

Date of Hearing: June 18, 2019

ASSEMBLY COMMITTEE ON HUMAN SERVICES

Eloise Gómez Reyes, Chair

SB 398 (Durazo) – As Amended May 21, 2019

**SENATE VOTE:** 38-0

**SUBJECT:** Protection and advocacy agency

**SUMMARY:** Adopts changes that conform to federal law, regulation, and guidance as they relate to the role and authority of the state’s protection and advocacy (P&A) agency to ensure the rights and safety of individuals with disabilities. Specifically, **this bill:**

- 1) Modifies certain definitions in current law related to the scope of authority of the P&A agency as follows, and as specified:
  - a) Clarifies that “abuse” means an act, or failure to act, that was performed or not performed, knowingly, recklessly, or intentionally, and that caused or may have caused, injury, or death to an individual with disabilities, which includes, but is not limited to, harassment, rape or sexual assault, or striking, among others, or any other violation of an individual’s legal rights, including, but not limited to, subjecting an individual to significant financial exploitation;
  - b) Clarifies that “complaint” includes, but is not limited to, any report or communication, received by the P&A agency, including, but not limited to, media accounts, newspaper articles, and electronic communications, among others;
  - c) Includes “service provider” in the definition of “facility” or “program,” includes a facility used to house or detain noncitizens for the purpose of civil immigration custody among the list of facility types to which the P&A agency has access, and, further, includes recreation among the services provided by such a facility or program;
  - d) Specifies that the terms “legal guardian,” “conservator,” or “legal representative” are individuals who are regularly reviewed by a state court or agency empowered under state law to appoint such positions, and clarifies that they do not include an executor or administrator of an estate;
  - e) Clarifies that “neglect” means a negligent act, or omission to act, by an individual, and includes, but is not limited to the failure to: establish or carry out an appropriate individual program plan or treatment plan; provide adequate nutrition, clothing, or health care to an individual with a disability; or, provide a safe environment;
  - f) Specifies that a condition of “probable cause” exists when it is believed that the health or safety of an individual is in serious and immediate jeopardy; and,
  - g) Includes “service provider” in the definition of “reasonable unaccompanied access” as it pertains to the P&A agency’s permission to meet and communicate with certain entities and review records, and, further, prohibits the P&A from being required to provide

certain information about the nature of certain meetings, with whom those meetings occurred, or justification for those meetings.

- 2) Makes changes to the scope of the authority of the P&A agency to protect and advocate for the rights of individuals with disabilities as follows, and as specified:
  - a) Includes monitoring a facility's, program's, or service provider's compliance with respect to the rights and safety of individuals with disabilities as within the purview of the P&A agency's authority;
  - b) Specifies that the P&A agency and its authorized agents have reasonable unaccompanied access to public or private facilities, programs, and service providers, including all areas of their respective premises;
  - c) Clarifies that the P&A agency has reasonable access to service recipients of public or private facilities, programs, or services providers without advance notice;
  - d) Specifies that "access" as it relates to the P&A agency's authority, includes the opportunity to interview any individual with a disability, employee, or other person who might be reasonably believed by the agency to have knowledge of an incident under investigation, and, further, prohibits the agency from being required to provide some information related to the nature of certain meetings, with whom those meetings occurred, or justification for those meetings;
  - e) Requires access to an individual to be afforded immediately upon request under specified circumstances and with certain exceptions;
  - f) Specifies the right of the P&A agency to have reasonable unaccompanied access during reasonable times, and further, requires agency activities be conducted in compliance with certain considerations related to the privacy and requests of recipients;
  - g) Permits the P&A agency to post, in an area in which individuals with disabilities receive services, a poster identifying the services available from the agency and the agency's contact information;
  - h) Specifies that P&A agency access does not include photographing or video recording individuals with disabilities without their consent;
  - i) Prohibits a facility, program, or service provider from being required to afford a P&A agency immediate access to the facility if complying with a request for access would interfere with treatment or therapy being provided to an individual with a disability, and, further, specifies certain requirements with which the facility, program, or service provider must comply in the event that the P&A agency is denied immediate access to an individual with a disability;
  - j) Permits the P&A agency to attend treatment planning meetings concerning individuals with disabilities, except in certain circumstances; and,
  - k) Deletes the ability of a care provider, as specified, to charge a reasonable fee to cover the costs of copying records.

