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Lawyers Who Break the Law: What Congress Can Do to Prevent Mental Health Patient Advocates from Violating Federal Legislation

In April of 1985, a U.S. Senate Subcommittee charged with investigating facilities that took care of individuals with mental illness began hearing testimony about the “disgrace” that existed behind institutional walls.¹ Congress determined that individuals with mental illness were susceptible to mistreatment and neglect, particularly in the hospitals and institutions where they lived and were treated.² After its investigation, Congress passed the Protection and Advocacy for Individuals with Mental Illness Act of 1986, otherwise referred to as PAIMI.³

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¹ *Care of Institutionalized Mentally Disabled Persons: Joint Hearings Before the Subcomm. on the Handicapped of the S. Comm. on Labor and Human Res. and the Subcomm. on Labor, Health and Human Servs., Education, and Related Agencies of the S. Comm. on Appropriations*, 99th Cong. 1 (1985) [hereinafter *Joint Hearings*] (statement of Sen. Lowell Weicker, Chairman, Subcomm. on the Handicapped of the S. Comm. on Labor and Human Res.).

² 42 U.S.C. §§ 10801(a)(3), 10802(5) (2006).

³ Protection and Advocacy for Individuals with Mental Illness Act of 1986, Pub. L. No. 99-319, 100 Stat. 478 (codified as amended in scattered sections of 42 U.S.C.). PAIMI, when it was first enacted in 1986, was named the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (PAMII).. *Id.* What was then referred to as PAMII has since been renamed the Protection and Advocacy for Individuals with Mental Illness Act, with the

PAIMI created a federally funded, national system of patient advocacy that gave lawyers, known as “patient advocates,” the authority to investigate patient allegations of neglect, abuse, and civil rights violations.⁴ PAIMI was also designed to protect individuals with mental illness who live and receive treatment outside inpatient treatment facilities.⁵ It is a wide-reaching Act that has protected countless individuals who are unable to defend themselves due to their circumstances or who might otherwise have died or suffered abuse in secret.

Patient advocates have a demanding job. In 2008, patient advocates investigated nearly 19,000 allegations of abuse, neglect, or rights violations on behalf of their clients.⁶ In 2009, Congress allotted \$35.8 million to patient advocacy groups to carry out these investigations.⁷ It is projected that Congress will review PAIMI next year.⁸

Despite the additional funding and PAIMI’s simple mandate, several problems exist with the patient advocacy system. In the past decade alone, the Department of Justice (DOJ) investigated and uncovered numerous incidents of widespread neglect and abuse in hospitals and institutions throughout the United States.⁹ What was

new acronym PAIMI. See Children’s Health Act of 2000, Pub. L. No. 106-310, § 3206, 114 Stat. 1101, 1193–94 (2000) (codified at 42 U.S.C. § 10801 note).

⁴ See 42 U.S.C. § 10801(b)(1).

⁵ *Id.* §§ 10802(3), (4)(B)(ii), 10841(3)(C)(i)–(iii); Conn. Office of Prot. & Advocacy for Persons with Disabilities v. Hartford Bd. of Educ., 464 F.3d 229, 240 (2d Cir. 2006) (protecting school students from abuse and neglect within educational settings).

⁶ NAT’L DISABILITY RIGHTS NETWORK, PROTECTION AND ADVOCACY FOR INDIVIDUALS WITH MENTAL ILLNESS: 2008 ANNUAL REPORT 28 (2008), available at <http://www.ndrn.org/pub/AnnRpt/2008/2008PAIMIAnnualReport.pdf>.

⁷ *Id.* at 3. Recently, President Barack Obama pledged another \$140 million to help individuals with mental disabilities and illness gain better access to housing, community support, and independent living arrangements. Press Release, Office of the Press Secretary, The White House, President Obama Commemorates Anniversary of *Olmstead* and Announces New Initiatives to Assist Americans with Disabilities (June 22, 2009), available at http://www.whitehouse.gov/the_press_office/President-Obama-Commemorates-Anniversary-of-Olmstead-and-Announces-New-Initiatives-to-Assist-Americans-with-Disabilities/. He made this declaration on the tenth anniversary of *Olmstead v. L.C.*, 527 U.S. 581 (1999), a U.S. Supreme Court case that granted the right to community treatment for certain individuals with mental disabilities. Press Release, Office of the Press Secretary, The White House, *supra*.

⁸ Interview with Andrew Sperling, Legislative Dir., Nat’l Alliance on Mental Illness (NAMI), in Arlington, Va. (Jan. 7, 2010).

⁹ See *Special Litigation Section: Documents and Publications*, CIV. RTS. DIVISION, U.S. DEP’T OF JUST., <http://www.justice.gov/crt/split/findsettle.php#MH%20Findings%20Letters> (last visited Oct. 6, 2010) [hereinafter *Special Litigation Section*].

said during congressional hearings twenty-five years ago—that “[p]rotection for these frailest of our society exists largely on paper”¹⁰—is unfortunately still true today, despite PAIMI’s enactment. The federal investigations raise concerns about why PAIMI’s patient advocacy system has been unable to stop the abuse, neglect, and civil rights violations it was created to prevent. One reason is that patient advocates have taken on additional and legally impermissible responsibilities that Congress never envisioned or authorized. These activities have taken them away from their core mission.

Patient advocates have violated congressional mandates against lobbying and have sometimes even lobbied against laws that would benefit mental health consumers. “Consumers” is the term used to describe individuals who require mental health services. Patient advocates have engaged in systematic advocacy efforts, leaving individuals with inadequate representation, despite the fact that they have a federal mandate to investigate only individual claims of abuse, neglect, and rights violations. They have battled and even ignored the families that helped create and pass PAIMI, people whom Congress found critical to the success of the Act. All of these activities exist outside of PAIMI’s mandate. Many patient advocates seem to have found a role not envisioned by Congress or any legislation that defines their mission.

The purpose of this Article is to examine these prohibited activities and suggest changes to PAIMI that Congress should consider when it revises and reenacts the Act next year. This Article begins by examining the genesis of modern-day patient advocacy and the conflicting legal theories that underlie the field of mental health law. It then explores relevant provisions of PAIMI and its legislative intent. Finally, this Article examines the legally impermissible activities in which patient advocates have engaged, the problems these activities present, and potential solutions to these problems. In the end, the author hopes that patient advocates will be held accountable to PAIMI, which governs their role as advocates and protectors of individuals with mental illness.

¹⁰ *Joint Hearings, supra* note 1, at 1 (statement of Sen. Lowell Weicker, Chairman, Subcomm. on the Handicapped of the S. Comm. on Labor and Human Res.).

I

THE GENESIS OF MODERN-DAY PATIENT ADVOCACY

In order to understand why Congress enacted federal legislation to protect persons who were institutionalized in mental health facilities, it is important to briefly examine when and how modern-day patient advocacy began.

A. Patient Advocacy's Roots

Though mental health advocacy began in the mid-1800s with crusaders like Dorothea Dix,¹¹ our current patient advocacy system was shaped by events that took place in the 1960s. The legal premises that shaped patient advocacy can be traced to a Harvard-educated medical doctor and lawyer¹² named Morton Birnbaum.¹³

In 1959, Dr. Birnbaum was enrolled in a postdoctoral public policy and mental health program at Harvard when he came up with a revolutionary idea to help people with mental illness.¹⁴ He argued that patients had a constitutional right to treatment; without treatment, hospitals took custody of patients and imprisoned them indefinitely.¹⁵ He asserted that, when patients were confined without treatment, they essentially were given a life sentence, which violated their Fourteenth Amendment rights to due process and liberty.¹⁶ Dr. Birnbaum's article was published in the *American Bar Association Journal* in 1960.¹⁷ Soon after, the renowned D.C. Circuit Judge David Bazelon

¹¹ Ralph Slovenko, *The Transinstitutionalization of the Mentally Ill*, 29 OHIO N.U. L. REV. 641, 641–42 (2003). Dorothea Dix, originally a school teacher from Boston, was horrified when she discovered that persons with mental illness were being jailed. *Id.* at 641. After her discovery, she traveled around the country, advocating for their release from jails. *Id.* at 642. She persuaded twenty states to view mental illness as a medical condition and succeeded in moving many individuals with mental illness into mental health institutions. *Id.*

¹² See Shari Lynne Kahn, *The Right to Adequate Treatment Versus the Right to Refuse Antipsychotic Drug Treatment: A Solution to the Dilemma of the Involuntarily Committed Psychiatric Patient*, 33 EMORY L.J. 441, 450 n.40 (1984).

