



*California's Protection & Advocacy System
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Summary of Disability Rights California's Authority under State and Federal Law

January 2005, Pub #5031.01

WHAT IS DISABILITY RIGHTS CALIFORNIA?

Disability Rights California is an independent, private, nonprofit agency established in 1978 pursuant to the Developmental Disabilities Assistance and Bill of Rights Act. 42 U.S.C. § 15001 *et seq.* ["DD Act"]. Congress mandated that each state receiving funds under the DD Act establish such an advocacy system to protect the rights and interests of persons with developmental disabilities. Disability Rights California is the advocacy system for California. Congress subsequently expanded the responsibilities of the existing protection and advocacy system to include advocacy for all persons with disabilities, including psychiatric and other disabilities. 42 U.S.C. § 10801 *et seq.* ["PAIMI Act"]; 29 U.S.C. § 794e *et seq.* ["PAIR Act"].

In 1991, the California legislature enacted legislation which acknowledged the authority of Disability Rights California under federal law and brought state law into compliance with federal requirements. Welf. & Inst. Code § 4900 *et seq.* In 2003, SB 577 was enacted (Kuehl) [Stats. 2003, ch. 878, eff. 1/1/04], bringing state law into compliance with the subsequent expansion of federal law and regulations.

WHAT ACTIVITIES DOES DISABILITY RIGHTS CALIFORNIA ENGAGE IN?

In protecting and advocating for the rights of persons with disabilities, Disability Rights California may do the following:

- **Investigate incidents of abuse and neglect** if the incident is reported to Disability Rights California or if Disability Rights California determines that there is probable cause to believe the incident occurred.
- **Pursue administrative, legal, and other appropriate remedies** or approaches to ensure the protection of rights of eligible persons with disabilities.
- **Provide information, referral and training** concerning programs and services addressing needs of eligible individuals, and training about individual rights and services available from Disability Rights California.

WHAT ARE DISABILITY RIGHTS CALIFORNIA'S ACCESS AUTHORITIES?

A. FACILITIES AND PROGRAMS

Disability Rights California is granted reasonable access to facilities or programs providing care and treatment to persons with disabilities. This access permits Disability Rights California to conduct abuse or neglect investigations¹, provide information and training about the rights of individuals with disabilities, and monitor the facility or program's compliance with respect to the rights and safety of service recipients. In the case of investigations into allegations of abuse or neglect, this access must be at all times necessary and includes the authority to examine all relevant records and interview program or facility service recipients, employees, or other persons who might have knowledge of the alleged abuse and neglect.² In carrying out all other functions, Disability Rights California has access to facilities, programs, services and service recipients during normal working hours and visiting hours or other reasonable times.³ Formal information and

¹ In the case of investigations into allegations of abuse or neglect, this access must be permitted, without advance notice, and at all times necessary to conduct a full investigation.

² Welf. & Inst. Code § 4902(b)(1). *See also*, 45 C.F.R. § 1386.22(f); 42 C.F.R. § 51.42(b).

³ Welf. & Inst. Code § 4902(b)(2). *See also*, 45 C.F.R. § 1386.22(g); 42 C.F.R. § 52.42(c).

training sessions must be scheduled at times mutually agreeable to Disability Rights California and program or facility management.⁴

A “facility” or “program” to which Disability Rights California is entitled to access includes a public or private facility providing services, support, care, or treatment to persons with disabilities. This specifically includes, but is not limited to, a hospital, long-term health care facility, community living arrangement for people with disabilities (including a group home, board and care home, individual residence or apartment of a person with a disability where services are provided), day program, juvenile detention facility, homeless shelter, jail or prison, any facility that is unlicensed but is not exempt from licensure, and a public or private school or other institution or program providing education, training, habilitation, therapeutic, or residential services to persons with disabilities.⁵

B. INFORMATION AND RECORDS

Disability Rights California has authority to access records of facilities serving people with disabilities and the confidential records of people with disabilities.⁶ The records available to Disability Rights California include, but are not limited to:

- Information and records prepared or received in the course of providing intake, assessment, evaluation, education, training, or other supportive services, including medical records, financial records, monitoring reports, or other reports, prepared by facility, program or service staff.⁷
- Reports prepared by an agency charged with investigating reports of incidents of abuse, neglect, injury, or death occurring at a facility,

⁴ Welf. & Inst. Code § 4902(b)(2).

⁵ Welf. & Inst. Code § 4900(e). *See also*, 45 C.F.R. § 1386.19; 42 C.F.R. § 51.2.

⁶ 42 U.S.C. § 15043(a)(2)(I); 42 U.S.C. § 10805(a)(4); Welf. & Inst. Code § 4514.3; Welf. & Inst. Code § 4902(a)(1); Welf. & Inst. Code § 5328.06.

