

Systems for the Protection and Advocacy for Persons with Disabilities in the U.S.

A. Kimberley Dayton*

[Contents]

- | | |
|---|--------------|
| I. Introduction | System |
| II. Part I: Protection and Advocacy
for Disabled Individuals—the P&A | III. Summary |

[Abstract]

Significant legal protection exists in U.S. federal and state law for persons with disabilities with respect to health care, housing, employment, social activities, and the like. In addition to these substantive laws, Congress has enacted several far-reaching statutes that obligate states to provide certain legal and supportive services to persons with disabilities to enable them to enforce and enjoy the protection of the substantive disability rights laws. In addition, all U.S. states and territories have put in place statutes that establish a system for reporting and investigating allegations of abuse and exploitation of vulnerable adults. These “adult protection” laws vary in the details among the states, but all have similar structures and objectives. Part I of this article will outline the nature of the various protection and advocacy services that are available for persons with disabilities in the U.S. through eight distinct, federally funded “P&A” programs. Part II, published separately, will discuss the typical framework of state adult protection schemes that are in place to address the widespread problem of abuse of vulnerable individuals who live either in the community or in institutions such as skilled nursing facilities (SNFs) (also called nursing homes or care homes). As appropriate, I will comment on areas in which the systems described could be improved to better serve the needs of persons with disabilities so that they can be fully integrated into all areas of public and private life.

Keywords: U.S. federal and state law for persons with disabilities, “P&A” programs.

* Professor Emerita, William Mitchell College of Law

I . Introduction

Significant legal protection exists in U.S. federal and state law for persons with disabilities with respect to health care, housing, employment, social activities, and the like. In addition to these substantive laws, Congress has enacted several far-reaching statutes that obligate states to provide certain legal and supportive services to persons with disabilities to enable them to enforce and enjoy the protection of the substantive disability rights laws.

In addition, all U.S. states and territories have put in place statutes that establish a system for reporting and investigating allegations of abuse and exploitation of vulnerable adults. These “adult protection” laws vary in the details among the states, but all have similar structures and objectives.

Part I of this article will outline the nature of the various protection and advocacy services that are available for persons with disabilities in the U.S. through eight distinct, federally funded “P&A” programs. Part II, published separately, will discuss the typical framework of state adult protection schemes that are in place to address the widespread problem of abuse of vulnerable individuals who live either in the community or in institutions such as skilled nursing facilities (SNFs) (also called nursing homes or care homes). As appropriate, I will comment on areas in which the systems described could be improved to better serve the needs of persons with disabilities so that they can be fully integrated into all areas of public and private life.

II . Part I: Protection and Advocacy for Disabled Individuals—the P&A System

Over the past forty-plus years, the U.S. Congress has enacted several federal laws that aim to protect persons with disabilities from discrimination in

education, housing, employment, and other areas. These laws include but are not limited to the Rehabilitation Act of 1973 (1973),¹⁾ Individuals with Disabilities Education Act (“IDEA”) (1975),²⁾ the Civil Rights of Institutionalized Persons Act³⁾ (1980), the Americans with Disabilities Act (1991),⁴⁾ and many others.⁵⁾ Each of these federal laws creates substantive rights that, in most cases, are enforceable by individuals as well as by the United States Department of Justice or other federal agencies. All U.S. states have disability rights laws in place that replicate and in some instances further expand the civil rights of persons with disabilities.

The Protection and Advocacy (P&A) Systems of the 50 states and several U.S. territories exist to enable the class of individuals whom these federal and state laws concern to better exercise the rights afforded them through the laws. Each state has at least one P&A organization; some states have multiple organizations that share responsibility for assisting clients with enforcing their various rights.⁶⁾ The first P&A program was the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program (1975) but the duties of P&A agencies in the states evolved over the years as the substantive rights of persons with disabilities were expanded under federal law. As a general matter, P&A agencies are charged with assisting *all* persons with disabilities through legal representation and advocacy, with certain services

1) 29 U.S.C. § 791-794d.

2) 20 U.S.C. §§ 1400 et seq.

3) 42 U.S.C. §§ 1997 et seq.

4) 42 U.S.C. §§ 12101 et seq.