¹³ PETE EARLEY, *CRAZY: A FATHER'S SEARCH THROUGH AMERICA'S MENTAL HEALTH MADNESS* 150–51 (2006).

¹⁴ *Id.* at 151.

¹⁵ Morton Birnbaum, *The Right to Treatment*, 46 A.B.A. J. 499, 499 (1960).

¹⁶ *Id.* at 504.

¹⁷ *Id.* at 499.

mentioned Dr. Birnbaum's article in an opinion, which boosted the credibility of Birnbaum's legal theory.¹⁸

After his article was published, Dr. Birnbaum agreed to help represent a Florida man who had been civilly committed against his will.¹⁹ He later worked with other attorneys who wanted to help institutionalized individuals. But these attorneys, who embraced Dr. Birnbaum's theory and worked with him later, argued that merely forcing states to treat mentally ill patients was not enough.²⁰ Like 1960s anti-psychiatry groups that advocated abolishing the mental health care system entirely,²¹ early patient advocates reasoned that, because medical and psychological treatment would wane once the lawsuits settled, states should simply close hospital doors rather than provide substandard treatment.²² Dr. Birnbaum disagreed with their position so strongly that he cut professional ties with them.²³ These lawyers formed a mental health law advocacy group in Washington, D.C., which is currently called the Judge David L. Bazelon Center for Mental Health Law.²⁴

¹⁸ Rouse v. Cameron, 373 F.2d 451, 453 n.6 (D.C. Cir. 1966); EARLEY, *supra* note 13, at 153.

¹⁹ EARLEY, *supra* note 13, at 152.

²⁰ *Id.* at 155.

²¹ Slovenko, *supra* note 11, at 646. Anti-psychiatry proponents arose within the field of psychiatry in the 1960s and 1970s. Sheldon Gelman, *Looking Backward: The Twentieth Century Revolutions in Psychiatry, Law, and Public Mental Health*, 29 OHIO N.U. L. REV. 531, 564 (2003). Anti-psychiatry advocates believed that mental illness was not due to a medical condition but was a socially, politically, or legally constructed label. *Id.* The anti-psychiatry movement eventually spread outside the field of psychiatry. Legal anti-psychiatry groups formed partly in reaction to abuses in the civil commitment process. David B. Wexler, *Two Decades of Therapeutic Jurisprudence*, 24 TOURO L. REV. 17, 23 (2008). Before the 1960s, psychiatrists had unfettered control over civil commitment proceedings, and judges gave psychiatric opinions too much judicial deference. *Id.* Anti-psychiatry proponents developed a "radical, abolitionist agenda" to counter these problems. Samuel Jan Brakel, *Searching for the Therapy in Therapeutic Jurisprudence*, 33 NEW ENG. J. ON CRIM. & CIV. CONFINEMENT 455, 460 n.16 (2007). Their goal was to eradicate the involuntary civil commitment procedure through the creation of legal roadblocks; with the courts' creation of legal hurdles in the 1970s, they were largely successful. *Id.* It was not until the homeless crisis of the 1980s that people began to question the wisdom of releasing from mental health institutions individuals who could not care for themselves. *Id.* Our country's legal system is now experiencing a resurgence of treatment ideology over civil liberty interest ideology, in part due to the overwhelming number of mentally ill individuals who receive no treatment or who receive psychiatric treatment in penal institutions.

²² EARLEY, *supra* note 13, at 155.

²³ *Id.*

²⁴ *Id.* at 160. The center says in its mission statement that it "envisions an America where people who have mental disabilities exercise their own life choices and have access

B. *Conflicting Mental Health Legal Theories*

To this day, patient advocacy is divided because of conflicting ideological views and legal theories. Some lawyers focus on the liberty of patients, adopting a civil libertarian view, while others focus on the treatment and welfare rights of patients, adopting a treatment-oriented view.²⁵

These conflicting ideological theories play out in predictable ways in any mental health commitment debate. There are two opposing legal positions at work:

one which is premised on the notions of police and *parens patriae* powers, under which a mentally ill person receives care and treatment because he or she is sick . . . and the other, premised under common law notions that adults are presumed to be competent to make decisions regarding their medical care.²⁶

Civil commitment laws also contain divisive theories, such as protection of the individual versus protection of the community.²⁷ Each case requires courts and lawyers to delicately balance these interests.²⁸ Common law-created mental health rights only add to the complexity of these legal theories.

In the past fifty years, courts have increasingly granted individuals with mental illness more rights. American courts have held that patients have a right to refuse medical treatment or at least to express their objections to it.²⁹ These courts reason that patients have “a due process-protected liberty interest in not being medicated against their will.”³⁰ Lawyers used a number of legal theories to advance the claims they raised on behalf of their clients. Though due process concepts were favored by these lawyers, they also used

to the resources that enable them to participate fully in their communities.” *Who We Are*, JUDGE DAVID L. BAZELON CENTER FOR MENTAL HEALTH LAW, <http://www.bazelon.org/about/index.htm> (last visited Oct. 6, 2010).

²⁵ Susan Lee, *Heller v. Doe: Involuntary Civil Commitment and the “Objective” Language of Probability*, 20 AM. J.L. & MED. 457, 463 (1994).

²⁶ Fernando J. Gutierrez, *Who is Watching Big Brother When Big Brother is Watching Mental Health Professionals: A Call for the Evaluation of Mental Health Advocacy Programs*, 20 LAW & PSYCHOL. REV. 57, 67 (1996).

²⁷ David Ferleger & Penelope A. Boyd, *Anti-Institutionalization: The Promise of the Pennhurst Case*, 31 STAN. L. REV. 717, 733–34 (1979).

²⁸ *See id.*

²⁹ Samuel Jan Brakel & John M. Davis, *Overriding Mental Health Treatment Refusals: How Much Process is “Due”?*, 52 ST. LOUIS U. L.J. 501, 525 (2008).

³⁰ *Id.*

state tort laws against unauthorized touching (battery), natural law concepts averring to the rights and entitlements of personhood, Bill of Rights claims stemming from the First Amendment's protection of free speech, the Eighth Amendment's prohibition against cruel and unusual punishment, "penumbral" privacy rights that emanate from the overall constitutional firmament, and any number of other legal theories that can and have been invoked to protect patients from unwanted treatment.³¹

It is only when the state's compelling interest overrides the patient's liberty interest that due process gives way to involuntary treatment.³² In sum, the area of mental health law includes many competing ideological and legal claims.

II

THE PROTECTION AND ADVOCACY FOR INDIVIDUALS WITH MENTAL ILLNESS ACT OF 1986

In the late 1960s, lawsuits involving allegations of patient abuse and neglect at state-supported facilities began to make their way through state and federal courts.³³ These cases,³⁴ which revealed widespread mistreatment of developmentally disabled and mentally ill individuals, became the catalyst for PAIMI, which was responsible for creating a federally funded system of patient advocacy.³⁵

A. *The Creation of PAIMI*

The first federal legislation that protected the rights of people who were institutionalized was the Developmental Disabilities Assistance and Bill of Rights Act of 1975.³⁶ This Act required States to create a protection and advocacy (P&A) system to protect individuals with mental retardation and to investigate allegations of abuse and neglect.³⁷ Ten years later, after numerous accounts of abuse and

³¹ *Id.*

³² *Id.* at 527.

³³ *See, e.g., Doe v. Gallinot*, 657 F.2d 1017 (9th Cir. 1981).

³⁴ *See, e.g.,* Melissa Bowman, Note, *Open Debate Over Closed Doors: The Effect of New Developmental Disabilities Regulations on Protection and Advocacy Programs*, 85 KY. L.J. 955, 959 (1997) (stating that employees at the Willowbrook State School in New York garnered national attention for neglecting and abusing their residents, who were mentally retarded).

³⁵ *Id.* at 959–63.

³⁶ *Id.* at 959.