- 3) Makes changes related to the P&A agency's access to records of individuals with disabilities as follows, and as specified:
  - a) Defines a "person with a disability" to include a person who died in a situation in which services, supports, or other assistance is, or has, customarily been provided to people with disabilities;
  - b) Specifies that probable cause to believe that the death of an individual with a disability resulted from abuse or neglect or any other specific cause is not required for the P&A agency to obtain access to records;
  - c) Clarifies the conditions under which the P&A agency may access the records of an individual who has a legal guardian, conservator, or other legal representative under certain circumstances;
  - d) Specifies that, if certain conditions exist, the P&A agency may access the records of any other person with a disability if the P&A agency determines that there is probable cause to believe that the health and safety of an individual is in serious and immediate danger;
  - e) Specifies that the records available to the P&A agency include records stored or maintained at sites other than that of the facility, program, or service provider, and records that were not prepared by the facility, but that were received by the facility, program, or service provider, in addition to a federal, state, or local governmental agency or a private organization, and include, but are not limited to, agencies in the foster care system, disabilities systems, and prison and jail systems, among others;
  - f) Requires an educational agency, to provide the P&A agency with the name and contact information for the parent or guardian of a student for whom the P&A agency has probable cause to obtain records;
  - g) Requires, in the event that the P&A agency's access to records is denied or delayed, the agency to be provided with a written statement of reasons for the denial or delay, and, further, allows the agency to inspect and copy information and records, subject to a reasonable charge, and in compliance with certain requirements;
  - h) Requires the P&A agency to obtain written consent from certain individuals before releasing information concerning those individuals to a person not otherwise authorized to receive it;
  - i) Allows the P&A agency to make a report to investigative or enforcement agencies that reveals the identity of an individual with a disability in certain circumstances; and,
  - j) Permits the sharing of health information and records with a P&A system, to the extent required and permitted by law, and, further, makes Legislative findings and declarations that the federal Health Insurance Portability and Accountability Act of 1996 privacy rule permits the disclosure of protected health information to a P&A agency without the authorization of the individual who is the subject of the records to the extent that the disclosure is required by law and the disclosure complies with the requirements of that law.

- 4) Makes technical and conforming changes.

**EXISTING LAW:**

- 1) Defines “abuse” as an act, or failure to act, by an employee of a facility rendering care or treatment which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury or death to an individual with developmental disabilities and includes but is not limited to acts such as: rape or sexual assault; striking; the use of excessive force; the use of bodily or chemical restraints not in compliance with federal or state laws and regulations; verbal, nonverbal, mental and emotional harassment; and, any other practice which is likely to cause immediate physical or psychological harm or result in long-term harm if such practices continue. (Welfare and Institutions Code [WIC] 4900 (b))
- 2) Defines “complaint” as any report or communication, whether formal or informal, written or oral, received by the P&A agency, including media accounts, newspaper articles, telephone calls (including anonymous calls) from any source alleging abuse or neglect of an individual with mental illness. (WIC 4900 (c))
- 3) Defines a “facility” or “program” as a public or private facility or program providing services, supports, care, or treatment to persons with disabilities, even if only on an as-needed basis or under contractual agreement, and includes, but is not limited to: a hospital, a long-term health care facility, a community living arrangement for people with disabilities, including a group home, a board and care home, an individual residence or apartment of a person with a disability where services are provided, a day program, a juvenile detention facility, a homeless shelter, a jail, or a prison, including all general areas, as well as special, mental health, or forensic units. (WIC 4900 (e))
- 4) Defines a “legal guardian,” “conservator,” or “legal representative” as 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. Further, states that this individual has the legal authority to make all decisions on behalf of an individual who has developmental disabilities, as defined. (WIC 4900 (f))
- 5) Defines “neglect” as a negligent act or omission by an individual responsible for providing services in a facility rendering care or treatment which caused, or may have caused, injury or death to an individual with a developmental disability(ies) or which placed an individual with developmental disability(ies) at risk of injury or death, and includes, but is not limited to, acts or omissions such as failure to: establish or carry out an appropriate individual program or treatment plan (including a discharge plan); provide adequate nutrition, clothing, or health care; and, the failure to provide a safe environment which also includes failure to maintain adequate numbers of appropriately trained staff. (WIC 4900 (g))
- 6) Establishes the existence of “probable cause” when the P&A agency determines that it is objectively reasonable for a person to entertain the belief that an individual has been subject to abuse or neglect, or is at significant risk of being subject to abuse or neglect. Further, allows the individual making a probable cause determination to base the decision on reasonable inferences drawn from their experience or training regarding similar incidents, conditions, or problems that are usually associated with abuse or neglect, or monitoring or

other activities, including, but not limited to, media reports and newspaper articles. (WIC 4900 (h))

