

# NJDC Fact Sheet

*"ensuring excellence in juvenile defense  
and promoting justice for all children"*

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## USING YOUR STATE PROTECTION AND ADVOCACY SYSTEM TO ACCESS SERVICES FOR YOUTH WITH DISABILITIES

*Every state has a Protection and Advocacy System (P&A) that can investigate complaints, monitor compliance and access services for youth with disabilities. Contact the National Juvenile Defender Center for information about the P&A in your state.*

Protection and Advocacy systems (P&As) can offer assistance to juveniles with disabilities when their disability-related rights have been violated or unmet. As is often the case, delinquent behavior may be directly related to an ignored or mishandled disability. P&As represent children with mental health problems, including youth who reside in juvenile correctional institutions. Some P&As act as advocates for juveniles during the dispositional phase of a delinquency or abuse/neglect proceeding and make recommendations to the court about appropriate placements.

Protection and advocacy systems are underutilized resources for improving the services received by disabled youth in the justice system. Federally funded and administered by the states, P&As exist in all 50 states and are designed to provide legal assistance and advocacy on behalf of persons with disabilities. They render a variety of services, including information dissemination, service referral, training and education, negotiations, legal services, investigation and monitoring. Topics potentially ripe for advocacy by a P&A include seclusion, restraints, treatment, discharge planning, and transition services.

There are three main federal programs in the P&A system and each targets a specific client group. First, the Protection and Advocacy System for Persons with Developmental Disabilities (PADD) was established by Congress as part of the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (DD Act).<sup>1</sup>

Next, using PADD as a model, Congress established the Protection and Advocacy System for Individuals with Mental Illness (PAIMI) in 1986.<sup>2</sup> The U.S. Department of Health and Human Services administers both PADD and PAIMI.

The Protection and Advocacy System for Individual Rights (PAIR) was created as a catchall program for individuals with severe or other disabilities who are not eligible for services under either PADD or PAIMI.<sup>3</sup> PAIR was enacted as part of the Rehabilitation Act of 1973 and is administered by the Rehabilitation Services Administration of the U.S. Department of Education.

A fourth grant-funded program called the Client Assistance Program (CAP) provides information and assistance to individuals seeking or receiving services

under the Rehabilitation Act.<sup>4</sup> It is also administered by the Rehabilitation Services Administration, under the U.S. Department of Education. CAP will not be focused on because of its limited scope, applicability, and various restrictions, such as its prohibition against class action lawsuits.

Each P&A has the authority to pursue legal, administrative, and other remedies on behalf of its clients; provide information and referral services to residential and nonresidential programs;<sup>5</sup> investigate abuse or neglect of its clients;<sup>6</sup> educate policymakers on decisions relevant to advocacy clientele;<sup>7</sup> and gain access to clients and their records.

The National Association of Protection & Advocacy Systems, Inc. exists as a voluntary membership organization to provide training, technical support, and legislative advocacy for its members and consumers.<sup>8</sup> No one central agency supervises and controls the state P&A systems.

P&As are subject to certain restrictions. For instance, federal law requires that the state P&A agency or office be independent of public and private service providers in the state.<sup>9</sup> Congress requires that P&As develop an annual statement of objectives and priorities to guide their activities. Finally, each P&A must select a governing board to oversee its activities that includes, in part, "individuals with developmental disabilities who are eligible for services," family members, guardians, advocates or individuals who have received services.<sup>10</sup>

### *The Statutory Programs*

Collectively, P&As provide the largest source of legal advocacy for persons with disabilities in the United States.<sup>11</sup> Following the principles that persons with disabilities are equal citizens under the law and are entitled to the same opportunities as all members of society, the P&As' strength lies in their ability to ensure enforcement of rights under the existing statutory entitlement.

*PADD* - The DD Act serves two major purposes. First, it sets out a bill of rights for the developmentally disabled.<sup>12</sup> Many of these rights are directly relevant to youth in the justice system, such as the right to appropriate treatment and rehabilitation services, to receive those services in the

least restrictive environment, to programs that maximize the individual's developmental potential, the right of those in residential treatment to be in facilities that meet their needs, and the right of residents to receive humane and sanitary care. Although this bill of rights cannot be asserted through litigation, it can be used as persuasive authority in advocating for a client and arguing that certain services should be provided in a specific way.

