



HAWAII DISABILITY RIGHTS CENTER

1132 Bishop Street, Suite 2102, Honolulu, Hawaii 96813

Phone (V/TTY): (808) 949-2922 Toll Free (V/TTY): 1-800-882-1057 Fax: (808) 949-2928

E-mail: Info@HawaiiDisabilityRights.org Website: www.HawaiiDisabilityRights.org

The
ACCESS
and
INVESTIGATIVE AUTHORITY
of the
PROTECTION & ADVOCACY SYSTEM
for
PEOPLE WITH DISABILITIES



HAWAII'S PROTECTION AND ADVOCACY SYSTEM FOR PEOPLE WITH DISABILITIES
HAWAII'S CLIENT ASSISTANCE PROGRAM



WHAT IS THE 'PROTECTION AND ADVOCACY SYSTEM' FOR PEOPLE WITH DISABILITIES?

In 1975, the United States Congress amended the Developmental Disabilities Assistance and Bill of Rights Act, to add a new requirement that each state and territory receiving federal funds under the Act must establish a Protection and Advocacy System for people with developmental disabilities. The system was established to:

- **Protect and advocate for the rights of people with developmental disabilities; and to**
- **Investigate abuse and neglect if reported to the system or if probable cause exists to believe such an incident occurred.**

Over the years, Congress has expanded the mandate of the protection and advocacy system. There are now four federal statutes establishing protection & advocacy for people with specific disabilities:

- **PADD – P&A for People with Developmental Disabilities**
- **PAIMI – P&A for People with Mental Illness**
- **PATBI – P&A for People with Traumatic Brain Injury**
- **PAIR – P&A for Individual Rights (All Others)**

There are also three federal statutes establishing protection & advocacy for specific disability-related issues:

- **PAAT – P&A for Assistive Technology**
- **PABSS – P&A for Beneficiaries of Social Security**
- **PAVA – P&A for Voter Access**

Congress intended to establish one P&A system in each state and territory of the U.S. Therefore, the authority created with each new P&A statute is specifically assigned to the organization holding the original P&A designation for people with developmental disabilities, the:

- ***Protection and Advocacy system established pursuant to Part C of Title I of the Developmental Disabilities Assistance and Bill of Rights Act.***

42 U.S.C. § 15001 *et seq.*

42 U.S.C. § 15043

42 U.S.C. § 15043
42 U.S.C. § 10803
42 U.S.C. § 300d-53
29 U.S.C. § 794e

29 U.S.C. §§ 3011-3012
42 U.S.C. § 1320B-21
42 U.S.C. § 15461

WHO IS THE 'PROTECTION AND ADVOCACY SYSTEM' FOR PEOPLE WITH DISABILITIES IN HAWAII?

On July 1, 1977, a group of disability advocates created a new organization specifically to carry out the new federal Protection and Advocacy mandate.

They registered *Kahua Ho`omalua Kina (A Place of Protection for Handicapped Persons), Inc.* with the State of Hawaii as a non-profit corporation. Shortly after, the corporation registered and began doing business as the *Protection and Advocacy Agency of Hawaii*.

In January 2000, the corporation changed its name to **Hawaii Disability Rights Center (HDRC)**.

As specified in federal law, this organization was designated by Executive Order 77-3 (and succeeding Executive Orders 82-4, 89-2 and 94-06) as Hawaii's Protection and Advocacy (P&A) system for people with disabilities.

42 U.S.C. §§ 15043(a)(1)-(4)

Over the years, the corporation has faithfully maintained its original mission to protect and advocate for the human, civil and legal rights of people with disabilities, as defined:

- **Human Rights** are those natural rights that are accorded to all human beings. They are clearly stated in the U.S. Constitution as the right to life, liberty and the pursuit of happiness.
- **Civil Rights** are an expansion of basic human rights and are specified in the U.S. Constitution, the Bill of Rights and the Hawaii State Constitution. They include the rights to: freedom of religion, speech, press, assembly; petition for change; equal protection under the law; privacy; confidentiality; appeal decisions; freedom from oppression, unlawful search and seizure; and cruel and unusual punishment.
- **Legal Rights** are an expansion of our human and civil rights as established by specific laws, such as those laws which authorize protection and advocacy for people with disabilities.