- 7) Defines a “protection and advocacy agency” as the private nonprofit corporation designated by the Governor pursuant to federal law for the protection and advocacy of the rights of persons with disabilities, as specified. (WIC 4900 (i))
- 8) Defines “reasonable unaccompanied access” as access that permits the P&A agency, without undue interference, to monitor, inspect, and observe conditions in facilities and programs, to meet and communicate with residents and service recipients privately and confidentially on a regular basis, formally, or informally, by telephone, mail, electronic mail, and in person, and to review records privately and confidentially, in a manner that minimizes interference with program or service activities, and that respects residents’ privacy interests and honors a resident’s request to terminate an interview, and that does not jeopardize the physical health or safety of a facility or program staff, residents, service recipients, or P&A agency staff. (WIC 4900 (j))
- 9) Authorizes the P&A agency, in protecting and advocating for the rights of people with disabilities, to investigate incidences of abuse or neglect of individuals with disabilities, as specified, pursue administrative, legal, and other appropriate remedies or approaches to ensure the protection of the rights of people with disabilities, and provide information and training on, and referral to, programs and services addressing the needs of people with disabilities, including information and training regarding individual rights and the services available from the P&A agency. (WIC 4902 (a))
- 10) Affords the P&A agency the right to reasonable access to facilities or programs in the state that provide care and treatment to people with disabilities, as well as access to the individuals receiving services from those facilities or programs. (WIC 4902 (b))
- 11) Requires, in the event that the P&A agency’s access to facilities, programs, service recipients, or records is delayed, the facility, program, or service to provide the agency with a written statement of reasons for the delay. (WIC 4902 (c))
- 12) Affords the P&A access to the records of individuals with disabilities and enumerates the scope of the records to which the agency has access. (WIC 4903 *et seq.*)

**FISCAL EFFECT:** This bill has been keyed non-fiscal by the Legislative Counsel.

**COMMENTS:**

***Establishment and expansion of protection and advocacy (P&A) agency authority:*** In 1975, H.R. 4005 (Rogers), P.L. 94-103, was signed into law and required each state to have a statewide P&A system in place by October 1, 1977, in order to protect the rights of individuals with developmental disabilities. P&A agencies were required to be independent of any state agency that provided residential or other services to individuals with developmental disabilities, and were required to provide legal and other advocacy services to protect individuals from abuse and neglect, and advocate on their behalf when they had been denied disability rights. In 1978, Governor Jerry Brown designated Disability Rights California (DRC) (known then as Protection & Advocacy, Inc. [PAI]) as California’s P&A agency. Over the course of the last 40 years, DRC has advocated for the rights of individuals with developmental disabilities, and, according to its

internet website, has worked to educate, investigate, and litigate to advance the rights, dignity, equal opportunities, and choice for people with disabilities.

Since 1975, the mandate of P&As has been expanded to include protection of and advocacy for individuals with other disabilities: in 1986, the adoption of S. 974 (Weicker), P.L. 99-319, known as the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act, included individuals with psychiatric disabilities, and in 1993, the adoption of S. 1295 (Harkin) P.L. 103-73, known as the Protection and Advocacy for Individual Rights (PAIR) Act, included individuals with physical, neurological, sensory, and other disabilities within the purview of P&A agencies. The adoption of these laws provided P&As with broad oversight authority to protect and advocate for the rights of individuals with disabilities, and to pursue administrative, legal, and other remedies in instances of abuse and neglect. Federal law grants P&As broad access to public and private entities that provide services to individuals with developmental disabilities, as well as the information and records prepared or maintained by those entities. In 1991, California enacted SB 1088 (McCorquodale), Chapter 534, Statutes of 1991, which codified in state statute the authority of the P&A agency to carry out federally mandated duties. After the enactment of the PAIR act, California implemented SB 577 (Kuehl), Chapter 878, Statutes of 2003, which, again, conformed state code to federal law. In 2015, federal regulations related to the Developmental Disabilities Assistance and Bill of Rights Act were updated to further specify and clarify the role and authority of the state P&As.