Second, the DD Act provides funding. It offers financial assistance for states to carry out programs designed to improve services and assistance to individuals with developmental disabilities, and it funds a comprehensive nationwide network of protection and advocacy organizations.<sup>13</sup> States receiving funding under the DD Act are required to establish an agency or office responsible for assisting and protecting individuals with developmental disabilities.<sup>14</sup> This funding for advocates encourages states to provide services in line with the bill of rights set out in the DD Act.

*PAIMI* - Unlike the other P&A systems, PAIMI was the result of a specific piece of legislation - the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (MI Act).<sup>15</sup> This act provided for the creation of a P&A system to serve only institutionalized or formerly institutionalized individuals with mental illness.<sup>16</sup> However, the statutory scheme merged PAIMI into the existing P&A systems by designating only PADD systems as eligible for funding under the MI Act.<sup>17</sup> Although PADD served as the basic model for PAIMI, there are some differences between the two statutes.

PAIMI clients must have a significant mental illness that has been diagnosed by a state-licensed mental health professional.<sup>18</sup> While PADD serves any individual who satisfies the definition of developmentally disabled, regardless of his or her living situation, the MI Act's mandate is further limited to residents, or those discharged within the past 90 days, of a care or treatment facility.<sup>19</sup> The MI Act's statutory definition says that facilities "need not be limited to" those listed.<sup>20</sup> Juvenile detention and correctional facilities are included in this language.

*PAIR* - The PAIR program was Congress' response to the gap left by the narrow clientele definitions of PADD and PAIMI. The program was originally enacted as a discretionary program under the Rehabilitation Act Amendments of 1978 but it lay dormant for 10 years because no funds were appropriated. Each year since 1989, however, some money has been designated for the program. In 1992, Congress amended the PAIR program to cover all individuals with disabilities not eligible for services under any of the other P&A programs.<sup>21</sup> In its current version, the PAIR program is similar in form and content to the PADD and PAIMI programs.

### *A Survey of the P&A Systems*

A survey conducted by the ABA Juvenile Justice Center confirmed that the P&A system can be an effective mechanism to oversee the provision of services to disabled youth in custody. Each state is responsible for establishing its own P&A system and the structure and functions of the systems vary from state to state. Within the requirements of the statutes, P&A systems have the discretion to design programs that reflect their own needs and resources.

Some generalizations, however, can be made about the structures of the P&A systems among states.<sup>22</sup> Currently, all P&A's are eligible for funding and most P&A's receive a blend of federal, state, and foundation funding. State service providers vary from private nonprofit groups to private agencies to designated state agencies. P&A staff generally consist of attorneys and advocates with experience in disability issues from diverse backgrounds such as social work, special education, nursing, public health, and administration. Advocates can be very helpful in non-litigious approaches to problem solving and are often very knowledgeable about available resources.

The division of responsibilities between attorneys and advocates is different from state to state – advocate responsibility can range from helping conduct interviews and investigations to no part at all. Many states reported that much of their client representation involved administrative hearings in the areas of special education, social security benefits, Medicaid, and claims under the Americans with Disabilities Act. Several states noted that special education claims constitute the largest percentage of their caseload. In New Hampshire, as much as 30% of the cases involve special education issues with children. South Carolina considers children's issues, mostly special education, to be a priority.

An area of emphasis for all P&As, but particularly for PAIMI, is investigation and monitoring of abuse and neglect in residential care and treatment facilities. To carry out these priorities, the P&A engages in investigative and monitoring work. While the statute provides that all P&As must have authority to investigate and monitor, some P&As have had to sue just to gain access to clients and their records.

If an investigation reveals serious rights violations, P&As usually prepare a report of their findings, present them to the responsible officials, and recommend remedial action. Some states also issue reports to the public to raise awareness and garner support. P&As first attempt to work with the institution, both to avoid costly litigation and to foster cooperation but will use sanctions if the institution does

not take appropriate action. Most P&As report that investigations rarely escalate to litigation.

P&As utilize litigation primarily for "impact litigation," or class action lawsuits and at least two states have teamed with private law firms to bring major institutional litigation. A majority of class action lawsuits filed by P&As concern large-scale institutional violations. Individual suits are usually referred to private attorneys.

