SUMMARY OF DISABILITY RIGHTS SOUTH DAKOTA'S ACCESS AUTHORITY

WHAT IS DISABILITY RIGHTS SOUTH DAKOTA?

Disability Rights South Dakota (DRSD) is an independent, private, nonprofit South Dakota agency established in 1977 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. Disability Rights South Dakota is the advocacy system for the State of South Dakota.

Congress subsequently expanded the responsibilities of the existing P&As to advocate for all persons with mental illness pursuant to the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act, 42 U.S.C. § 10801 *et seq*. Congress later 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 DISABILITY RIGHTS SOUTH DAKOTA ENGAGE IN?

In protecting and advocating for the rights of persons with disabilities, Disability Rights South Dakota has authority to:

- **Investigate incidents of abuse and neglect** if the incident is reported to Disability Rights South Dakota or if Disability Rights South Dakota determines that there is probable cause to believe the incident occurred.[2]

- **Pursue administrative, legal, and other appropriate remedies** or approaches to ensure the protection of rights of eligible persons with disabilities.[3]

- **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 South Dakota.[4]

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[1] Congress intended that the authorities under the DD, PAIMI and PAIR laws be applied in a consistent manner. The PAIR Program expressly incorporates by reference (at 29 U.S.C. § 794e(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. The PATBI and PAVA Programs also incorporated by reference the DD Act's authority. 42 U.S.C. § 300d-53(k) (PATBI); 42 U.S.C. §15461(a) (PAVA). As a result, citations below are only to the DD and PAIMI Acts.

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

[3] 42 U.S.C. § 10805(1)(B); 42 U.S.C. § 15043(A)(2)(A)(i).

[4] 42 U.S.C. § 15043(a)(2)(A)(ii).

WHAT ARE DISABILITY RIGHTS SOUTH DAKOTA'S INVESTIGATIVE ACCESS AUTHORITIES?

Federal laws and regulations grant DRSD broad authority to access public and private facilities and programs providing services to persons with disabilities. While the PADD and PAIMI Acts' access authorities are identical in many respects, one difference is in their descriptions of the type of facilities in which DRSD has access. The PADD Act regulations broadly permit access to all "service providers" and individuals with developmental disabilities.[5] This authority provides for "access at reasonable times to any individual with a developmental disability in a location in which services, supports, and other assistance are provided to such an individual."[6] The PAIMI Act regulations define "facilities" as: "general and psychiatric hospitals, nursing homes, board and care homes, community housing, juvenile detention facilities, homeless shelters, and jails and prisons, including all general areas as well as special mental health or forensic units."[7] This authority extends to all settings that provide care and treatment to individuals with mental illness.[8]

These statutes provide for two types of authority: Monitoring; and investigation of allegations of abuse and neglect, which includes access to records.

DRSD'S MONITORING AUTHORITY

Congress has enacted statutes granting all P&As the authority to access public and private facilities/service providers and residents/individuals with developmental disabilities[9] for the purposes of monitoring and observation to ensure the safety and health of the residents, and to provide information on resident rights.

DRSD is entitled to unaccompanied access to facilities, which includes all areas that are used by residents or are accessible to the residents.[10] DRSD is permitted such unaccompanied access to service providers at reasonable times, which includes, at a minimum, normal working hours and visiting hours.[11] Such access shall be allowed without advance notice.[12] Monitoring activities,

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[5] 45 C.F.R. § 1326.27(a).
[6] 42 U.S.C. § 15043(a)(2)(H).
[7] 42 C.F.R. § 51.2.
[8] 42 U.S.C. §10805(a)(3).
[9] Because the PAIMI Act refers to "facilities" and "residents," and the PADD Act refers to "service providers" and "individuals with developmental disabilities," these terms may be used interchangeably herein when both laws or regulations are cited because the language of the statutes/regulations are identical or substantially identical but for that difference. Individuals with disabilities who do not meet PADD and PAIMI eligibility criteria are eligible under DRSD's PAIR Program, which adopted the PADD access authorities. 29 U.S.C. 794e.
[10] 42 C.F.R. §51.42(c); 45 C.F.R. § 1326.27(c).
[11] 42 C.F.R. §51.42(c); 45 C.F.R. § 1326.27(c).
[12] *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).

however, will be conducted so as to minimize interference with programs and to respect the privacy of service recipients or residents.[13] This access is granted for purposes of:

1. Providing information and training on, and referral to, programs addressing the needs of individuals with disabilities, providing information and training on individual rights, and providing information on DRSD;[14]

2. Monitoring compliance with respect to the rights and safety of residents;[15] and

3. Inspecting, viewing and photographing (and/or video recording) all areas of the facility which are used by or accessible to residents.[16] This does not include photographing or video recording individuals without written consent.