5) The substance of federal disability rights laws is beyond the scope of this article. For an overview of all such U.S. laws, see U.S. Department of Justice, Civil Rights Division, Disability Rights Section, A Guide to Disability Rights Laws (2009), available at <https://www.ada.gov/cguide.htm>.

6) A listing of all P&A entities by state is available from the National Disability Rights Network, <http://www.ndrn.org/ndrn-member-agencies.html>

given priority. Depending on the state, the P&A agency or agencies that provide these services may be private non-profit entities or part of another state agency. All government and private entities that provide services to, house, employ, or otherwise are engaged with individuals with disabilities are required to notify their clients of the availability of services provided by the P&A organization(s) in that state.

An entity designated as a P&A organization must remain independent of any organization that provides direct substantive services to persons with disabilities. Most entities designated by the states as P&As are private non-profit organizations created specifically for the purpose of providing P&A services under the DD Act and other federal laws. Some, however, are located within state agencies, while a few are hybrid quasi-public agencies, and a few are components of broader legal services programs.

P&A systems are funded and administered primarily through grants from several different federal agencies, and in some states through additional allocations from the state. Federal agencies that provide funding to P&As in the states include the U.S. Department of Education, the Department of Health and Human Services, and the Social Security Administration.

It should be noted that, while the P&A services described below theoretically offer persons with disabilities a full panoply of resources to enforce their statutory rights to be free from discrimination, in fact most programs suffer from inadequate funding and must prioritize and limit the services they are actually able provide. Federal grants to some programs, such as PAAT, are minimal and fall far short of enabling the P&A entities to serve the needs of their intended client base.

P&As have broad investigatory authority under federal and state laws, allowing them access to client records that would otherwise be private and not discoverable.⁷⁷ This authority enables P&As to identify issues and seek resolution without the need for litigation. It should be noted, however, that

litigation is often the remedy of choice when systemic barriers to full equality exist in the public and private realms.

P&A Organizations and Types of Services

As Congress expanded the substantive rights of persons with disabilities, so did it expand the duties of state P&A entities. With the exception of the Client Assistance Program (see below) these new programs were required by Congress to be housed within the same agency that provides services to individuals with disabilities under the Developmental Disabilities Assistance and Bill of Rights Act of 1975 (DD Act).⁸⁾

Due to the evolution of substantive disability rights laws over the years, eight distinct programs exist for which P&A organizations are responsible. They are:

- Client Assistance Program (CAP)
- Protection and Advocacy for the Developmentally Disabled (PADD)
- Protection and Advocacy for Individuals with Mental Illness (PAIMI)
- Protection and Advocacy for Individual Rights (PAIR)
- Protection and Advocacy for Assistive Technology (PAAT)
- Protection and Advocacy for Beneficiaries of Social Security (PABSS)
- Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI)
- Protection and Advocacy for Voting Access (PAVA)

Together, these comprise the protection and advocacy systems within states and serve the needs of all persons with disabilities, whatever the nature of their limitations. The statutory basis for and duties of these various programs are

7) National Disability Rights Network, P&A/CAP Network, <http://www.ndrn.org/about/paacap-network.html>

8) P.L. 94-103, 89 Stat. 487.

summarized below.

PADD

Statutory authority: Developmental Disabilities Assistance and Bill of Rights Act of 1975 (DD Act).⁹⁾

Administration: Administration on Developmental Disabilities of the Administration for Children and Families, U.S. Department of Health and Human Services

Eligibility for services: An individual who has a federally defined developmental disability (DD). Examples of such disabilities include mental retardation, cerebral palsy, autism, and severe learning disabilities.

PADD was the very first P&A program. Its implementing legislation mandated that each state create protection and advocacy programs as a condition to receiving certain federal grant funding in order to serve the needs of *persons with developmental disabilities*. “In its broadest sense, PADD was established to ‘protect and advocate’ for persons who, because of their disabilities, are incapable of protecting their own interests.”¹⁰⁾ The original “PADD” (protection and advocacy for individuals with developmental disabilities) programs were required to pursue legal, administrative, and other appropriate remedies to protect and advocate for the rights of individuals with developmental disabilities under all applicable federal and state laws.