⁷ Welf. & Inst. Code 4903(b)(1). *See also*, 42 U.S.C. § 15043(c)(1); 42 U.S.C. § 10806(b)(3)(A); 45 C.F.R. 1386.22(b)(1); 42 U.S.C. 51.41(c)(1).

where the individual with a disability is receiving services for care.⁸ In an abuse or neglect investigation, this includes personnel records prepared by or maintained by the facility in connection with reports of incidents of abuse, neglect, injury or death.⁹

- Discharge planning records.¹⁰
- Pursuant to an investigation into abuse or neglect allegations, information in possession of a facility including:
 - reports prepared by individuals and entities performing certification or licensure reviews, or by professional accreditation organizations, and related assessments prepared for a facility by its staff, contractors, or related entities, subject to any other provision of state law protecting records produced by medical care evaluation or peer review committees;¹¹ and
 - information in professional, performance, building, or other safety standards, demographic or statistical information relating to a facility.¹²

Disability Rights California has the authority to access the records listed above, whether written or in another medium, draft or final, including but not limited to handwritten notes, electronic files, photographs, videotapes, or audiotapes.

⁸ Welf. & Inst. Code § 4903(b)(2). *See also*, 42 U.S.C. § 15043(c)(2); 42 U.S.C. § 10806(b)(3)(A); 45 C.F.R. § 1386.22(b)(2); 42 U.S.C. 51.41(c)(2).

⁹ Welf. & Inst. Code § 4903(b)(2). *See also*, 45 C.F.R. § 1386.22(b)(2)(iii); 42 C.F.R. § 51.41(c)(2)(iii).

¹⁰ Welf. & Inst. Code § 4903(b)(3). *See also*, 45 C.F.R. § 1386.22(b)(3); 42 C.F.R. § 51.41(c)(3).

¹¹ Welf. & Inst. Code § 4903(c)(1). *See also*, 45 C.F.R. § 1386.22(c)(1); 42 C.F.R. § 51.41(c)(4);

Pennsylvania Protection and Advocacy, Inc. v. Houstoun, 228 F.3d 423 (3d Cir. 2000) (P&As are entitled to access “peer review” records despite state law restrictions on their disclosure); *Center for Legal Advocacy v. Hammons*, 323 F.3d 1262 (10th Cir. 2003) (same holding).

¹² Welf. & Inst. Code § 4903(c)(2). *See also*, 45 C.F.R. § 1386.22(c)(2); 42 C.F.R. § 51.41(c)(5).

WHOSE RECORDS CAN DISABILITY RIGHTS CALIFORNIA ACCESS?

Disability Rights California is entitled to access the confidential records of people with disabilities¹³ under the following authority:

- Any person who is a Disability Rights California client, if that person, or legal guardian, conservator, or other legal representative of that person, has authorized Disability Rights California to have access to information and records.¹⁴ A “legal guardian,” “conservator,” or “legal representative” is the person who has legal authority to consent to health or mental health care or treatment on behalf of the individual.¹⁵

- Any person, including any person who cannot be located, to whom all of the following conditions apply:
 - The individual, due to his or her mental or physical condition, is unable to authorize Disability Rights California to have access to his or her records;

 - The individual does not have a legal guardian, conservator, or other legal representative, or the individual’s representative is a public entity, including the state; and

¹³ “Disability” means a developmental disability as defined in the DD Act, a mental illness as defined in the PAIMI Act, a disability within the meaning of the Americans with Disabilities Act, or a disability within the meaning of the California Fair Employment and Housing Act. 42 U.S.C. § 15002(8); 42 U.S.C. § 10802(4); 42 U.S.C. § 12102(2); Govt. Code §§ 12926(i), 12926(k).

¹⁴ Welf. & Inst. Code § 4903(a)(1). *See also*, 45 U.S.C. § 15043(a)(2)(I)(i); 42 U.S.C. § 10805(a)(4)(A).

¹⁵ “Legal guardian,” “conservator,” or “legal representative,” means a person appointed by a state court or agency empowered under state law to appoint and review the legal guardian, conservator, or legal representative, as appropriate. These terms include the parent of a minor who has legal custody of the minor. These terms do not include a person acting solely as a representative payee, a person acting solely to handle financial matters, an attorney or other person acting on behalf of an individual with a disability solely in legal matters, or an official or his or her designee who is responsible for the provision of treatment or services to an individual with a disability. Welf. & Inst. § Code 4900(f). *See also*, 45 C.F.R. § 1386.19; 42 C.F.R. § 51.2.