WHAT ARE THE PROTECTION AND ADVOCACY SYSTEM'S ACTIVITIES?

Federal law authorizes the P&A System to conduct the following activities. The staff of the Hawaii Disability Rights Center may be present at disability facilities and programs for any or all of these purposes.

- | | |
|--|---|
| 1. Provide information, referral and training concerning programs and services for eligible individuals, and training about individual rights and services available from HDRC. | 42 U.S.C. § 15043(a)(2)(A)(ii),
45 C.F.R. § 1386.22(g)(1);
42 C.F.R. § 51.42(c)(1) |
| 2. Investigate incidents of abuse and neglect if the incident is reported to HDRC, or if HDRC determines that there is probable cause to believe the incident occurred. | 42 U.S.C. § 15043(a)(2)(B),
45 C.F.R. § 1386.22(f);
42 U.S.C. § 10805(a)(1)(A),
42 C.F.R. § 51.42(b) |
| 3. Pursue administrative, legal, and other appropriate remedies to ensure the protection of rights of eligible persons with disabilities. | 42 U.S.C. § 15043(a)(2)(i);
42 U.S.C. § 10805(a)(1)(B) |
| 4. Monitor facility or program compliance with respect to the rights and safety of service recipients and individual treatment plans. | 45 C.F.R. § 1386.22(g)(2);
42 C.F.R. § 51.42(c)(3) |

WHAT IS THE PROTECTION AND ADVOCACY SYSTEM'S AUTHORITY TO ACCESS FACILITIES AND PROGRAMS?

The P&A system is authorized under federal law to access facilities or programs providing care and treatment to persons with disabilities, for the purpose of conducting the activities noted in the previous section.

A “**facility**” or “**program**” is defined in the DD Act as a public or private facility providing services, support, care, or treatment to persons with disabilities. These may include:

- Hospitals
- Long-term health care facilities
- Community living arrangements for people with disabilities (including group homes, board and care homes, individual residences or apartments of people with a disability where services are provided)
- Day programs
- Juvenile detention facilities
- Homeless shelters
- Jails or prisons
- Any facilities that are unlicensed but not exempt from licensure
- Public or private schools or other institution or program providing education, training, habilitation, therapeutic, or residential services to people with disabilities.

45 C.F.R. § 1386.19;
42 C.F.R. § 51.2

WHAT IS 'UNANNOUNCED AND UNACCOMPANIED' ACCESS?

Clients of a facility or program may want to complain in confidence about the treatment or services furnished by the provider or facility.

Federal law does not therefore require advance notice for a P&A system to access clients in facilities and programs:

[The P&A] system shall have the authority to...have access at reasonable times to any individual with a developmental disability in a location which services, supports, and other assistance are provided to such an individual[.]

**42 USC § 15043(a)(2)(H),
45 C.F.R. § 1386.22(f);
PAIMI preamble at 53561**

Moreover, federal law specifically authorizes a protection & advocacy system to access clients in facilities and programs on an unescorted basis:

[T]he system and all of its authorized agents shall have unaccompanied access to all residents of a facility at reasonable times, which at a minimum shall include normal working hours and visiting hours, for the purpose of...providing information and training on, and referral to, programs addressing the needs of individuals with developmental disabilities, and the protection and advocacy services available from the system, including the name, address, and telephone number of the system and other information and training about individual rights; and monitoring compliance with respect to the rights and safety of service recipients.

**45 C.F.R. § 1386.22(g);
42 C.F.R. § 51.42(c)**

Unaccompanied access to residents of a facility shall include the opportunity to meet and communicate privately with such individuals regularly, both formally and informally, by telephone, mail and in person.