³⁷ *Id.* at 959–60.

neglect surfaced in the mental health and state hospital settings, Congress passed PAIMI to ensure that the rights of individuals with mental illness were protected.³⁸ PAIMI was supported by legal advocates for the mentally ill, individuals with mental illness, and their family members.³⁹ By establishing and funding state-governed P&A systems to monitor mental health treatment facilities and the patients within them, Congress hoped that the incidents of abuse and neglect would decrease.⁴⁰

B. Congressional Findings and PAIMI's Intent

The congressional committee that created PAIMI determined that persons with mental illness who were institutionalized were susceptible to neglect in the forms of inadequate nutrition and clothing, substandard mental health treatment, deficient general health care, nonexistent patient discharge plans, and poorly trained staff.⁴¹ Congress sought not only to prevent these forms of neglect, but also to prevent abuse. It defined patient abuse as physical or sexual abuse and included abuse through the use of chemical and bodily restraints.⁴²

The committee's executive summary stated that documented incidents of abuse and neglect included staff members' failing to report injuries, "kicking or otherwise striking patients, sexual advances and rape, [and] verbal threats of injury."⁴³ The report also stated that staff members verbally harassed patients, chemically and mechanically restrained patients, and isolated patients as methods of control.⁴⁴ Most patients received medication only when the staff deemed that it was needed, which was not often.⁴⁵ Some patients received no exercise or recreational activity.⁴⁶ Finally, the report stated that the living conditions in most institutions were deplorable;

³⁸ 42 U.S.C. § 10801(b)(1) (2006).

³⁹ Marianne R. Woodside & Bobbie H. Legg, *Patient Advocacy: A Mental Health Perspective*, 12 J. OF MENTAL HEALTH COUNSELING 38, 40 (1990).

⁴⁰ Bowman, *supra* note 34, at 960–63.

⁴¹ 42 U.S.C. §§ 10801(a)(3), 10802(5).

⁴² *Id.* § 10802(1)(A)–(D).

⁴³ *Joint Hearings, supra* note 1, at Part 2 app. at 2 (Executive Summary, Staff Report on the Institutionalized Mentally Disabled).

⁴⁴ *Id.* at 2–3.

⁴⁵ *Id.* at 3.

⁴⁶ *See id.* at 66–67 (stating that patients spent the majority of their time sleeping or watching television).

some institutions smelled of urine and cigarette smoke, bathroom floors were used as sleeping quarters, and patient bathrooms were lacking basic privacy measures like shower curtains and doors.⁴⁷

During congressional hearings, Senators heard from individuals who testified about patients who had been raped,⁴⁸ employees who had been violent,⁴⁹ and widespread neglect that resulted in death.⁵⁰ Most of these accounts were ignored and never investigated by hospital administrators.⁵¹ There was also substantial testimony about civil rights violations,⁵² under-trained and inadequate staff,⁵³ and a general lack of treatment behind institutional walls.⁵⁴ In sum, patients were being warehoused with little treatment or care in institutions around the country.

Congress identified two significant problems with patient protection: states often did not monitor institutions, and they failed to protect the rights of patients.⁵⁵ Congress created P&A systems to protect patients' civil rights and to police state mental health facilities. Congress sought to create legal advocates who would foster communication between patients and people outside the hospital walls.

With this testimony and these goals in mind, Congress, through PAIMI, created a privileged attorney-client relationship between the patient and the legal advocate. PAIMI encourages advocates to meet with patients to discuss treatment options and patients' rights.⁵⁶ PAIMI permits patient advocates to monitor and have access to

⁴⁷ *Id.* at 3–4.

⁴⁸ *See, e.g., id.* at 79 (statement of Carol Sands, Assistant Deputy Public Advocate, State of New Jersey).

⁴⁹ *See, e.g., id.* at 5, 67 (statement of Harold Cockerham, father of Chris Cockerham, a young man who was beaten so severely that he lost his hearing during his institutionalization).

⁵⁰ *See, e.g., id.* at 67, 72 (account of Mark Jones, a patient who drowned in a bathtub due to inadequate training and supervision of staff).

⁵¹ *See, e.g., id.* at 78–82 (statement of Carol Sands, Assistant Deputy Public Advocate, State of New Jersey).

⁵² *See, e.g., id.* at 78–82, 176–77 (statement of Carol Sands, Assistant Deputy Public Advocate, State of New Jersey).

⁵³ *See, e.g., id.* at 235–37 (statement of David B. Pharis, Coordinator, R.A.J. Review Panel, Austin, Texas).

⁵⁴ *See, e.g., id.* at 78–82 (statement of Carol Sands, Assistant Deputy Public Advocate, State of New Jersey).

⁵⁵ 42 U.S.C. § 10801(a)(4) (2006).

⁵⁶ *See id.* § 10802(3), (4)(B)(ii).

patients⁵⁷ and patient records⁵⁸ at schools,⁵⁹ mental health institutions, hospitals, penal institutions, and nursing homes.⁶⁰ It also protects patients in community-run programs like outpatient facilities, boarding and group homes, homeless shelters, and even the patient's own home.⁶¹ PAIMI applies equally to state and private treatment facilities, regardless of whether they receive federal funds.⁶²

When patient advocates find the requisite probable cause to warrant an investigation into possible abuse or neglect, they are entitled full access to investigate the allegations.⁶³ Courts are divided as to whether the P&A system or its supervising court is the final arbiter of probable cause.⁶⁴ Nevertheless, probable cause is the legal standard that is required to begin an investigation into patient abuse or neglect.

C. Federal Funding and PAIMI in Action

PAIMI provides federal funds to state P&A systems to provide services to persons with mental illness.⁶⁵ "PAIMI grant awards are used by State P&A systems to pursue administrative, legal (individual and class action litigation), systemic and legislative activities, or other appropriate remedies to redress complaints of abuse, neglect, and civil

⁵⁷ *Id.* § 10841(3)(C)(i).

⁵⁸ *Id.* § 10806. The Health Insurance Portability and Accountability Act (HIPAA) of 1996, Pub. L. No. 104-191, 110 Stat. 1936 (codified in scattered sections of 26, 29, and 42 U.S.C.), does not prevent patient advocates from accessing patient records. *Prot. & Advocacy Sys., Inc. v. Freudenthal*, 412 F. Supp. 2d 1211, 1220 (D. Wyo. 2006).

⁵⁹ *Conn. Office of Prot. & Advocacy for Persons with Disabilities v. Hartford Bd. of Educ.*, 464 F.3d 229, 240 (2d Cir. 2006).

⁶⁰ 42 U.S.C. § 10802(3), (4)(B)(ii).

⁶¹ *Id.* However, Congress has stated that the focus of state P&A systems should be on patients who reside in residential settings, not on patients who reside at home. Substance Abuse and Mental Health Servs. Admin., U.S. Dep't of Health and Human Servs., *Protection and Advocacy: PAIMI Program*, SAMHSA'S NAT'L MENTAL HEALTH INFO. CENTER, <http://mentalhealth.samhsa.gov/cmhs/p&a/about.asp> (last visited Jul. 24, 2010) [hereinafter PAIMI Program Web site].

⁶² *Wis. Coal. for Advocacy, Inc. v. Czaplewski*, 131 F. Supp. 2d 1039, 1046–50 (E.D. Wis. 2001) (stating that the Act's application is not limited to facilities that receive federal funding).

⁶³ *See, e.g., Office of Prot. & Advocacy for Persons with Disabilities v. Armstrong*, 266 F. Supp. 2d 303, 311 (D. Conn. 2003).

⁶⁴ *See, e.g., Iowa Prot. & Advocacy Servs., Inc. v. Gerard Treatment Programs, L.L.C.*, 152 F. Supp. 2d 1150, 1172 (N.D. Iowa 2001) (stating that courts may review P&A's probable cause determination); *Ariz. Ctr. for Disability Law v. Allen*, 197 F.R.D. 689, 693 (D. Ariz. 2000) (stating that the P&A system is the final arbiter of probable cause).

⁶⁵ Bowman, *supra* note 34, at 956–57.

rights violations.”⁶⁶ However, the federal government has also declared that these program grants are “not intended to accomplish systemic reform of the mental health system.”⁶⁷ In return for federal funding, the government requires each state to establish a P&A system to provide advocacy services and protect individuals with mental illness.⁶⁸

D. The Modern-Day P&A System

Today, each state has its own P&A system that provides a legal advocate to any individual with mental illness who alleges abuse, neglect, or civil rights violations within a treatment or residential facility.⁶⁹ Citing the inadequacy of state-created advocacy systems,⁷⁰ Congress provides the Substance Abuse and Mental Health Services Administration (SAMHSA), which is a division of the U.S. Department of Health and Human Services (HHS), with funding to assist each state in creating its own P&A system.⁷¹ Currently, forty-five states have nonprofit organizations running their P&A systems, whereas the remaining states have created state-run agencies or departments to provide advocacy services.⁷²

In order to qualify for P&A services, a person must be diagnosed with a serious mental or emotional impairment (as defined by the state of residence), be a resident of a public or private facility serving the needs of those with mental illness, and be susceptible to abuse or neglect.⁷³ Patient advocates are legally authorized to intervene on behalf of individuals who meet the above qualifications either during their treatment or up to ninety days after they have been released from inpatient care⁷⁴ if those individuals die in a facility, are reported

⁶⁶ PAIMI Program Web site, *supra* note 61.

