disabilities.</p> <p><i>[source: North Bay Regional Center website https://nbrc.net/client-services/adult-services/living-arrangements/intermediate-care-facilities/.]</i></p>

Term	Definition
Mental Health Information	<p>Patient/consumer records, or discrete portions thereof, specifically relating to evaluation or treatment of a mental disorder. Mental health records include, but are not limited to, all alcohol and drug abuse records not regulated by 42 C.F.R. Part 2, or Cal. Health & Safety Code § 11845.5.</p> <p><i>[source: Cal. Civ. Code § 56.30; Cal. Health & Safety Code § 123105(b); Cal. Welf. & Inst. Code § 5328.]</i></p>
Minimum Necessary	<p>The amount of information, to the extent necessary, to accomplish the intended purpose of a use, disclosure, or request.</p> <p><i>[source: 45 C.F.R. §§ 164.502(b), 164.514(d).]</i></p>
Patient-Identifying Information	<p>Health information related to the diagnosis or treatment (including referral for treatment) of a SUD, such as patient’s name, address, social security number (SSN), biometrics, or similar information by which the identity of the patient can be established with reasonable accuracy.</p> <p><i>[source: Created by the SHIG team, based on 42 C.F.R. § 2.11.]</i></p>
Patient/Consumer	<p>An individual who is living with an intellectual and/or developmental disability, that originates before an individual attains 18 years of age, and that can be expected to continue indefinitely, may be eligible for Regional Center services to include initial intake, diagnostic and counseling services, treatment, assessment if needed, and ongoing services.</p> <p><i>[source: 17 C.C.R. §§ 54000, 54001, 54010 (paraphrased); Cal. Welf. & Inst. Code § 4512 (paraphrased).]</i></p>

Term	Definition
Patient's/Consumer's Representative	<p>A person who:</p> <ul style="list-style-type: none"> • has the authority under law to make healthcare decisions for another person, or • has the authority to administer the estate of a deceased person (including executor) <p>A provider using clinical judgment may choose not to deal with an individual as the patient's/consumer's representative, if there is a reasonable belief that:</p> <ul style="list-style-type: none"> • the individual has or will abuse/neglect the patient/consumer with violence, or • may endanger the patient/consumer if the information is provided to the individual; and • it would not be in the best interest of the patient/consumer to deal with the individual as the patient's/consumer's representative. <p><i>[source: 45 C.F.R. § 164.502(g) and HHS website http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/personalreps.html.]</i></p>
Protected Health Information (PHI)	<p>Protected Health Information (PHI) is individually identifiable health information related to a patient's/consumer's medical history, mental or physical condition, treatment, or payment.</p> <p><i>[source: SHIG 2.0, Appendix 3.0.]</i></p>
Privacy	<p>The right of individuals and organizations to control the collection, storage, and dissemination of information about themselves.</p> <p><i>[source: California Department of Technology website https://cdt.ca.gov/security/technical-definitions/.]</i></p>
Psychiatric Health Facility	<p>A psychiatric health facility is a health facility, licensed by the State Department of Health Care Services, that provides 24-hour inpatient care for people with mental health disorders. This care includes psychiatry, clinical psychology, psychiatric nursing, social work, rehabilitation, drug administration, and appropriate food services for those persons whose physical health needs can be met in an affiliated hospital or in outpatient settings.</p> <p><i>[source: Cal. Health & Safety Code § 1250.2.]</i></p>
Qualified Professional Persons	<p>Persons whose training and experience are appropriate to the nature and level of work in which they are engaged. May be a physician, psychologist, or non-clinician professionals.</p> <p><i>[source: Created by the SHIG team.]</i></p>

