

WHAT IS DISABILITY RIGHTS OREGON?

Disability Rights Oregon (DRO) 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 a protection and advocacy (P&A) system to protect the rights and interests of persons with developmental disabilities. DRO is the advocacy system for the State of Oregon.

Congress subsequently expanded the responsibilities of the existing P&As to advocate for all persons with mental illness, under the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act, 42 U.S.C. § 10801 *et seq.* Most recently, Congress authorized P&As to advocate on behalf of persons with physical and other disabilities not covered under either the DD or PAIMI Acts; this authority is provided under the Protection and Advocacy of Individual Rights (PAIR) Program of the Rehabilitation Act, 29 U.S.C. § 794e.¹

WHAT ACTIVITIES DOES DRO ENGAGE IN?

In protecting and advocating for the rights of persons with disabilities, DRO may engage in the following activities:

- **Investigate incidents of abuse and neglect** if the incident is reported to DRO or if DRO 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 DRO.

WHAT ARE DRO'S INVESTIGATIVE ACCESS AUTHORITIES?

A. Facilities and Programs

DRO, as a P&A, is granted reasonable unaccompanied access to facilities or programs providing services to persons with disabilities. DRO must be permitted such access for

¹ Congress intended that the authorities under the DD, PAIMI and PAIR laws be applied in a consistent manner. Indeed, the PAIR Program expressly incorporates by reference (at 29 U.S.C. § 794(e)(f)) the authority regarding access to facilities and records for the purpose of investigating abuse and neglect (which is discussed below) set forth in the DD Act. Given that authority under the PAIR Program is substantially identical to that under the DD Act, statutory and regulatory citations regarding DRO's federal investigative authority are provided below only with respect to the DD and PAIMI Acts.

the purposes of conducting an investigation of abuse or neglect, providing information and training on the rights of individuals with disabilities, and monitoring compliance with respect to the rights and safety of service recipients.² 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. This mandate includes authority to interview program or facility service recipients, employees, or other persons who might have knowledge of the alleged abuse and neglect.³

With regard to its monitoring activities, DRO shall be permitted access to all areas of a facility or program that are accessible to service recipients, at all reasonable times, including beyond normal working and visiting hours; such access shall be allowed without advance notice.⁴ Monitoring activities, however, will be conducted so as to minimize interference with programs and to respect the privacy of service recipients or residents. DRO shall also be permitted to provide information and training at all reasonable times, but will schedule such activities at times mutually agreeable to DRO and program or facility management.

A “facility” or “program” to which DRO is entitled access includes a public or private facility or program providing services, supports, care, treatment or other assistance 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, and a public or private school.⁵

B. Information and Records

DRO has authority to access records of programs serving people with disabilities and the confidential records of people with disabilities.⁶ The records available to DRO 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, where the individual with a

² 45 C.F.R. § 1386.22(f)-(h); 42 C.F.R. § 51.42(b)-(e)

³ 45 C.F.R. § 1386.22(f); 42 C.F.R. § 51.42(b).

⁴ 45 C.F.R. §1386.22(g); 42 C.F.R. § 51.42(c); *Equip for Equality v. Ingalls Memorial Hospital*, 292 F. Supp. 2d 1086 (N.D. Ill. 2003) and 329 F. Supp.2d 982 (N.D. Ill. 2004) (order establishing protocol for monitoring).

⁵ 45 C.F.R. § 1386.19; 42 C.F.R. § 51.2.

⁶ 42 U.S.C. §§ 15043(a)(2)(I), (B) and (J); 42 U.S.C. § 10805(a)(4); 45 C.F.R. § 1386.22(a)-(d); 42 C.F.R. § 51.41(a)-(c).

⁷ 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).

disability is receiving services for care.⁸ In an abuse or neglect investigation, this includes personnel records prepared by or maintained by the facility or program 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;¹¹ and
 - information in professional, performance, building, or other safety standards, demographic or statistical information relating to a facility.¹²

DRO 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.¹³

WHOSE RECORDS CAN DRO ACCESS?

DRO is entitled to access the confidential records of people with disabilities¹⁴ under the following authority:

- Any person who is a DRO client, if that person, or legal guardian, conservator, or other legal representative of that person, has authorized DRO to have access to information and records.¹⁵ 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.¹⁶

⁸ 42 U.S.C. § 15043(c)(2); 42 U.S.C. § 10806(b)(3)(A); 45 C.F.R. § 1386.22(b)(2); 42 C.F.R. § 51.41(c)(2).

⁹ 45 C.F.R. § 1386.22(b)(2)(iii); 42 C.F.R. § 51.41(c)(2)(iii).

¹⁰ 45 C.F.R. § 1386.22(b)(3); 42 C.F.R. § 51.41(c)(3).

¹¹ 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 (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 45 C.F.R. § 1386.22(c)(2); 42 C.F.R. § 51.41(c)(5).

¹³ 45 C.F.R. § 1386.22(b); 42 C.F.R. 51.41(c).

¹⁴ “Disability” means a developmental disability as defined in the DD Act, a mental illness as defined in the PAIMI Act, or a disability within the meaning of the Rehabilitation Act. 42 U.S.C. § 15002(8); 42 U.S.C. § 10802(4); 29 U.S.C. § 705(9).