⁶⁷ *Id.*

⁶⁸ Bowman, *supra* note 34, at 956–57.

⁶⁹ *See infra* note 73 and accompanying text.

⁷⁰ Protection and Advocacy for Individuals with Mental Illness Act of 1986, Pub. L. No. 99-319, 100 Stat. 478 (codified as amended in scattered sections of 42 U.S.C.).

⁷¹ PAIMI Program Web site, *supra* note 61.

⁷² *Id.* PAIMI allows states to contract with nonprofit organizations or set up state agencies; it requires only that the P&A system be independent from the facility or institution providing treatment to the patient. 42 U.S.C. § 10804(a) (2006).

⁷³ PAIMI Program Web site, *supra* note 61.

⁷⁴ 42 U.S.C. § 10805(a)(1). *But see* Doe v. Stincer, 175 F.3d 879, 887–88 (11th Cir. 1999) (citing failure to make a specific allegation regarding a particular person whose rights were violated within the ninety-day period of time in a lawsuit’s dismissal).

missing from a facility, or are involuntarily confined to a detention facility for a noncriminal matter.⁷⁵ In other words, the primary responsibility of patient advocates is to protect individuals at or about the time they are institutionalized or receiving treatment.⁷⁶

Since PAIMI was passed in 1986, lawyers have sought to use federal money and statutory authority to protect countless mentally ill people from abuse and neglect. As much as the public would like to believe that this kind of protection is not warranted anymore, tragic news reports suggest that patient advocates are just as necessary now as in 1986, when PAIMI was first enacted.⁷⁷ Indeed, between 2002 and 2006, investigative journalists discovered 115 suspicious deaths in Georgia mental health facilities.⁷⁸ Unaware that investigating deaths in treatment facilities is a role PAIMI entrusts to patient advocates,⁷⁹ the public was probably left to wonder how so many people died without anyone noticing.

These tragic events demonstrate that protecting mentally ill individuals from abuse and neglect is a job that requires diligence, perseverance, and determination. However, some patient advocates

⁷⁵ PAIMI Program Web site, *supra* note 61. In the late 1980s and early 1990s, during the first decade of PAIMI's existence, many institutions and states fought with P&As in court on a regular basis, hid evidence of wrongdoing, and made access to medical records and individuals next to impossible. Bowman, *supra* note 34, at 958–65. As a result, much of the federal money given to P&As to investigate allegations of abuse and neglect was spent on prolonged legal battles, thereby frustrating the “P&As’ watchdog status.” *Id.* at 966–67.

⁷⁶ Woodside & Legg, *supra* note 39, at 38. Patients who do not want advocates to intervene on their behalf and guardians of minors who do not want advocates to access patient records have won lawsuits preventing advocate involvement or advocate-instigated investigations. *Ga. Advocacy Office, Inc. v. Camp*, 172 F.3d 1294, 1297 (11th Cir. 1999) (stating that an individual who refuses visits with an advocate is protected from P&A involvement); *Advocacy, Inc. v. Brown Schs., Inc.*, No. Civ.A.SA-00-CA-0297-, 2001 WL 1910563, at *2–4 (W.D. Tex. Oct. 1, 2001) (stating that the parents of a minor child who died in a mental health facility won the right to prevent P&A access to the child's medical and patient records).

⁷⁷ See, e.g., Alan Judd & Andy Miller, *A Hidden Shame: Death in Georgia's Mental Hospitals*, ATLANTA J.-CONST., Jan. 7, 2007, <http://psychrights.org/Stories/GeorgiaHiddenShame.htm> (counting an alarming number of suspicious deaths in Georgia's state hospitals for the mentally ill); Joseph Shapiro, *Abuse At Texas Institutions Is Beyond 'Fight Club'*, NPR, Mar. 18, 2009, <http://www.npr.org/templates/story/story.php?storyId=101937985> (detailing abuse by forcing patients to fight one another at a state hospital for the “entertainment” of hospital employees).

⁷⁸ Judd & Miller, *supra* note 77; see also Alan Judd, *System was Deaf to Pleas; Mother Died*, ATLANTA J.-CONST., June 28, 2009, <http://www.ajc.com/services/content/printedition/2009/06/28/mental06281.html>.

⁷⁹ PAIMI Program Web site, *supra* note 61.

have neglected their primary job and instead focused on other activities, which take them away from their core mission. These secondary activities are the subject of this Article.

III

ADVOCATES ARE OPERATING OUTSIDE THE SCOPE OF PAIMI

While some critics disagree with patient advocacy ideology, which sometimes takes an anti-treatment approach, everyone agrees that their core responsibility as protector and advocate is a legally permissible and honorable one. However, some activities that advocates have participated in are legally impermissible. This Part of the Article examines those activities that appear to violate PAIMI, the Act's legislative intent, or other related federal regulations.

A. *Prohibited Lobbying Efforts*

Patient advocates are limited to the roles and activities outlined earlier in this Article.⁸⁰ By lobbying against proposed laws at the state and federal levels, patient advocates have engaged in activities that are not authorized by PAIMI and that directly violate other federal regulations. Advocates have been both open and aggressive with their lobbying activities.⁸¹ Unfortunately, these activities have actually hurt patients by eliminating a less restrictive alternative to institutionalization, which is a right granted to individuals with mental illness.⁸² This section analyzes the laws that prohibit patient advocate lobbying, examine some of their recent lobbying efforts and the problems that arise from these efforts, and suggest ways that Congress can prevent patient advocate lobbying.

⁸⁰ See *supra* notes 56–76 and accompanying text.

⁸¹ See Kelsey McCowan Heilman, Comment, *The Rights of Others: Protection and Advocacy Organizations' Associational Standing to Sue*, 157 U. PA. L. REV. 237, 239 (2008) (“P&As also regularly meet with local, state, and national government officials, [and] comment on proposed regulations”); *P&A Special Report: The Nation's Disability Rights Network Responds to Deadly Restraint and Seclusion*, NAT'L DISABILITY RTS. NETWORK (Sept. 2000), <http://www.napas.org/pub/SpecRpt/rs.htm> (stating that the NDRN has the “legal authority” to “[e]ducate policy makers on needed reforms to disability-related laws and services”).

⁸² See, e.g., *In re Brown*, 640 N.W.2d 919, 924 (Sup. Ct. Minn. 2002); *In re D.Z.*, 649 N.W.2d 231, 234 (Sup. Ct. N.D. 2002).

1. *Federal Anti-Lobbying Provisions*

Though PAIMI is silent about patient advocate lobbying, Congress has explicitly prohibited any HHS agency, including SAMHSA, from using federal funds to influence legislation.⁸³ HHS finances SAMHSA, which in turn finances and oversees the national P&A system. While SAMHSA permits using legislative remedies to correct confirmed incidents of abuse, neglect, and rights violations,⁸⁴ it has never authorized advocate lobbying efforts or funding to change or defeat proposed legislation. This means that patient advocates must not use the federal monies they receive to operate for lobbying efforts before state or federal legislatures.⁸⁵ While one could argue that patient advocates are entitled to lobby against proposed laws if they are not spending federal funds, their funds are fungible. It is easy to spend federal dollars on lobbying expenses, yet hide that from SAMHSA. Given the amount of time and money that some patient advocates spend lobbying, it is highly unlikely that they are using their personal funds or vacation time for these activities. However, even if they use state funds to support their lobbying efforts, depending on the state, that too may be in violation of the stipulations that come with such funding.

Though P&A systems are federally funded, they may also be funded by both state funds and private donations. At the state level, legal aid offices are often prohibited from using state funding for lobbying.⁸⁶ One of the reasons for this prohibition is that the number of clients these nonprofit legal aid organizations serve is great, though their funding is not.⁸⁷ Like these nonprofit legal aid attorneys, patient advocates, because of the critical nature of their role and because of the number of patients they represent, must not deviate from their core mission. Lobbying is a distraction to patient advocates.

⁸³ See, e.g., H.R. 3293, 111th Cong. § 503 (2009).