- Disability Rights California has received a complaint that the individual has been subject to abuse or neglect, or has determined that probable cause exists to believe that the individual has been subject to abuse or neglect.¹⁶
- Any person who is deceased, and for whom Disability Rights California has received a complaint that the individual has been subject to abuse or neglect, or has determined that probable cause exists to believe that an individual has been subjected to abuse or neglect.¹⁷ Disability Rights California is entitled to access such records without consent from another party.¹⁸
- Any person who has a legal guardian, conservator, or other legal representative with respect to whom a complaint has been received by Disability Rights California, or with respect to whom Disability Rights California has determined that probable cause exists to believe that the person has been subjected to abuse or neglect, whenever all of the following conditions exist:
 - Disability Rights California has contacted the representative upon receipt of the representative's name and address,
 - Disability Rights California has offered assistance to the representative to resolve the situation; and
 - The representative has failed or refused to act on behalf of the person.¹⁹

Under state and federal law, Disability Rights California is the final arbiter of determining if there is probable cause to believe that an individual has been subject to abuse or neglect, or is at significant risk of being subjected to

¹⁶ Welf. & Inst. Code § 4903(a)(2). *See also*, 45 U.S.C. § 15043(a)(2)(I)(ii); 42 U.S.C. § 10805(a)(4)(B).

¹⁷ Welf. & Inst. Code § 4903(a)(3). *See also* 42 U.S.C. § 15043(a)(2)(J); 42 U.S.C. § 10805(a)(4)(B).

¹⁸ Welf. & Inst. Code § 4903(e)(2). *See also* 42 U.S.C. § 15043(a)(2)(J); 42 U.S.C. § 10805(a)(4)(B); *Alabama Disabilities Advocacy Program v. J.S. Tawater Development Center*, 97 F.3d 492 (11th Cir. 1996) (consent for release of records from guardian of deceased person need not be obtained as the guardianship terminated at death).

¹⁹ Welf. & Inst. Code 4903(a)(4). *See also*, 42 U.S.C. §15043(a)(2)(I)(iii); 42 U.S.C. §10805(a)(4)(C).

abuse or neglect. The probable cause determination is based upon reasonable inferences drawn from individual experience or training regarding similar incidents, conditions, or problems that are usually associated with abuse or neglect. Information supporting a probable cause determination may arise from monitoring or other activities, including but not limited to, media reports and newspaper articles.²⁰

If Disability Rights California is denied access due to lack of authorization, the facility, program or service provider shall promptly provide Disability Rights California with the name, address, and telephone number of the legal guardian, conservator, or other legal representative of the individual with a disability for whom authorization is required. Reasons for delay or denial of access must be provided in writing to Disability Rights California promptly.²¹

Disability Rights California's authority to access records is not affected by the regulations implementing the Health Insurance Portability and Accountability Act [HIPAA]. The HIPAA regulations provide additional protections regarding the release of protected health information by health care providers and other entities.²²

WHAT ARE THE TIME FRAMES FOR DISABILITY RIGHTS CALIFORNIA ACCESS TO RECORDS?

Disability Rights California shall have access to the records that are relevant to conducting an abuse or neglect investigation, not later than three business days after Disability Rights California makes a written request for the records. Disability Rights California shall have immediate access to the records, not later than 24 hours after Disability Rights California makes a request, without consent from another party, if Disability

²⁰ Welf. & Inst. Code § 4900(h). *See also*, *Arizona Center for Disability Law v. Allen*, 197 F.R.D. 689, 692 (D.Ariz.2000); *Office of Protection and Advocacy Programs for Persons with Disabilities v. Armstrong*, 266 F. Supp. 2d 303 (D. Conn. 2003).

²¹ Welf. & Inst. Code 4902(c). *See also*, 45 C.F.R. 1386.22(i); 45 C.F.R. § 51.43. Civil Code § 1798.24b

²² 45 C.F.R. § 164.512(a)(1).

Rights California determines that the individual is in serious and immediate jeopardy, or in the case of a death of an individual with a disability.²³

WHAT CAN DISABILITY RIGHTS CALIFORNIA DO WITH THE INFORMATION AND RECORDS THAT IT OBTAINS?

Confidential information kept or obtained by Disability Rights California shall remain confidential and may not be subject to disclosure.²⁴ However, Disability Rights California may do any of the following:

- **Share the information with the individual client** who is the subject of the record or report or other document, or with his or her legally authorized representative, subject to any limitation on disclosure to recipients of mental health services.
- **Issue a public report of the results of an investigation** that maintains the confidentiality of individual clients.
- **Report the results of an investigation to responsible investigative or enforcement agencies** including, but not limited to, agencies that are responsible for facility licensing or accreditation, employee discipline, employee licensing or certification suspension or revocation, or criminal prosecution.
- **Pursue alternative remedies**, including the initiation of legal action.
- **Report suspected elder or dependent adult** abuse pursuant to the Elder Abuse and Dependent Adult Civil Protection Act, Welf. & Inst. Code § 15600 et seq.²⁵

²³ Welf. & Inst. Code § 4903(e). *See also*, 42 U.S.C. § 15043(a)(2)(J).

²⁴ Welf. & Inst. Code § 4903(f). *See also*, 42 U.S.C. § 10806(a); 42 C.F.R. § 51.45(a).

²⁵ Welf. & Inst. Code § 4903(f).

Disability Rights California is funded by a variety of sources, for a complete list of funders, go to <http://www.disabilityrightsca.org/Documents/ListofGrantsAndContracts.html>.