Unaccompanied access includes the opportunity to meet and communicate privately with the residents of a facility, both formally and informally, by telephone, mail, or in person.[17] A resident includes minors and adults who have legal guardians.[18]

INVESTIGATION OF ALLEGATIONS OF ABUSE OR NEGLECT

A. Facilities and Programs

Disability Rights South Dakota is granted reasonable unaccompanied access to public and private facilities/service providers and programs in South Dakota providing services to persons with disabilities.[19] Disability Rights South Dakota must be permitted such access without advance notice and access must be made immediately upon request and at all times necessary for the purposes of conducting a full investigation of abuse or neglect. In addition, DRSD shall have reasonable unaccompanied access to individuals with disabilities at all times necessary to conduct a full investigation of abuse and neglect. This authority includes the opportunity to interview any service recipient/individual with a disability, employee, or other persons, including the person thought to be the victim of abuse or neglect, who DRSD reasonably believes may have knowledge of the incident under investigation.[20]

The access described above shall be afforded upon request by DRSD when:

1. An incident is reported or a complaint is made to DRSD;

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[13] 42 C.F.R. § 51.42(c); 45 C.F.R. § 1326.27(c)(2).
[14] 42 C.F.R. § 51.42(c)(1); 45 C.F.R. § 1326.27(c)(2)(i).
[15] 42 C.F.R. § 51.42(c)(2); 45 C.F.R. § 1326.27(c)(2)(ii).
[16] 42 C.F.R. § 51.42(c)(3); 45 C.F.R. § 1326.27(c)(2)(iii).
[17] 42 C.F.R. § 51.42(d); 45 C.F.R. § 1326.27(d).
[18] 42 C.F.R. § 51.42(c); 45 C.F.R. § 1326.27(c)(1).
[19] 42 C.F.R. § 51.42(b); 45 C.F.R. § 1326.27(b)(2).
[20] 42 C.F.R. § 51.42(b); 45 C.F.R. §1326.27(b), (b)(2).

2. DRSD determines there is probable cause to believe that an incident has or may have occurred; or

3. DRSD determines that there is or may be imminent danger of serious abuse or neglect of an individual with a disability.[21]

"Probable cause. The term 'probable cause' means a reasonable ground for belief that an individual with developmental disability(ies) has been, or may be, subject to abuse or neglect, or that the health or safety of the individual is in serious and immediate jeopardy. The individual making such determination may base the decision on reasonable inferences drawn from his or her experience or training regarding similar incidents, conditions or problems that are usually associated with abuse or neglect."[22]

Under federal law, Disability Rights South Dakota 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.[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]

B. Information and Records

Disability Rights South Dakota is entitled to access the records of people with disabilities[25] under the following circumstances:

- If an individual who is a client of DRSD or has sought services from DRSD, or the individual's guardian, conservator, or other legal representative authorizes DRSD to have access to information and records.[26,27]

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[21] 42 C.F.R. § 51.42(b)(1-3); 45 C.F.R. § 1326.27(b)(1)(i-iii).
[22] 45 C.F.R. § 1326.19; *See also* 42 C.F.R. § 51.2.
[23] *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).
[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] "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).
[26] 42 C.F.R. § 51.41(b)(1); 45 C.F.R. § 1326.25(a)(1).
[27] "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, and who has the authority to consent to health/mental health care or treatment of an individual with mental illness or make decisions on behalf of an individual with a developmental disability. These terms include the parent of a minor, unless the State has appointed another legal guardian. These terms do not include a person acting

- Any individual, including an individual who has died or whose whereabouts are unknown, 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 South Dakota 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 guardian is the State (or one of its political subdivisions); and

  - A complaint or report has been received by DRSD and/or DRSD has probable cause to believe the individual has been or may be subject to abuse and neglect.[28]

- An individual who has a legal guardian, conservator, or other legal representative with respect to whom a complaint or report has been received by DRSD, and/or with respect to whom DRSD has determined that probable cause exists to believe that the health or safety of the individual is in serious and immediate jeopardy/the individual has been subject to abuse and neglect, whenever all of the following conditions exist:

  - DRSD has made a good faith effort to contact the representative upon prompt receipt of the representative's name and address;[29]

  - DRSD has offered assistance to the representative to resolve the situation; and

  - The representative has failed or refused to act/provide consent on behalf of the person. [30]

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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, supports and assistance to an individual with a disability. 45 C.F.R. § 1326.19; 42 C.F.R. § 51.2.