⁸⁴ Substance Abuse and Mental Health Servs. Admin., U.S. Dep't of Health and Human Servs., *Protection and Advocacy*, SAMHSA'S NAT'L MENTAL HEALTH INFO. CENTER, <http://mentalhealth.samhsa.gov/cmhs/P&A/> (last visited Jul. 24, 2010).

⁸⁵ See H.R. 3293.

⁸⁶ See, e.g., 42 U.S.C. § 2996e(d)(4) (2006) ("Neither the Corporation nor any recipient shall contribute or make available corporate funds or program personnel or equipment for use in advocating or opposing any ballot measures, initiatives, or referendums.").

⁸⁷ Spencer Rand, *A Poverty of Representation: The Attorney's Role to Advocate for the Powerless*, 13 TEX. WESLEYAN L. REV. 545, 550-51 (2007) ("[A]ttorneys working in legal service offices are often hardpressed to help people with family law, housing issues, and government benefits matters among others. These concerns are so overwhelming that they cannot focus on issues of oppression in society.").

2. *The Least Restrictive Alternative*

In order to understand patient advocate lobbying efforts, it is important to understand core mental health law theories and the types of laws patient advocate lobbyists have sought to prevent. The following two subsections provide some background for the rest of this section.

One of the many rights won for mental health patients by Bazelon Center lawyers was the right to be treated in the least restrictive setting available.⁸⁸ Known as the least restrictive alternative, the underlying legal theory is that “the state may restrict the exercise of fundamental liberties only to the extent necessary to effectuate the state’s interest.”⁸⁹ In the mental health context, this means that if a person can be treated in the community, then the state cannot confine him against his will to a state hospital, where his liberties would be compromised.⁹⁰ In fact, the U.S. Supreme Court has noted that many individuals with mental illness prefer to be treated in the comfort of their own homes rather than in an institution.⁹¹ Being treated in an outpatient setting is one way of ensuring that a patient is able to reside at home rather than in an institution.⁹²

3. *Assisted Outpatient Treatment Laws*

“Under the [least restrictive alternative] concept, any feasible alternative must be implemented in lieu of involuntary hospitalization.”⁹³ Therefore, assisted outpatient treatment (AOT) laws, which allow consumers to live freely in the community as long as they comply with a treatment program, are a less restrictive alternative to civil commitment.⁹⁴ The objective of AOT laws “is to ensure treatment for those who otherwise resist, avoid, stop, slip-through-the-cracks-of, and recycle through the mental health and criminal justice systems to their own as well as their fellow citizens’

⁸⁸ Slovenko, *supra* note 11, at 648 (stating that “[t]he first enunciation of [the least restrictive alternative] was in the 1966 case of *Lake v. Cameron*, [364 F.2d 657, 661 (D.C. Cir. 1966)],” which was penned by Judge Bazelon).

⁸⁹ *Id.*

⁹⁰ See *Olmstead v. L.C.*, 527 U.S. 581, 602–03 (1999).

⁹¹ *O'Connor v. Donaldson*, 422 U.S. 563, 575 (1975).

⁹² Slovenko, *supra* note 11, at 648.

⁹³ Ralph Slovenko, *Civil Commitment Laws: An Analysis and Critique*, 17 T.M. COOLEY L. REV. 25, 32 (2000).

⁹⁴ Slovenko, *supra* note 11, at 648.

detriment.”⁹⁵ Inpatient treatment requires a person to be in crisis before getting help.⁹⁶ Outpatient treatment has become a better option for many who need earlier intervention to prevent a crisis. Mental health observers note that the era of involuntary civil commitment may eventually be replaced with an outpatient model.⁹⁷

Currently, forty-four of the fifty states have AOT laws;⁹⁸ however, passing and implementing these laws has been a battle because of the lobbying efforts of patient advocates. Instead of supporting these laws because they allow patients to get treatment in the community while living at home, patient advocates have argued that these laws “widen[] the net and subject[] more people to the coercive power of the state.”⁹⁹ However, advocates who have lobbied against AOT or delayed legislation have actually limited their clients’ options by forcing many into involuntary commitment because no less restrictive alternatives were available.

4. *Specific Instances of Prohibited Lobbying*

Though there are numerous examples of lobbying efforts to prevent or stall proposed legislation, this section highlights just a few. In February of 2002, Ellen Piekalkiewicz, then Deputy Director of Operations for Florida’s P&A, testified against Senate Bill 2030, which was Florida’s proposed AOT law.¹⁰⁰ During her testimony, she stated that the law “impinge[d] upon the rights of individuals with mental illnesses.”¹⁰¹ Though Piekalkiewicz no longer serves as the

⁹⁵ Brakel & Davis, *supra* note 29, at 569.

⁹⁶ Milton L. Mack, Jr., *Involuntary Treatment for the Twenty-First Century*, 21 QUINNIPIAC PROB. L.J. 294, 299 (2008).

⁹⁷ *Id.* at 295.

⁹⁸ Press Release, Treatment Advocacy Ctr., Maine Becomes 44th State to Reform Mental Illness Treatment Laws (Apr. 14, 2010), *available at* http://www.treatmentadvocacycenter.org/storage/tac/documents/tac--maine_bill_signed_news_release_final--_04-14-2010.pdf. Connecticut, Maryland, Massachusetts, New Mexico, Nevada, and Tennessee are the only six states remaining that do not have AOT laws. *Assisted Outpatient Treatment*, TREATMENT ADVOC. CENTER, http://www.treatmentadvocacycenter.org/index.php?option=com_content&task=view&id=471&Itemid=122 (last visited Oct. 6, 2010) [hereinafter Treatment Advocacy Center Web site].

⁹⁹ Brakel & Davis, *supra* note 29, at 569–70 & nn.370–71 (internal quotation marks omitted) (humorously describing the many efforts of patient advocates to discredit the assisted outpatient treatment trend).

¹⁰⁰ Testimony on Senate Bill 2030 from Ellen Piekalkiewicz, Deputy Dir. of Operations, The Advocacy Ctr. for Persons with Disabilities, Inc. (Feb. 20, 2002) (on file with author) [hereinafter Piekalkiewicz Testimony on Senate Bill 2030].

¹⁰¹ *Id.*

director for Florida's P&A, she is now a registered lobbyist in Florida for another mental health nonprofit organization.¹⁰²

In October of 2007, Carol Horowitz, the managing attorney for Pennsylvania's P&A, the Disability Rights Network, testified before the state's legislature against Senate Bill 226, which was Pennsylvania's proposed AOT law.¹⁰³ After identifying her employment position and stating that her group was federally supported, she said that the law was coercive, violated patients' constitutional rights,¹⁰⁴ and had "no intrinsic benefits."¹⁰⁵

In her testimony before the Pennsylvania legislature, Horowitz said that AOT laws are "ineffective because forced treatment does not work."¹⁰⁶ In making this statement, she relied on her own experiences as the mother of a child with mental illness.¹⁰⁷ However, there is no evidence that her child was ever an AOT consumer. Studies reveal that, had her child been in an AOT program, her child's treatment likely would have been successful.¹⁰⁸

Though several states have kept data about their AOT programs,¹⁰⁹ the data compiled by New York¹¹⁰ and North Carolina¹¹¹ are perhaps the most comprehensive. Both states' data demonstrate that AOT laws can be extremely effective in guaranteeing a continuing course of treatment among consumers and that those consumers experience both fewer problems with the criminal justice system and shorter periods of hospitalization.

¹⁰² FLA. LEGISLATURE, 2010 REGISTRATIONS BY LOBBYIST NAME 235 (Sept. 10, 2010), available at http://www.leg.state.fl.us/data/lobbyist/Reports/Lobbyist_LEG_2010.pdf.

¹⁰³ Testimony on Senate Bill 226 from Carol Horowitz, Managing Attorney, Disability Rights Network of PA (Oct. 2, 2007), available at <http://www.senatorerickson.com/health/2007/100207/horowitz.pdf> [hereinafter Horowitz Testimony on Senate Bill 226].

¹⁰⁴ *Id.* at 7–9.

¹⁰⁵ *Id.* at 4.

¹⁰⁶ *Id.* at 16.

¹⁰⁷ *Id.* at 16–17.

¹⁰⁸ See *infra* notes 109–24 and accompanying text.

¹⁰⁹ Arizona, the District of Columbia, Florida, Iowa, Ohio, and Tennessee have all collected data on AOT effectiveness. See Treatment Advocacy Center Web site, *supra* note 98.