*Using the P&A System To Improve Conditions for Juveniles With Disabilities*

A story of a P&A lawyer who began working with delinquent youth sheds some insight on how to effectively use P&As. A mom noticed that her son was emotionally declining while in detention and consulted a P&A lawyer. The lawyer successfully arranged for a mental health evaluation and his client was correctly treated for depression. The lawyer realized that a great number of incarcerated youth had serious mental health problems and that many youth deteriorate emotionally as a result of the conditions under which they are confined, particularly when they are locked in their own rooms or isolation cells. He worked to devise the following two-part strategy for his case:

- 1) Parents and institutional staff were encouraged to call the local P&A to request assistance in arranging mental health services for incarcerated youth with disabilities.
- 2) The P&A began a series of meetings to enhance mental health treatment in the juvenile institution. As a result, correctional facility staff psychiatrists were partly freed from doing court-ordered evaluations so they could be available to treat emotionally disturbed youth who were already incarcerated.

P&As are invaluable because they have the authority to investigate abuses, access records, ensure that the rights of youth in custody are not being violated and pursue administrative remedies on behalf of persons with disabilities. Advocates can then access the current monitoring done by P&As to shed enough light on service deficiencies and create enough pressure so that litigation can often be avoided.

*Conclusion*

Seeking assistance from a P&A requires defining problems or issues so that they fit within the P&A's area of authority. Given the paucity of their resources, advocates must be ready to refer issues or potential clients to the P&A and be able to identify what type of help is most needed. Even if a P&A cannot seize the area of concern, it may be able to assist with problem solving.

Not all incarcerated youth fit the narrow definition of

disabilities under PADD, PAIMI, or PAIR, but for those who do, P&As can be valuable resources in individual cases and can help obtain services systemically without litigation. On behalf of a distinct and disadvantaged client group, P&As act as individual/group advocates and monitors as they pursue remedies to institutional abuses. Advocates for juveniles must be creative and should contemplate using the current P&A system in their state to access evaluations and services for young offenders with disabilities.

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1. Pub. L. No. 94-103, 89 Stat. 486 (codified as amended at 42 U.S.C. §§ 6000-6083) (1996) (the Developmental Disabilities Act was an extension of the Developmental Disabilities Service and Facilities Construction Act of 1970, Pub. L. No. 91-517, 84 Stat. 1316).
  2. 42 U.S.C §§ 10801-10807 (1996).
  3. 29 U.S.C. § 794e (1996).
  4. 29 U.S.C. § 732 (1996).
  5. 42 U.S.C. § 6042(a)(2)(A) (1996).
  6. *Id.* § 6042(a)(2)(B).
  7. *Id.* § 6042(K).
  8. *See* National Association of Protection & Advocacy Systems, Inc., Annual Report of the P&A System, 1995-1996, 18 (1996).
  9. 42 U.S.C. § 6042(a)(2)(G) (1996).
  10. *Id.* § 6042 (d).
  11. NAPAS report, *supra* note 8, at 10.
  12. 42 U.S.C. § 6009 (1996).
  13. 42 U.S.C. §§ 6021-6030 (1996).
  14. *Id.* § 6001.
  15. 42 U.S.C. §§ 10801-10807.
  16. *Id.* § 10802(4).
  17. *Id.* § 10802(2) (defining "eligible system" as PADD).
  18. *Id.* § 10802(4).
  19. *Id.* § 10802(4)(B).
  20. *Id.* § 10802(3).
  21. Rehabilitation Act Amendments of 1992, Pub. L. No. 102-569, § 510(a), 106 Stat. 4430 (codified at 29 U.S.C. § 794e (1996)).
  22. Telephone Conferences with P&A's in Twelve States (1994) (the jurisdictions that contributed are Alabama, California, the District of Columbia, Maryland, Michigan, Nevada, New Hampshire, New Jersey, New York, South Carolina, Virginia, and Wisconsin).

—Prepared by Stephanie Hu for the NJDC.  
 This is an edited excerpt from *Beyond the Walls: Improving Conditions of Confinement for Youth in Custody*. More detailed information can be found at <http://www.ojjdp.ncjrs.org/pubs/walls/contents.html>.

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## Statement of Beliefs

All children in the justice system must have ready and timely access to capable, well-resourced, well-trained legal counsel.

All children are entitled to legal representation that is individualized, developmentally and age appropriate, and free of racial, ethnic, gender, social, and economic bias.

All children have strengths and the potential to become productive members of society and each has the right to constitutional and statutory protections.

The juvenile defense bar must build its capacity, develop leadership and demonstrate a commitment to professionalism.

The juvenile defense bar must promote accountability and bring about reform in the juvenile justice system.

The juvenile defense bar's role in the justice system will be advanced through collaboration and partnerships.

The juvenile defense system will be enhanced by greater community involvement.