The provisions of this bill will largely conform state law to federal regulations. While federal law includes jails and prisons within the definition of facilities for P&A agencies and extends access to facilities to all authorized agents of a P&A system, neither federal nor state law explicitly include a “facility used to house or detain noncitizens for the purpose of civil immigration custody” in the definition of “facilities.” However, federal guidance provides clarity here: the Administration for Children and Families (ACF) Office of Refugee Resettlement (ORR), on July 13, 2018, issued a memo to grantees providing services to unaccompanied alien children stating:

“A Protection and Advocacy System (P&A) may seek access to your facility(ies), in order to protect any individual with developmental or other disabilities and individuals with a significant mental illness or emotional impairment who may be located in the facility from abuse, neglect, or other violation of rights. The Department of Health and Human Services (HHS) recognizes the authority of P&As...to access the care facilities managed by grantees of the ORR in the HHS ACF.”

The provisions of this bill include a “facility used to house or detain noncitizens for the purpose of civil immigration custody” in the definition of facilities, programs, and service providers.

***Need for this bill:*** The provisions of this bill seek to build upon previously-adopted state and federal legislation that codifies the authority of P&As to investigate abuse and neglect of individuals with developmental disabilities and to pursue administrative, legal, and other remedies when abuse and neglect occurs. Like SB 1088 (McCorquodale) and SB 577 (Kuehl), the provisions of this bill seek to conform state law to federal law as it relates to definitions, scope of the P&A’s authority, and the right of the P&A to access records. This bill also includes “a facility used to house or detain noncitizens for the purpose of civil immigration custody,” which is not explicitly stated in federal law or regulations, among the definition of “facility,” “program,” or “service provider.” This inclusion is based upon information provided in a July

2018 memo from the ORR in which the ACF acknowledges the authority of P&As to access the care facilities managed by grantees of the ORR.

According to the author, “Disability Rights California, California’s Protection and Advocacy Program (P&A), has the responsibility to investigate abuse or neglect of people with disabilities. To fulfill this mandate, federal law provides P&A programs unique authority to access facilities, information and records. [This bill] would ensure that California’s P&A access authority is consistent with federal law. This bill also clarifies that a ‘facility’ or ‘program’ also includes those that are used to house or detain individuals for the purpose of civil immigration custody. It is critical that our state laws recognize this authority and are clear that the federal access authority extends to these facilities. DRC has used this authority to inspect a number of civil immigration adult and juvenile detention facilities in California. DRC recently released a report on the conditions in the Adelanto ICE detention [facility] based on this access authority.”

*Double referral:* This bill will be referred to the Assembly Judiciary Committee should it pass out of this committee.

#### **PRIOR AND RELATED LEGISLATION:**

*SB 1088 (McCorquodale), Chapter 534, Statutes of 1991*, codified the rights and responsibilities of California’s P&A in state law.

*SB 577 (Kuehl), Chapter 878, Statutes of 2003*, amended California law related to the P&A agency to conform to changes made to federal law pursuant to the enactment of the federal PAIR Act.

*S. 1295 (Harkin), P.L. 103-72, 1993*, adopted the PAIR Act to protect and advocate for the legal and human rights of individuals with disabilities.

*S. 974 (Weicker), P.L. 99-319, 1986*, expanded the authority of P&As to include individuals with psychiatric disabilities, among other changes.

*H.R. 4005 (Rogers), P.L. 94-103, 1975*, also known as the Developmental Disabilities Assistance and Bill of Rights Act of 1975, required each state to have a statewide protection and advocacy system in place by October 1, 1977, in order to safeguard the rights of people with developmental disabilities.

#### **REGISTERED SUPPORT / OPPOSITION:**

##### **Support**

California Immigrant Policy Center  
Disability Rights Advocates  
Disability Rights California  
State Council on Developmental Disabilities

##### **Opposition**

None on file

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