¹¹⁰ MARVIN S. SWARTZ ET AL., NEW YORK STATE ASSISTED OUTPATIENT TREATMENT PROGRAM EVALUATION (2009), available at http://www.macarthur.virginia.edu/aot_finalreport.pdf.

¹¹¹ *Assisted Outpatient Treatment Laws*, TREATMENT ADVOC. CENTER, http://www.treatmentadvocacycenter.org/index.php?option=com_content&task=view&id=39&Itemid=68 (last visited Oct. 6, 2010).

In 1999, researchers in North Carolina determined that, when patients participated in court-ordered outpatient services at least three times a month for six months, hospital admissions decreased by fifty-seven percent, and the average length of a hospital stay decreased by twenty days when compared with those of individuals who were not subjected to court-ordered treatment.¹¹² The results were even more dramatic for individuals with schizophrenia and other psychotic disorders: hospital admissions decreased by seventy-two percent, and the length of the average hospital stay decreased by twenty-eight days when compared to individuals who were not subject to court-supervised treatment.¹¹³

Most of these consumers, when they began their treatment, believed they were not mentally ill or in need of treatment.¹¹⁴ However, several studies show that consumers' perceptions changed dramatically after treatment and that most were thankful for having received it.¹¹⁵ One individual, named Carl, was especially thankful after he sought pharmacological treatment, stating "I would have been angry and fought [against forced medication], but if they had stuffed pills down my throat, I would have kissed their asses and thanked them once I got my mind back, because no one wants to be crazy like that."¹¹⁶ A recent New York study of the effects of Kendra's Law, New York's AOT statute, confirms that many AOT participants share Carl's sentiments.

¹¹² Marvin S. Swartz et al., *Can Involuntary Outpatient Commitment Reduce Hospital Recidivism?: Findings From a Randomized Trial with Severely Mentally Ill Individuals*, 156 AM. J. OF PSYCHIATRY 1968, 1971 (1999).

¹¹³ *Id.*

¹¹⁴ *Id.* at 1969.

¹¹⁵ See, e.g., William Gardner et al., *Patients' Revisions of Their Beliefs About the Need for Hospitalization*, 156 AM. J. OF PSYCHIATRY 1385, 1387 (1999) (stating that seventy-six percent of all patients surveyed believed they needed to be hospitalized, and fifty-two percent of patients who believed upon commitment that they did not need to be hospitalized changed their minds post treatment); William M. Greenberg et al., *Patients' Attitudes Toward Having Been Forcibly Medicated*, 24 BULL. OF THE AM. ACAD. OF PSYCHIATRY & THE LAW 513, 519 (1996) ("[W]eeks after their hospital discharge . . . two-thirds of interviewable patients supported their having been previously forcibly medicated."); John M. Kane et al., *Attitudinal Changes of Involuntarily Committed Patients Following Treatment*, 40 ARCHIVES OF GEN. PSYCHIATRY 374, 376 (1983) (stating that, after involuntary commitment, ninety-three percent of readmissions were voluntary); Harold I. Schwartz et al., *Autonomy and the Right to Refuse Treatment: Patients' Attitudes After Involuntary Medication*, 39 HOSP. & COMMUNITY PSYCHIATRY 1049, 1050 (1988) (stating that seventeen out of twenty-five patients surveyed after their involuntary commitment agreed that they should have been medicated against their will).

¹¹⁶ EARLEY, *supra* note 13, at 332.

In 2009, New York published a report on the results of Kendra's Law, which was enacted a decade earlier.¹¹⁷ One of Kendra's Law's key goals is to "motivate consumers to actively engage in treatment during and after their involvement with the program."¹¹⁸ According to the report, Kendra's Law has accomplished this goal. After six months of AOT, consumers were as motivated to take part in their treatment as individuals who voluntarily sought treatment.¹¹⁹ After a year of AOT, consumers were *more* motivated than voluntary patients to continue their course of treatment.¹²⁰

Researchers reported that during their participation in AOT, Kendra's Law consumers experienced a decrease in hospitalizations, a reduction in the likelihood of being arrested, a subjective improvement in many areas of their personal functions, and an increased desire to continue pharmacological treatment.¹²¹ Those consumers who participated for more than six months in the program were likely to continue their treatment successfully without any supervision.¹²²

The study also disproved pessimistic advocate predictions that AOT laws would deplete or prevent community services for those who did not qualify for them.¹²³ Kendra's Law, after its first five years of operation, increased community services for those not in its program.¹²⁴ With fewer individuals in mental health crisis and more individuals maintaining a course of treatment on their own, more individuals are able to partake in what the state's mental health system has to offer.

Regardless, the success of Kendra's Law has not swayed patient advocates from lobbying against AOT laws across the country or stopped the National Disability Rights Network (NDRN), which is a "federal interagency project" that receives federal funds to train

¹¹⁷ SWARTZ ET AL., *supra* note 110.

¹¹⁸ *Id.* at vii.

¹¹⁹ *Id.*

¹²⁰ *Id.*

¹²¹ *Id.* at vii–viii.

¹²² *Id.* at viii.

¹²³ *See, e.g.,* Piekalkiewicz Testimony on Senate Bill 2030, *supra* note 100 ("[F]orced outpatient treatment will detract from the necessity of funding assertive outreach programs, housing, and other basic community services"); Horowitz Testimony on Senate Bill 226, *supra* note 103, at 16 (AOT "simply covers up the real problem relating to the lack of funding for services and the unnecessary fragmentation of the mental health system.").

¹²⁴ SWARTZ ET AL., *supra* note 110, at 1.

patient advocates across the nation, from gloating over the defeat of potential AOT legislation in other states.¹²⁵

In its 2006 annual report, the NDRN, which is the voice for P&A systems, stated that the New Mexico P&A “devoted considerable time and effort to educating state legislators about the problems with” New Mexico’s AOT bill.¹²⁶ It then boasted that, even though changes were made to the bill, in large part because of the advocates’ concerns, the bill ultimately died.¹²⁷

The fact that the initial bill died did not end New Mexico’s battle to enact AOT legislation. Immediately after the law was defeated, the Albuquerque city council enacted a city ordinance permitting AOT.¹²⁸ Shortly thereafter, New Mexico’s P&A and the ACLU sued the city to prevent it from enforcing the law.¹²⁹ After a federal judge struck down Albuquerque’s ordinance based on home rule authority,¹³⁰ the state legislature attempted in 2007 to enact another AOT law, only to have it defeated again by New Mexico’s P&A system.¹³¹ Last year, for the third time, a new AOT law was proposed in the New Mexico legislature.¹³² New Mexico will have to wait to see if patient advocates will attempt to kill the legislation once again; based upon their aggressive efforts in the past, it is almost certain they will.

California’s AOT legislation, Laura’s Law, has faced some of the same hurdles. Only two California counties currently enforce Laura’s

¹²⁵ *Training and Advocacy Support Center (TASC) at NDRN*, NAT’L DISABILITY RTS. NETWORK, <http://www.ndrn.org/aboutus/TASC/default.htm> (last updated Jan. 16, 2008).

¹²⁶ NAT’L DISABILITY RIGHTS NETWORK, 2006 ANNUAL REPORT 24 (2006), available at <http://www.ndrn.org/pub/AnnRpt/2006/06FYAnnRpt.pdf>.

¹²⁷ *Id.*

¹²⁸ Heath Haussamen, *Albuquerque City Council Approves ‘Kendra’s Law;’ Las Cruces Might Want to do the Same*, HEATH HAUSSAMEN ON NEW MEXICO POLITICS (Sept. 19, 2006, 10:50 AM), <http://haussamen.blogspot.com/2006/09/albuquerque-city-council-approves.html>.

¹²⁹ *Civil Rights Organizations Sue City Over Kendra’s Law*, AM. CIV. LIBERTIES UNION OF NEW MEXICO (Oct. 2, 2006), http://edgewiseblog.com/aclu/PDF/Kendras_Law_10_2_2006.pdf.

¹³⁰ *Prot. & Advocacy Sys. v. City of Albuquerque*, 195 P.3d 1, 17, 24 (N.M. Ct. App. 2008); see also Sally Satel, *Sane Mental Health Laws? Don’t Hold Your Breath. Federal “Advocates” are Standing in the Way of Reform*, WKLY. STANDARD, May 28, 2007, at 3, available at http://www.aei.org/docLib/20080603_6908Satelarticle.pdf.

¹³¹ Satel, *supra* note 130, at 3.

¹³² Eyewitness News 4, *Group Pushes for Kendra’s Law in NM*, KOB.COM NEW MEXICO, Aug. 17, 2009, <http://www.kob.com/article/stories/S1089466.shtml>.