¹⁵ 45 U.S.C. § 15043(a)(2)(l)(i); 42 U.S.C. § 10805(a)(4)(A).

¹⁶ “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

- 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 or age¹⁷ is unable to authorize DRO 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
 - DRO 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.¹⁸
- Any person who is deceased, and for whom DRO has received a complaint that the individual has been subject to abuse or neglect, or has determined that probable cause exists to suspect abuse or neglect.¹⁹ DRO is entitled to access such records without consent from another party.²⁰
- Any person who has a legal guardian, conservator, or other legal representative with respect to whom a complaint has been received by DRO, or with respect to whom DRO 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:
 - DRO has contacted the representative upon receipt of the representative's name and address.
 - DRO has offered assistance to the representative to resolve the situation; and
 - The representative has failed or refused to act on behalf of the person.²¹

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. 45 C.F.R. § 1386.19; 42 C.F.R. § 51.2.

¹⁷ Age, while not specifically listed under federal law, is an additional category under Oregon law. See ORS 192.517(1)(b)(A).

¹⁸ 45 U.S.C. § 15043(a)(2)(I)(ii); 42 U.S.C. § 10805(a)(4)(B).

¹⁹ 42 U.S.C. § 15043(a)(2)(J); 42 U.S.C. § 10805(a)(4)(B).

²⁰ 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).

²¹ 42 U.S.C. §15043(a)(2)(I)(iii). In the case of a person with a mental illness (and no other disability), access is provided under these circumstances if there is a complaint or DRO has probable cause to suspect that the health or safety of the individual is in serious and immediate jeopardy. 42 U.S.C. § 10805(a)(4)(C).

Under federal law, DRO is the final arbiter for purposes 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 abuse or neglect.²² 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.²³ Information supporting a probable cause determination may arise from monitoring or other activities, including but not limited to, media reports such as newspaper articles.²⁴

If DRO is denied access due to lack of authorization, the facility, program or service provider shall promptly provide DRO 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 DRO promptly.²⁵

DRO's authority to access records as described above is not affected by the regulations implementing the Health Insurance Portability and Accountability Act (HIPAA). The HIPAA regulations provide that health care providers and other entities covered under the regulations "may use or disclose protected health information to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law."²⁶ Further, state law restrictions on the disclosure of records or other information are preempted by DRO's federal access authority to the extent such restrictions may pose an obstacle to such authority.²⁷

WHAT ARE THE TIME FRAMES FOR DRO'S ACCESS TO RECORDS?

_____ DRO shall have access to the records that are relevant to conducting an abuse or neglect investigation not later than three business days after DRO makes a written request for the records. DRO shall have immediate access to the records, not later than 24 hours after DRO makes a request, without consent from another party, if DRO determines that the individual is in serious and immediate jeopardy, or in the case of a death of an individual with a disability.²⁸

²² *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).

²³ 45 C.F.R. § 1386.19; 42 C.F.R. § 51.2.

²⁴ *Alabama Disabilities Advocacy Program v. J.S. Tawater Development Center*, 97 F.3d 492, 498 (11th Cir. 1996); *Georgia Advocacy Office v. Borison*, 520 S.E. 2d 701 (Ga. Ct. Apps. 1999).

²⁵ 45 C.F.R. § 1386.22(i); 45 C.F.R. § 51.43.

²⁶ 45 C.F.R. § 164.512(a)(1). That section also provides that covered entities may disclose protected health information without the written authorization of the individual to whom the information pertains. The disclosures of information to DRO discussed above clearly are "required by law" within the meaning of the regulation. See the definition of that term, at 45 C.F.R. § 164.103, which states that "required by law means a mandate contained in law that compels an entity to make a use or disclosure of protected health information and that is enforceable in a court of law. Required by law includes . . . a civil or authorized investigative demand . . . and statutes or regulations that require production of information." As discussed above, DRO's enabling legislation contains express, judicially enforceable, requirements for the disclosure of records of individuals, including medical information.

²⁷ 42 C.F.R. § 1386.21(f); 42 C.F.R. § 51.31(i).

²⁸ 42 U.S.C. § 15043(a)(2)(J).

WHAT CAN DRO DO WITH THE INFORMATION AND RECORDS THAT IT OBTAINS?

Confidential information kept or obtained by DRO shall remain confidential and may not be subject to disclosure.²⁹ However, DRO 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.³⁰
- **Issue a public report of the results of an investigation** that maintains the confidentiality of individual clients.³¹
- **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.³²
- **Pursue alternative remedies**, including the initiation of legal action.³³

Report suspected abuse concerning a client pursuant to state law.

²⁹ 42 U.S.C. § 10806(a); 42 C.F.R. § 51.45(a).

³⁰ 42 C.F.R. § 51.46(a).

³¹ 42 C.F.R. § 51.45(b)(1).

³² 42 C.F.R. 51.45(b)(2).

³³ 42 U.S.C. § 15043(a)(2)(A); 42 U.S.C. § 10805(a)(1)(B)