**45 C.F.R. § 1386.22(h);
42 C.F.R. § 51.42(d)**

**WHAT IS THE PROTECTION AND ADVOCACY SYSTEM'S
AUTHORITY TO ACCESS FACILITY RECORDS AND INFORMATION?**

Congress authorized the P&A System to access the records of facilities serving people with disabilities and the confidential records of people with disabilities.

The types of records that may be accessed are specified by law and include (but are not limited to):

- | | |
|--|---|
| <ul style="list-style-type: none">• 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. | <p>42 U.S.C. § 15043(c)(1),
45 C.F.R. § 1386.22(b)(1);
42 U.S.C. § 10806(b)(3)(A),
42 C.F.R. § 51.41(c)(1)</p> |
| <ul style="list-style-type: none">• Reports prepared by an agency charged with investigating reports of incidents of abuse, neglect, injury, or death occurring at a facility. | <p>42 U.S.C. § 15043(c)(2),
45 C.F.R. § 1386.22(b)(2);
42 U.S.C. § 10806(b)(3)(A),
42 C.F.R. § 51.41(c)(2)</p> |
| <ul style="list-style-type: none">• Personnel records prepared by or maintained by the facility in connection with reports of incidents of abuse, neglect, injury or death. | <p>45 C.F.R. § 1386.22(b)(2)(iii);
42 C.F.R. § 51.41(c)(2)(iii)</p> |
| <ul style="list-style-type: none">• Discharge planning records. | <p>45 C.F.R. § 1386.22(b)(2)(iii);
42 C.F.R. § 51.41(c)(3)</p> |

**WHAT IS THE PROTECTION AND ADVOCACY SYSTEM'S
AUTHORITY TO ACCESS INDIVIDUAL RECORDS AND
INFORMATION?**

The P&A system is entitled to access the confidential records of any person who is a system client, if that person or his or her legal guardian has authorized the system to have access to information and records.

**42 U.S.C. § 15043(a)(2)(I)(i),
45 C.F.R. § 1386.22(a)(1);
42 U.S.C. § 10805(a)(4)(A),
42 C.F.R. § 51.41(b)(1)**

In certain circumstances, the system is authorized to access confidential records without consent:

- If the individual, due to his or her mental or physical condition, cannot be located or is unable to authorize the system to have access to his or her records, has no guardian, and if the system 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.
- If the individual is deceased, and the system 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.
- For an individual with a legal guardian: If a complaint has been received by the system, or if the system has determined that probable cause exists to believe that the person has been subjected to abuse or neglect, and the system has attempted to contact the legal guardian upon receipt of the representative's name and address, has offered assistance to the representative to resolve the situation, and the representative has failed or refused to act on behalf of the individual.

**42 U.S.C. § 15043(a)(2)(I)(ii),
45 C.F.R. § 1386.22(a)(2);
42 U.S.C. § 10805(a)(4)(B),
42 C.F.R. § 51.41(b)(2)**

**42 U.S.C. § 15043(a)(2)(I)(ii);
45 C.F.R. § 1386.22(a)(2);
42 U.S.C. § 10805(a)(4)(B),
42 C.F.R. § 51.41(b)(2)**

**42 U.S.C. § 15043(a)(2)(I)(iii),
45 C.F.R. § 1386.22(a)(3);
42 U.S.C. § 10805(a)(4)(C),
42 C.F.R. § 51.41(b)(3)**

WHAT IF A FACILITY OR PROGRAM DENIES ACCESS TO THE PROTECTION AND ADVOCACY SYSTEM?

A facility or program must promptly provide in writing its reasons for delaying or denying access to the P&A system.

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

If the P&A system is denied access because it does not have the required authorization of a legal guardian or conservator, federal law requires that the facility, program or service provider promptly provide the system 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.