Law;¹³³ this is in part because California's P&A lobbied against the law and filed a lawsuit to prevent some counties from enforcing it.¹³⁴

One of the problems with these lawsuits is that PAIMI specifically discourages advocates from initiating lawsuits. Congress hoped that advocates would pursue a "non-litigative approach to advocacy and dispute resolution" by urging advocates to pursue administrative remedies before initiating lawsuits.¹³⁵

Another more serious problem is that this litigation indirectly harms patients. One commentator noted that increased, but necessary, litigation in the past frustrated the "P&As' watchdog status."¹³⁶ In other words, litigation distracts patient advocates from their responsibility to protect individuals with mental illness. The litigation in New Mexico and California was not necessary. If laws affecting mental health consumers need to be challenged, individuals affected and non-P&A mental health advocacy groups are free to lobby against the laws.

Proposed AOT laws are not the only ones susceptible to aggressive patient advocate lobbying. Provisions, whether included in AOT legislation or not, that address additional mental health laws have been challenged by advocate lobbyists as well. For example, Maine's P&A system, the Disability Rights Center, has lobbied against provisions that would allow families and law enforcement officers to petition a court to initiate civil commitment proceedings.¹³⁷ It has also lobbied against laws in Maine that would loosen patient confidentiality restrictions for family members and allow patients to

¹³³ Peter Neibert, *How to Tell Marin Board of Supervisors: Implement Laura's Law*, NAMIMARIN.ORG (Mar. 9, 2010), <http://namimarinblog.wordpress.com/2010/03/09/marin-board-supervisors-lauras-law/>.

¹³⁴ Dave Moller, *Second Try for Laura's Law*, THEUNION.COM, Mar. 2, 2006, <http://www.theunion.com/article/20060302/NEWS/103020136>. The law has not been widely implemented in part because the law requires each county to appoint a board of supervisors to adopt Laura's Law and because the law came with no state funding. See, e.g., Amy Yannello, *Losing Laura*, NEWSREVIEW.COM, Jan. 5, 2006, <http://www.newsreview.com/sacramento/content?oid=45814> (suggesting that though the Mental Health Services Act was supposed to fund Laura's Law, the funds have not been made available to counties interested in using Laura's Law); see also Neibert, *supra* note 133.

¹³⁵ S. REP. NO. 99-109, at 10 (1985), *reprinted in* 1986 U.S.C.C.A.N. 1361, 1371.

¹³⁶ Bowman, *supra* note 34, at 967.

¹³⁷ Memorandum from Helen Bailey, Disability Rights Ctr., to Senator Joseph Brannigan, Representative Anne Perry, and the Joint Legislative Comm. on Health & Human Servs. (Apr. 28, 2009) (on file with author); E-mail from Joe Bruce to author (Aug. 19, 2009) (on file with author).

be medicated over their objections.¹³⁸ Advocates in Maryland have lobbied against proposed changes to Maryland's civil commitment criteria.¹³⁹

Though federal law prohibits patient advocates from lobbying, some academics believe that advocates can educate legislatures about proposed legislation.¹⁴⁰ Suggesting that advocates are uniquely qualified to voice concerns to legislatures because of their repeated contact with mentally ill individuals, one scholar believes that "patient advocate[s] can work at the local, county, and state levels to make policy changes benefiting clients."¹⁴¹ However, patient advocate lobbying is not authorized through PAIMI nor is it permitted by SAMHSA. To ensure that advocates are not using federal funds to lobby, Congress should consider instituting a complete ban on lobbying.

Patient advocacy groups acknowledge time and time again that their funds are limited.¹⁴² With limited resources, they should be following the strict letter of the law and assisting patients who have suffered abuse and neglect; they should not be taking on additional and legally impermissible responsibilities. For every legislative hearing at which an advocate testified, for every dollar spent on travel expenses to that hearing, and for every hour spent on litigation designed to prevent enacted legislation from being enforced, patient advocates could have been investigating individual cases of abuse, neglect, and rights violations.

¹³⁸ E-mail from Joe Bruce to author, *supra* note 137.

¹³⁹ Letter from Laura Cain, Staff Attorney, Md. Disability Law Ctr., to Clarence Blount, Chairman, Educ., Health and Envtl. Affairs Comm. (not dated) (on file with author).

¹⁴⁰ See Paula Galowitz, *Restrictions on Lobbying by Legal Services Attorneys: Redefining Professional Norms and Obligations*, 4 B.U. PUB. INT. L.J. 39, 75–84 (1994) (arguing that preventing nonprofit attorneys from lobbying results in an unethical litigation-first focus); Woodside & Legg, *supra* note 39, at 44 (suggesting that the crux of patient advocacy policy changes may center around how services are provided or delivered).

¹⁴¹ Woodside & Legg, *supra* note 39, at 44.

¹⁴² See, e.g., Richard West, *From the Chair of NJP&A's Governing Board*, NJ P&A LEDGER 3 (2006–2007) (on file with author) ("Protection and advocacy program goals and priorities assist NJP&A as it faces a demand for representation that often exceeds the resources of the protection and advocacy system."); NAT'L DISABILITY RIGHTS NETWORK, ANNUAL REPORT OF THE P&A SYSTEM 1996–97, at 11 (1997) ("Congress was aware that they were not providing P&As with unlimited resources. This would mean that P&As would have to make difficult decisions about how to use the resources they had to impact and improve the quality of life of people with disabilities in the most efficient manner.").

5. *What Congress Can Do*

Congress has been effective at preventing other federally funded legal organizations from lobbying. It can use the same measures to prevent federally funded patient advocate lobbying efforts that it used with Legal Services Corporation, which is the largest nonprofit legal aid organization serving the nation's indigent population.¹⁴³

Legal Services Corporation was created by Congress in 1974 with the specific purpose of providing legal aid services to needy individuals.¹⁴⁴ Since its creation, federal law has prohibited Legal Services Corporation's employees from lobbying.¹⁴⁵ Moreover, the federal government has barred federally funded legal service organizations from "lobbying on behalf of client interests . . . even if the organizations use funds from other sources to support these initiatives."¹⁴⁶ This prevents groups with fungible funds from arguing that lobbying efforts are not funded by federal monies but are instead funded through private donations or state funds.

Congress's rationale for its prohibition is that it prefers to "direct the finances and resources of the Corporation toward the provision of legal services to the poor and insulate the Corporation from the political influence, abuses, and criticisms that had characterized . . . previous . . . program[s]."¹⁴⁷ Other reasons include the fact that nonprofit, federally funded lawyers have little funding and great responsibility,¹⁴⁸ and they may use the funds to get around their legislatively mandated responsibilities.¹⁴⁹

¹⁴³ *What is LSC?*, LEGAL SERVICES CORP., <http://www.lsc.gov/about/lsc.php> (last visited Oct. 6, 2010).

¹⁴⁴ *Id.*

¹⁴⁵ *See, e.g.*, 45 C.F.R. § 1612.3(a)(1) (2008) (preventing members from influencing the passage or defeat of any legislation); 45 C.F.R. § 1612.4 (2008) (preventing members from engaging in grassroots lobbying).

¹⁴⁶ Martha F. Davis, *Preparing for the Worst: Re-Envisioning Disaster Legal Relief in the Era of Homeland Security*, 31 FORDHAM URB. L.J. 959, 975 (2004).

¹⁴⁷ *Grassley v. Legal Servs. Corp.*, 535 F. Supp. 818, 823 (S.D. Iowa 1982).

¹⁴⁸ *See Rand, supra* note 87, at 550–51 ("[A]ttorneys working in legal service offices are often hardpressed to help people with family law, housing issues, and government benefits matters among others. These concerns are so overwhelming that they cannot focus on issues of oppression in society.")

¹⁴⁹ John C. Scully, *Mandatory Pro Bono: An Attack on the Constitution*, 19 HOFSTRA L. REV. 1229, 1267 (1991).

Courts have upheld Congress's lobbying restrictions.¹⁵⁰ When Legal Services Corporation employees or offices have violated lobbying prohibitions, the Corporation has attempted to unfund them.¹⁵¹ It is important to note that Legal Services Corporation's lobbying restrictions do not prevent their consumers from lobbying for legislative change.¹⁵²

The same regulations and punishments that have worked to ban Legal Services Corporation employees and offices from lobbying could work to change the aggressive lobbying culture currently present in the P&A systems. Though they are prohibited from lobbying, no P&A has been punished or reprimanded by any federal agency for violating lobbying restrictions. Without fear of punishment for spending funds on lobbying efforts, advocates will continue to lobby as they have done in the past.