Term	Definition
Qualified Service Organization	<p>An individual or entity who:</p> <ol style="list-style-type: none"> 1) provides services to a 42 C.F.R. Part 2 program, such as data processing, bill collecting, dosage preparation, laboratory analyses, or legal, accounting, population health management, medical staffing, or other professional services, or services to prevent or treat child abuse or neglect, including training on nutrition and child care and individual and group therapy, and 2) has entered into a written agreement with a 42 C.F.R. Part 2 program under which that individual or entity: <ol style="list-style-type: none"> (i) acknowledges that in receiving, storing, processing, or otherwise dealing with any patient records from the 42 C.F.R. Part 2 program, it is fully bound by the regulations in this part; and (ii) if necessary, will resist in judicial proceedings any efforts to obtain access to SUD patient-identifying information. <p><i>[source: 42 C.F.R. § 2.11 (paraphrased).]</i></p>
Regional Center	<p>Regional Centers are nonprofit private corporations that contract with the California Department of Developmental Services (DDS) to provide or coordinate services and supports for individuals with intellectual and/or developmental disabilities.</p> <p><i>[source: DDS website https://www.dds.ca.gov/rc/.]</i></p>
Regional Center Vendors	<p>Regional Centers contract with vendors to provide services and supports to individual living with intellectual and/or developmental disabilities. Vendors include but are not limited to community care facilities, intermediate care facilities, psychiatric health facilities, acute care facilities, healthcare facilities, and other community-based organizations.</p> <p><i>[source: created by SHIG team.]</i></p>
Security	<p>The administrative, physical and technical safeguards in, or protecting, an information system.</p> <p><i>[source: 45 C.F.R. § 164.304; Cal. Health & Safety Code § 1280.18.]</i></p>
State Developmental Center	<p>A multi-disciplinary, service-oriented facility licensed by the California Department of Public Health, that provides general acute care, skilled nursing care, intermediate care, or acute crises services to individuals with intellectual and developmental disabilities.</p> <p><i>[source: DDS website https://www.dds.ca.gov/ (paraphrased)]</i></p>

Term	Definition
State-Operated Facility (SOF)	<p>California Department of Developmental Services (DDS) operates one developmental center, one community facility and several crisis stabilization homes. These state-operated facilities provide 24-hour services designed to provide competency services (at one site), increase independence, improve living skills, stabilize significant behavioral challenges and facilitate transitions back into the community.</p> <p><i>[source: California DDS website https://www.dds.ca.gov/services/state-facilities/.]</i></p>
Treatment	<p>The provision, coordination, or management of healthcare and related services by one or more health providers, including the coordination or management of healthcare by a health provider with a third party; consultation between health providers relating to a patient/consumer; or the referral of a patient/consumer for healthcare from one health provider to another.</p> <p><i>[source: 45 C.F.R. § 164.501.]</i></p>

Appendix 7 – Acronyms

Acronym	Meaning
42 C.F.R. Part 2	Part 2 of Title 42 of the Code of Federal Regulations also known as Confidentiality of Substance Use Disorder Patient Records
BA	Business Associate
BH	Behavioral Health
CalHHS	California Health and Human Services Agency
CCPA	California Consumer Privacy Act
C.C.R.	California Code of Regulations
CDII	Center for Data Insights and Innovation
C.F.R.	Code of Federal Regulations
CHCF	California Health Care Foundation
CMIA	Confidentiality of Medical Information Act
CMS	Centers for Medicare and Medicaid Services
DDS	California Department of Developmental Services
DHCS	Department of Health Care Services
HIPAA	Health Insurance Portability and Accountability Act
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
IFSP	Individualized Family Services Plan
IHCP	Individual Health Care Plan
IPP	Individual Program Plan
IT	Information Technology
Lanterman	Lanterman Developmental Disabilities Services Act
LGBT	Lesbian, Gay, Bisexual, Transgender
LPS	Lanterman–Petris–Short Act
PHF	Psychiatric Health Facility

Acronym	Meaning
PHI	Protected Health Information
QSO	Qualified Service Organization
RC	Regional Center
SHIG	State Health Information Guidance
SHIPM	Statewide Health Information Policy Manual
SOF	State-Operated Facility(ies)
SSN	Social Security Number
SUD	Substance Use Disorder