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

If facility or program access is denied, a P&A is authorized to pursue administrative, legal, and other appropriate remedies, as part of its mandate to ensure the protection of rights of eligible persons with disabilities.

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

WHAT ARE THE DEFINITIONS OF 'NEGLECT' AND 'ABUSE'?

Neglect means a negligent act or omission by an individual responsible for providing treatment or habilitation services which causes or may cause injury or death to an individual with developmental disabilities, or which places an individual with developmental disabilities at risk of injury or death, and includes acts or omissions such as failure to:

- Establish or carry out an appropriate individual program plan or treatment plan (including a discharge plan);
- Provide adequate nutrition, clothing, or health care to an individual with developmental disabilities; and
- Provide a safe environment (which also includes the failure to maintain adequate numbers of trained staff).

Abuse means any act or failure to act which is performed, or fails to be performed, knowingly, recklessly, or intentionally, and which causes, or may cause, injury or death to an individual with developmental disabilities, and includes such acts as:

- Verbal, nonverbal, mental and emotional harassment;
- Rape or sexual assault;
- Striking;
- The use of excessive force when placing such an individual in bodily restraints;
- The use of bodily or chemical restraints which is not in compliance with Federal and State laws; and
- Regulations or any other practice which is likely to cause immediate physical or psychological harm, or result in long-term harm if such practices continue.

45 C.F.R. § 1386.19;
42 C.F.R. § 51.2

45 C.F.R. § 1386.19;
42 C.F.R. § 51.2

WHAT CONSTITUTES NEGLECT OR ABUSE?

In addition to the P&A System, there are a number of regulatory agencies with responsibilities to respond to reports of neglect or abuse, such as Adult Protective Services (APS) and the Office of Health Care Assurance (OCHA). Each agency uses its own statutory and regulatory standards to assess the presence of neglect or abuse. The standards of one agency may require no action to cite, fine, or revoke the license of a facility, while the standards of another will.

In establishing the Protection and Advocacy System, Congress intended to protect individuals who historically, were especially vulnerable to horrific abuse and neglect, and empowered the system with a broad scope of activities, access authority, and remedies.

In the DD Act, Congress also declared that:

- Treatment and services for individuals with disabilities should maximize their potential and should be provided in a setting that is least restrictive of their personal liberty.
- Individuals should be able to achieve full individual integration and inclusion into society, consistent with individual capabilities.
- Such individuals are entitled to humane care and treatment, and self-determination to exert control and choice over their lives.

It is an essential function of the P&A System to protect the civil and human rights of individuals with disabilities. In this context, the abuse and neglect that is the subject of a P&A investigation may be wholly different -- in definition and act -- from the abuse and neglect standards of any other agency.

**Preamble to the DD Act,
42 U.S.C. § 15000(a)**

42 U.S.C. § 15009(a)(2)

42 U.S.C. § 15001(a)(16)(G)

42 U.S.C. § 15002(27)

HOW DOES THE P&A SYSTEM LEARN OF NEGLECT OR ABUSE?

The P&A System has a responsibility to maintain a regular presence at facilities and programs that provide services for people with disabilities.

- Incidents of neglect or abuse may come to the attention of the P&A system through its own observations while present at the facility for routine monitoring, to provide training, or as advocates for individual clients.
- Individuals may make an allegation or report of neglect or abuse to the P&A system. Such an allegation of neglect or abuse will require an investigation by the P&A system to substantiate or disprove the allegation.
- The federal Center on Medicare & Medicaid Services (CMS) delegates licensing and oversight of Intermediate Care Facilities (Mental Retardation) to the State. Under federal law, the State must provide the P&A system with a copy of each independent review of such a facility within the State, not later than 30 days after the availability of such a review.

If a review finds violations, the State issues a written report that requires the facility to undertake corrective or remedial action, with specific deadlines for the action(s). It is highly unusual for the State to do more than cite violations, such as imposing a fine or revoking the license of the facility. This does not necessarily mean, however, that the violations are insignificant.