Activities of the PADD programs include investigating allegations of abuse and neglect of persons with developmental disabilities who are housed in

9) P.L. 94-103, 89 Stat. 487. This statute has been amended several times since 1975 to broaden its mandate, as discussed in the material that follows herein. See also The Developmental Disabilities Assistance and Bill of Rights Act, Legislative History of the Act, https://mn.gov/mnddc/dd_act/documents/FEDREG/90-DDA-LEGISLATIVEHISTORY.pdf.

10) Sheldon, *supra*, at p. 6.

institutions, working to move such individuals from institutions into the community, and assisting children and young adults to receive special education services to which they are entitled under federal laws. Frequently, PADDs initiate litigation aimed at rectifying systemic problems affecting the rights of individuals with developmental disabilities.

CAP

Statutory authority: 1984 amendments to the Rehabilitation Act of 1973.¹¹⁾

Administration: Rehabilitation Services Administration of the United States Department of Education.

Eligibility for services: An individual with a disability who is seeking or receiving vocational (VR) services under the federal Rehabilitation Act.

The Client Assistance Program is a P&A programs that exists in conjunction with the Rehabilitation Act of 1973, a federal law that provides funding to states so that they may assist persons with disabilities to find appropriate employment. The CAP furnishes assistance to all individuals with disabilities in pursuing legal, administrative, and other remedies “to persons receiving or seeking services from state rehabilitation agencies under the Rehabilitation Act. A CAP agency may provide assistance and advocacy with respect to services that are directly related to employment for the client or client applicant.”¹²⁾

The mandate of CAPs concerns the ability of persons with disabilities to find appropriate, gainful employment. Thus,

“[while] a CAP is authorized to assist individuals in obtaining vocational services from a range of public and private agency providers, CAP

11) P.L. 98-527, 98 Stat. 2662, codified at 29 U.S.C. § 732

12) National Disability Rights Network, <http://www.ndrn.org/about/paacap-network.html>

advocates typically are involved in resolving disputes between individuals and state Vocational Rehabilitation (VR) agencies. A dispute could involve a question of VR agency sponsorship for a particular education or training program; funding for a wide range of goods or services related to an employment goal; or post-employment services needed to retain a job. Most of these disputes are resolved by CAP programs through negotiation or mediation, with a smaller number involving administrative hearings, and an even smaller number involving court action.”¹³⁾

PAIMI

Statutory authority: Protection and Advocacy for Individuals with Mental Illness Act of 1986.¹⁴⁾

Administration: Center for Mental Health Services, U.S. Department of Health and Human Services

Eligibility for services: Individuals with a diagnosis of a significant mental illness or emotional impairment, with priority for persons with mental illness who live in residential treatment facilities.

The PAIMI statute obliges P&As to protect and advocate for the rights of people with mental illness and investigate reports of abuse and neglect in facilities that care for or treat individuals with mental illness, whether they reside in an institution or in the community.

The activities of PAIMI are similar to those of PADDs, except that the client base served is persons with mental illness and emotional disorders. In particular, PAIMIs often engage in services aimed at locating suitable non-institutional housing for such persons, inasmuch as rampant discrimination in the housing industry persists with regard to individuals with mental illness.

13) Sheldon, *supra*, at p. 11.

14) 42 U.S.C. § 10801 et seq.

PAIR

Statutory authority: 1993 amendments to the Rehabilitation Act of 1973.

Administration: Rehabilitation Services Administration within the U.S. Department of Education.

Eligibility for services: An individual who has a disability and (1) needs services that are beyond the scope of CAP and (2) is ineligible for PADD and PAIMI due to lack of qualifying impairments.

The PAIR program was established by Congress under an amendment to the Rehabilitation Act in 1993. PAIR programs provide for services to persons with disabilities who are not eligible for services under the three previously established P&A programs (PADD, PAIMI, and CAP). The addition of PAIR funding effectively authorized P&A services for persons *with all types of disabilities*. Although PAIR is funded at a lower level than PADD and PAIMI, it represents an important component of a comprehensive system to advocate for the rights of all persons with disabilities. Because of limited funding, PAIR programs must be selective in the type of advocacy services they offer, and their specific focus varies among jurisdictions. Many programs direct most of their resources towards fighting accessibility issues arising under the Americans with Disabilities Act.

PAAT

Statutory authority: 1994 amendments to the Technology-Related Assistance to Individuals with Disabilities Act.¹⁵⁾

Administration: Rehabilitation Services Administration of the Department of Education.