[28] 42 C.F.R. § 51.41(b)(2); Note, the PADD regulation differs, as the clause, "including an individual who has died or whose whereabouts are unknown," is not contained therein at 45 C.F.R. § 1326.25(a)(2). However, a separate section states: "In the case of death, no consent from another party is needed. Probable cause to believe that the death of an individual with a developmental disability resulted from abuse or neglect or any other specific cause is not required for the P&A system to obtain access to the records. Any individual who dies in a situation in which services, supports, or other assistance are, have been, or may customarily be provided to individuals with developmental disabilities shall, for the purposes of the P&A system obtaining access to the individual's records, be deemed an 'individual with a developmental disability.'" 45 C.F.R. § 1325(a)(5).

[29] The PADD regulation adds telephone number and email address. 45 C.F.R. § 1325(a)(3)(i).

[30] 42 C.F.R. § 51.41(b)(3); 45 C.F.R. § 1326.25(a)(3).

- If DRSD determines there is probable cause to believe the health or safety of an individual is in serious and immediate jeopardy, no consent from another party is needed.[31]

- In the case of a death, no consent from another party is needed. Probable cause to believe the death of an individual with a developmental disability resulted from abuse or neglect or any other specific cause is not required in this instance for DRSD to obtain access to the records.[32]

DRSD has authority to access information and individual records, whether written or in another medium, draft or final, including handwritten notes, electronic files, photographs or video or audiotape recordings. These 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 provider staff. This includes records stored or maintained at sites other than that of the facility/program/service provider, as well as records that were not prepared by the service provider, but received from other service providers.[33]

- Reports prepared by an agency (Federal, State, or local governmental agency or a private organization) charged with investigating reports of incidents of abuse, neglect, injury, or death. The reports described herein describe any of the following: Incidents of abuse, neglect, injury, or death (occurring at the facility); the steps taken to investigate the incidents; reports and records, including personnel records, prepared or maintained by the facility/service provider in connection with such reports of incidents; or supporting information that was relied upon in creating a report, including all information and records used or reviewed in preparing reports, such as records describing persons who were interviewed, physical and documentary evidence that was reviewed, and the related investigative findings.[34]

- Discharge planning records.[35]

- 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

[31] 45 C.F.R. § 1326.25(a)(4).
[32] 45 C.F.R. § 1326.25(a)(5); *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).
[33] 42 C.F.R. § 51.41(c)(1); 45 C.F.R. § 1326.25(b)(1).
[34] 42 C.F.R. § 51.41(c)(2); 45 C.F.R. § 1326.25(b)(2).
[35] 42 C.F.R. § 51.41(c)(3); 45 C.F.R. § 1326.25(b)(3).

assessments prepared for a facility by its staff, contractors, or related entities;[36] and

- Information in professional, performance, building, or other safety standards, and demographic or statistical information relating to a facility.[37]

DRSD also has authority to have access to "other records that are relevant to conducting an investigation."[38]

DRSD shall have reasonable access and authority to interview and examine all relevant records of any facility service recipient or employee.[39]

DRSD shall be permitted to inspect and copy records, subject to a reasonable charge to offset duplicating costs.[40]

Educational agencies, including public, private, and charter schools, as well as public and private residential and non-residential schools, must provide DRSD with the name and contact information for the parent or guardian of a student when DRSD has probable cause to obtain records.[41]

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

If DRSD determines there is probable cause to believe the health or safety of an individual with a developmental disability is in serious and immediate jeopardy, or in any case involving a death, access of records shall be provided within 24 hours of DRSD's written request for records without consent of another party. In all other situations, access to records of individuals with developmental disabilities shall be provided within three business days after receipt of such written request.[42]

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[36] 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).
[37] 42 C.F.R. § 51.41(c)(5); 45 C.F.R. § 1326.25(b)(4).
[38] 42 U.S.C. § 15043(a)(2)(J)(i).
[39] 42 C.F.R. § 51.41(d).
[40] 42 C.F.R. § 51.41(e); 45 C.F.R. § 1326.25(d). The PADD regulation further states the service provider cannot charge more than it would charge other non-profit or State government agencies, the P&A may use its own photocopying equipment, and if a party other than the P&A performs the photocopying or reproduction, it must provide the copies within the 24-hour or three business day timelines. Records that are kept or maintained electronically shall be provided electronically.
[41] 45 C.F.R. § 1326.25(f).
[42] 45 C.F.R. § 1326.25(c). The PAIMI Act requires records access to occur "promptly." 42 C.F.R. § 51.41(a).