These reports, particularly when they provide evidence that no corrective action has been undertaken by a facility, may provide a basis for the P&A system to conclude that “neglect or abuse” within the definitions of the DD Act may be occurring, thus triggering its own investigation of the violation(s).

42 U.S.C. § 15043(a)(2)(B),
45 C.F.R. § 1386.22(a)(2);
42 U.S.C. § 10805(a)(4)(B),
42 C.F.R. § 51.42

42 U.S.C. § 15043(a)(1),
45 C.F.R. § 1386.22(a)(3)
and (f);
42 U.S.C. § 10805(a)(1)(A),
42 C.F.R. § 51.42(b)

42 U.S.C. § 15043(a)(3)

WHAT IS 'PROBABLE CAUSE'?

Probable cause is defined in DD Act regulations as:

[A] reasonable ground for belief that that an individual with developmental disabilities has been, or may be, subject to abuse or neglect. 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.

The regulations establish a low threshold on the amount of factual information required to make a determination of probable cause.

Some of the confusion surrounding "probable cause" stems from criminal law requirements that pertain to search or arrest warrants. In the criminal law context, there is a stringent requirement for probable cause because such a finding will result in the serious infringement of someone's liberty. The legal system will not permit actions such as search, seizure and arrest without a reasonable threshold of hard evidence.

In the context of an investigation by the P&A System, however, the courts have uniformly held that the liberty interest to be protected is significantly lower. P&A systems are not regulatory agencies or oversight agencies and they do not have the power to fine or arrest individuals or entities. If the P&A System declares probable cause, all it can do is to enter a facility to observe conditions, meet with individuals or residents with disabilities, take photographs, or examine records.

45 C.F.R. § 1386.19

See also nearly identical
PAIMI definitions at:
42 C.F.R. § 51.2

WHO DETERMINES 'PROBABLE CAUSE'?

The P&A System determines probable cause 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.

Case law makes it very clear the determination of probable cause by the P&A System cannot be questioned, second-guessed, or otherwise subject to third-party review. Every court to consider this issue has concluded that the P&A System is the sole and final arbiter of whether it has probable cause to conduct an investigation of alleged abuse and neglect. To conclude otherwise would frustrate the purpose of the DD Act and its establishment of the nationwide P&A system.

45 C.F.R. § 1386.19;
42 C.F.R. § 51.2

WHAT HAVE THE FEDERAL COURTS SAID ABOUT 'PROBABLE CAUSE'?

The **U.S. Court of Appeals for the Eleventh Circuit** upheld a determination of probable cause made by a P&A on the basis of an anonymous phone call. The Court elaborated:

[W]e also agree with the district court's finding that "the anonymous phone call provides enough evidence to support allegations of abuse and neglect and thereby establishes probable cause."

In so doing, we note that unlike criminal law probable cause, the consequence of a P&A's determination of probable cause is not an indictment or an accusation, but rather a civil investigation. Moreover, no fundamental liberty or privacy interest is impinged when a P&A finds probable cause to investigate an incident at a facility.

...Minor inconveniences to staff or some disruption of the facility's routine hardly rise to the level of the liberty interest that is generally at issue in a criminal investigation. Indeed, one would suppose that a facility's legitimate interests are served when abuse and neglect are uncovered and can be corrected. Likewise, when a P&A makes a finding of probable cause, no liberty interest of the developmentally disabled person is threatened, as it is precisely that individual's interest that the P&A seeks to protect. [citations omitted]

Alabama Disabilities
Advocacy Program vs.
J.S. Tarwater
Developmental Center,
97 F.3d 492, 498 (1996)

WHAT HAVE THE FEDERAL COURTS SAID ABOUT 'PROBABLE CAUSE'?