Eligibility for services: An individual with a disability who seeks funding for

15) P.L. 103-218, 108 Stat. 50 (1994), codified at 29 U.S.C. §§ 2201 et seq.

an assistive technology device or service.

The PAAT program provides funding to P&As for the purpose of helping individuals with disabilities “in the acquisition, utilization, or maintenance of assistive technology devices or assistive technology services through case management, legal representation and self advocacy training.” Due to severely limited funding, many PATTs focus primarily on education and technical support. They have also been successful in broadening coverage by the Medicaid and Medicare programs of assistive technology for their client base.

PABSS

Statutory authority: Ticket to Work and Work Incentives Improvement Act of 1999.¹⁶⁾

Administration: Social Security Administration

Eligibility for services: Individuals who are entitled to Supplemental Security Income or Social Security Disability Insurance benefits based on disability or blindness, and individuals who have in the past received such benefits who seek continued health care coverage through either of the federal health insurance programs, Medicaid and Medicare

Under this program, the federal government provides grants to the P&A programs both to advise Social Security beneficiaries of their right to vocational and rehabilitation services from state VRs, and to assist beneficiaries of Social Security in securing or regaining gainful employment.¹⁷⁾¹⁷

16) P.L. 106-170, 113 Stat. 1860 et seq., codified at 42 U.S.C. § 1320b-21

17) For a more detailed listing of the activities and priorities of PABSS, see Sheldon, *supra*, at 12-14.

PATBI

Statutory authority: Traumatic Brain Injury (TBI) Act authorized as part of the Children's Health Act of 2000.¹⁸⁾

Administration: Federal Health Resources and Services Administration (HRSA)

Eligibility for services: A individual who has suffered a traumatic brain injury.

The PATBI program is aimed at individuals with a documented TBI. It allows P&A to expand their ranges of services to this group, whether or not the TBI results in a disability within the meaning of the other P&A programs. While many persons with TBI are eligible for services under PAIR, CAP, or PABSS, the PATBI program provides more resources to be used exclusively for the benefit of this particular client group.

PAVA

Statutory authority: Help America Vote Act of 2002.¹⁹⁾

Administration: Administration on Intellectual and Developmental Disabilities, Department of Health and Human Services

Eligibility for services: An individual with a disability who seeks assistance with registering to vote, casting a vote, and/or accessing a polling place.

The PAVA program is the newest P&A program, and has been in place only since 2003. Under this program, "P&As have a mandate to help ensure that individuals with disabilities participate in the electoral process through voter education, training of poll officials, registration drives, and polling place accessibility surveys. P&A agencies may not use PAVA program funds for

18) P.L. 110-206, 122 Stat. 714 (2008), codified at 42 U.S.C. § 300d-53.

19) P.L. 107-252, 116 Stat. 1666 (2002), codified at 42 U.S.C. §§ 15481-15485.

litigation. There is no such restriction in any of the other P&A programs.”

III . Summary

The network of state P&As is intended as a comprehensive solution to the difficulties facing persons with disabilities who wish to participate fully in all aspects of public and private life. Although federal and state laws have long protected such individuals from discrimination, and have sought to correct systemic patterns of exclusion and derogation, persons with disabilities have yet to become fully integrated into American social, political, and cultural life. While the P&A system has achieved some major successes in the past two decades, the lack of adequate funding remains problematic. It remains to be seen whether the future will bring a greater understanding of the needs of the 20% of U.S. citizens who live with one or more disabilities, and a concomitant increase in the financial resources needed by P&A entities if they are to exercise fully their statutory mandates.

투고일: 2018. 1. 10. 심사일: 2018. 1. 18. 게재확정일: 2018. 1. 29.

■ References ■

미국연방법전(U.S.C.)

U.S. Department of Justice(2009), Civil Rights Division, Disability Rights Section,
A Guide to Disability Rights Laws

<http://www.ada.gov/cguide.html>.

National Disability Rights Network,

<http://www.ndrn.org/ndrn-member-agencies.html>.

National Disability Rights Network, P&A/CAP Network, <http://www.ndrn.org/about/paacap-network.html>.

http://mn.gov/mnddj/dd_act/documents/FEDREG/90-DDA_LEGISLATIVEHISTORY.pdf.