DENIAL OR DELAY OF ACCESS

If DRSD's access to facilities, programs, residents, or records is delayed or denied, DRSD shall promptly be provided with a written statement of reasons, including, in the case of a denial for alleged lack of authorization, the name, address, and telephone number of the legal guardian, conservator, or other legal representative of the individual with a disability.[43]

Disability Rights South Dakota's authority to access records as described above is not affected by the regulations implementing the Health Insurance Portability and Accountability Act (HIPAA).[44] 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."[45] Further, state law restrictions on the disclosure of records or access to minors or individuals with guardians for monitoring purposes are preempted by Disability Rights

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[43] 42 C.F.R. § 51.43. The PADD regulations specify that if access to records is denied or delayed beyond the one or three business day time limits, the written statement for the reason for the delay or denial must be provided within one business day after expiration of such deadline. 45 C.F.R. § 1326.26. The PADD regulations require access to service providers for monitoring purposes "immediately upon an oral or written request by the P&A system." Except where complying would interfere with the treatment or therapy, services providers shall provide access to individuals. 45 C.F.R. § 1326.27(c)(1). This section further states, if access to an individual must be delayed beyond 24 hours, DRSD must have access to the individual "as soon as possible thereafter," but then provides a lengthy description of the process that must be followed should access to the individual be denied on grounds that such access would interfere with the individual's treatment or therapy.

[44] 45 C.F.R. § 1326.25(e). The PADD Act specifically states HIPAA permits the disclosure of protected health information without authorization of the individual to P&As to the extent such disclosure is required by law and the disclosure complies with the requirements of that law.

[45] 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 DRSD discussed above are "required by law" within the meaning of the regulation. 45 C.F.R. § 164.103 states, "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, DRSD's enabling legislation contains express, judicially enforceable, requirements for the disclosure of records of individuals, including medical information. See also, *Prot. & Advocacy Sys., Inc. v. Freudenthal*, 412 F. Supp.2d 1211, 1212 (D. Wyo. 2006) ("[N]either HIPAA nor the Medicaid Act bars the [Protection and Advocacy Agency] from accessing records at [the hospital] and [the school] as long as the disclosure is required by a P & A act and P & A complies with all requirements set forth in the P & A act."). Similarly, FERPA and IDEA do not bar P&A access to records. *See Disability Law Ctr. of Alaska, Inc. v. Anchorage Sch. Dist.*, 581 F.3d 936 (9th Cir. 2009); *Michigan Protection and Advocacy, Inc., v. Miller*, 849 F. Supp 1202 (W.D. Mich. 1994).

South Dakota's federal access authority to the extent such restrictions may pose an obstacle to such authority.[46]

WHAT ARE DISABILITY RIGHTS SOUTH DAKOTA'S CONFIDENTIALITY RESPONSIBILITIES?

DRSD must ensure records are protected from loss, damage, tampering or use by unauthorized individuals. DRSD must keep confidential all records and information, including information contained in any automated electronic database pertaining to: clients, individuals who have been provided general information or technical assistance, identity of individuals who report incidents of abuse or neglect or furnish information that forms the basis for a determination of probable cause, and names of individuals who are resident and provide information for the record.[47] DRSD must obtain written consent from the client, or from his or her legal representative; individuals who have been provided general information or technical assistance on a particular matter; and individuals who furnish reports or information that form the basis for a determination of probable cause, before releasing information concerning such individuals to those not otherwise authorized to receive it.[48] However, Disability Rights South Dakota may do any of the following:

- **Issue a public report of the results of an investigation** that maintains the confidentiality of individuals described above.[49]

- **Report the results of an investigation which maintains confidentiality of service recipients 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.[50]

[46] 42 C.F.R. § 51.31(i), 51.42(e); 45 C.F.R. § 1326.21(f).
[47] 42 U.S.C. § 10806(a); 42 C.F.R. § 51.45(a); 45 C.F.R. § 1326.28(b)(1).
[48] 42 C.F.R. § 51.45(a)(3); 45 C.F.R. § 1326.28(b)(3).
[49] 42 C.F.R. § 51.45(b)(1); 45 C.F.R. § 1326.28(c).
[50] 42 C.F.R. 51.45(b)(2); 45 C.F.R. § 1326.28(c). The PADD Act regulations further state that notwithstanding the confidentiality requirements of this section, the P&A may make a report to investigative or enforcement agencies that reveals the name of an individual and his or her status or treatment when DRSD has received a complaint the individual has been or may be subject to abuse and neglect or has probable cause (which may be the result of monitoring or other activities such as media reports) to believe the individual may be subject to abuse or neglect, when DRSD determines there is probable cause to believe the health or safety of the individual is in serious and immediate jeopardy, or in any case involving a death of a person believed to have had a developmental disability. 45 C.F.R. § 1326.28(d)(1-3).