The **U.S. District Court for the District of Connecticut** provides a very detailed analysis of this issue as well as numerous citations of cases which have held along these lines, very clearly stating:

[I]t is by now a settled principle that the P&A is the "final arbiter of probable cause for the purpose of triggering its authority to access all records for an individual that may have been subject to abuse or neglect." Such a position has been overwhelmingly agreed with by other courts. [citations omitted]

Furthermore, courts have limited similar attempts to question the probable cause determination made by a P&A. For example, courts have rejected attempts to require judicial review of the P&A's probable cause determination. [citations omitted] In Maryland Disability Law Ctr v. Mt. Washington Pediatric Hospital, the court found that "[t]he initial determination of probable cause to undertake an investigation must be made by the [P&A]," and that the "requirement that the [P&A] convince the circuit court that probable cause exists prior to having access to patients, personnel, and records is burdensome and unnecessary." The court emphasized that the P&A must have "sufficient means of access" in order to fulfill the role it had been entrusted with. [citations omitted]

The **U.S. District Court for the District of Arizona** stated that:

[T]he P&A laws and the regulations promulgated there under support the conclusion that a P&A is the final arbiter of probable cause for the purpose of triggering its authority to access all records for an individual that may have been subject to abuse or neglect. To conclude otherwise would frustrate the purpose of the P&A laws to establish an effective system to protect and advocate for the rights of individuals with disabilities. Without access to records, a P&A system is unable to accomplish its congressional mandate to investigate incidents of abuse and neglect when the P&A has probable cause to believe that such incidents have occurred.

Office of Protection and Advocacy for Persons with Disabilities vs. Armstrong, 266 F. Supp. 2d 303 (D. Conn. 2003)

Ariz. Cen. for Disability Law v. Allen, 197 F.R.D. 689 (D. Az. 2000)

'HIPAA' AND THE P&A SYSTEM

The P&A System's federal authority to access records, facilities and individuals is not affected by the regulations implementing the Health Insurance Portability and Accountability Act (HIPAA).

The HIPAA Privacy Rule expressly permits a covered entity to disclose protected health information without the authorization of the individual to a protection and advocacy system, when that disclosure is required by laws such as the DD Act and the disclosure complies with the requirements of that law.

45 C.F.R. § 164.512(a)(1)

See also frequently asked questions on the HHS HIPAA website, at: www.healthprivacy.answers.hhs.gov.

'FERPA' AND THE P&A SYSTEM

The P&A System's federal authority to access records, facilities and individuals is not affected by the regulations implementing the Family Education Rights and Privacy Act (FERPA).

FERPA does not specifically prohibit HDRC from access to education records, facilities, students, or staff, when a parent or legal guardian has given their consent.

If consent is withheld or not obtainable, access may still be required under the DD Act based on the specific circumstances discussed above.

20 U.S.C. § 1232g(b)(2)

**42 U.S.C. §§ 15043(a)(2)(I)-(J),
45 C.F.R. § 1386.22;
42 U.S.C. § 10805(a)(4),
42 C.F.R. § 51.41**

WHAT CAN THE P&A SYSTEM DO WITH THE RECORDS AND INFORMATION THAT IT OBTAINS?

Confidential information kept or obtained by the P&A System is protected by federal laws that prohibit a protection and advocacy system from re-disclosing information.

45 C.F.R. § 1386.22(e);
42 U.S.C. § 10806(a),
42 C.F.R. § 51.45

Federal law permits a P&A System to:

- **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.

42 C.F.R. § 51.46(a)

42 C.F.R. § 51.45(b)(1)

42 C.F.R. § 51.45(b)(2)

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

The P&A System may also report suspected elder or dependent adult abuse to the State's Adult Protective Services (APS).

H.R.S. §§ 28-94 and
346-224, respectively



The
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(HDRC)**
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for
PEOPLE WITH DISABILITIES

**For More Information; or
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Please Contact:**

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1132 Bishop Street, Suite 2102, Honolulu, Hawaii 96813

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