The only effective way of preventing lobbying is to do as Congress has done with the Legal Services Corporation: consider passing additional laws that prevent patient advocates from using *any* funds to lobby, set up an agency to closely monitor their spending and lobbying efforts, and come up with a plan to unfund or otherwise punish advocates who nevertheless engage in such activity. As one commentator noted, the need for legal services has never been greater; there are critical legal problems that have yet to be met, and nonprofit lawyers should therefore not take on causes "beyond the bread-and-butter basics."¹⁵³ Mental health consumers, their family members, and other nonprofit and grassroots organizations who are involved in the causes that affect individuals with mental illness are not prevented

¹⁵⁰ See, e.g., *Legal Servs. Corp. v. Velazquez*, 531 U.S. 533, 547–49 (2001) (stating that legislative reform can be challenged by people affected by proposed legislation); *Velazquez v. Legal Servs. Corp.*, 349 F. Supp. 2d 566, 613 (E.D.N.Y. 2004) (finding federal restrictions against lobbying lawful), *modified*, 356 F. Supp. 2d 267 (E.D.N.Y. 2005).

¹⁵¹ See, e.g., *W. Ctr. on Law & Poverty, Inc. v. Legal Servs. Corp.*, 592 F. Supp. 338, 340–42 (D.D.C. 1984); Liza Q. Wirtz, *The Ethical Bar and the LSC: Wrestling with Restrictions on Federally Funded Legal Services*, 59 VAND. L. REV. 971, 972–73 (2006).

¹⁵² See *Legal Servs. Corp.*, 531 U.S. at 547–49 (stating that individuals affected by proposed legislation have the opportunity to challenge the legislation even if their legal aid attorney cannot); Memorandum from Laurie Tarantowicz, Assistant Inspector Gen. and Gen. Counsel, Legal Servs. Corp., to Kirt West, Inspector Gen., Legal Servs. Corp. 5–6 (Apr. 24, 2007), available at <https://www.oig.lsc.gov/gov/OIG%202007%20regulatory%20recommendations.pdf>.

¹⁵³ Rhonda McMillion, *LSC Down but Not Out: With Reauthorizations Stalling, ABA Carries on Fight for Legal Services*, 82 A.B.A. J. 118, 118 (1996).

from lobbying. Therefore, lobbying should be left to these individuals and groups alone.

PAIMI's funding does not include resources for advocate lobbying. This means that every dollar spent on lobbying efforts is a dollar that advocates are not spending on investigations into claims of abuse, neglect, and civil rights violations. Congress must redirect the patient advocate's priorities to correspond with PAIMI's underlying mandate.

B. "Systematic Advocacy Approaches" vs. Individual Representation

PAIMI requires that patient advocates focus their attention on individual allegations of abuse, neglect, and rights violations. Patient advocates have been given broad authority and federal funding to access records, individuals, and staff to achieve this goal. However, when Congress recently authorized greater funds to accomplish a larger mission in noninstitutional settings,¹⁵⁴ advocates turned from individual representation to systematic representation. As a result, they have abandoned their role as protectors and advocates to countless individuals who need them.

1. PAIMI's Mandate and SAMHSA's Prohibition

PAIMI was enacted to protect *individuals* with mental illness. When PAIMI was written, senators heard from countless family members, medical professionals, and state officials about the atrocities committed behind institutions' closed doors.¹⁵⁵ Senators also heard that many institutions were doing everything possible to prevent investigations and to destroy or hide evidence from patients' families¹⁵⁶ and lawyers.¹⁵⁷ Consequently, PAIMI gave advocates full authority to open those doors and access all materials and persons necessary to their investigation.

SAMHSA is the government agency that oversees federally funded patient advocates. SAMHSA has declared that its program grants, which are used to fund state P&A systems, are not intended to accomplish *systematic* reform of the mental health system.¹⁵⁸

¹⁵⁴ See *infra* notes 159–66 and accompanying text.

¹⁵⁵ See *supra* notes 48–54 and accompanying text.

¹⁵⁶ See, e.g., *Joint Hearings*, *supra* note 1, at 66 (statement of Harold Cockerham, father of Chris Cockerham, a young man who was abused in the institution where he lived).

¹⁵⁷ See, e.g., *id.* at 80–82 (statement of Carol Sands, Assistant Deputy Public Advocate, State of New Jersey).

¹⁵⁸ PAIMI Program Web site, *supra* note 61.

Therefore, PAIMI and SAMHSA advocates are required to investigate individual cases of abuse and neglect, and they are not to spend funds advocating for systematic reform. Ironically, while P&A funding has increased over the years, advocates have shifted their focus away from individual representation and toward systematic advocacy. Unfortunately, this shift increases the likelihood of abuse, neglect, and civil rights violations.

2. *New Funding and a New Mission*

In 2000, President Bill Clinton, shortly before leaving office, authorized a substantial increase in PAIMI's appropriations; for the first time in history, advocates saw a national budget that surpassed the \$30 million mark.¹⁵⁹ But with that increase in funding, advocates also saw an increase in responsibility: for the first time ever, they were required to investigate cases of abuse and neglect in community treatment facilities.¹⁶⁰ With more individuals being treated outside institutions and more states enacting laws that permitted outpatient treatment, patient advocates should have anticipated that their role would shift to protect individuals who resided and received treatment in boarding homes, outpatient facilities, and elsewhere within the community.

The NDRN¹⁶¹ is the organization that acts as the collective voice for each state's P&A system.¹⁶² Though it receives funding from a variety of sources, it gets two percent of PAIMI's budget for training patient advocates.¹⁶³ Through its training, the NDRN sets the agenda for national advocacy and patient advocate groups. In 2001, the NDRN contemplated its new funding and its new role in a document addressed to advocates across the nation entitled, "*Implementing the New PAIMI Act Authority: Where Do We Go from Here?*"¹⁶⁴ In it,

¹⁵⁹ ATTAC & The Center for Public Representation Under Contract with NAPAS, *Implementing the New PAIMI Act Authority: Where Do We Go From Here?* (May 2001), <http://www.napas.org/aboutus/laws/PAIMIpaper501.htm> [hereinafter *Implementing the New PAIMI Act Authority*].

¹⁶⁰ *Id.*

¹⁶¹ The National Disability Rights Network was formerly named the National Association of Protection and Advocacy Systems. See NAPAS—National Association of Protection and Advocacy Systems, WISER EARTH, <http://www.wiserearth.org/organization/view/72f128d1a2517074d995437d2d1d1454> (last visited Oct. 6, 2010).

¹⁶² See *About Us*, NAT'L DISABILITY RTS. NETWORK, <http://www.napas.org/aboutus/default.htm> (last updated Mar. 22, 2010).

¹⁶³ *Training and Advocacy Support Center (TASC) at NDRN*, *supra* note 125.

¹⁶⁴ *Implementing the New PAIMI Act Authority*, *supra* note 159.

the NDRN recommends that patient advocacy groups use the increased funding and responsibility to “focus on using systemic advocacy approaches to address community-based issues for people with mental illness, but . . . continue to pursue individual cases *to the extent possible*.”¹⁶⁵ The NDRN advised advocates to turn their attention away from investigating individual allegations of abuse, neglect, and rights violations and toward systemic issues that affect those living in the community.¹⁶⁶ “Systemic issues” has never been defined by the NDRN. However, it is important to note that *none* of the advocacy goals mentioned on the NDRN’s Web site relate to investigating allegations of abuse, neglect, or rights violations.¹⁶⁷ Likewise, none of the advocate training seminars available through NDRN focused on developing the skills necessary to investigate allegations of abuse, neglect, or rights violations.

At a 2001 P&A executive directors’ meeting, those in attendance expressed concerns about how to spend the newly allocated community funds.¹⁶⁸ They contemplated enhancing investigation capacity; strengthening their advocacy role; and serving new, previously unserved mental health consumers, including those living in nursing homes.¹⁶⁹ However, after this meeting, the NDRN reported that P&A systems should focus primarily on systematic advocacy of issues within the community and on individual cases of abuse and neglect only if time and resources allowed.¹⁷⁰ The executive directors acknowledged that P&A systems may not be able to meet the high expectations of their consumers and warned that “[t]hese people may be disappointed or angry when they see what P&As actually do.”¹⁷¹

¹⁶⁵ *Id.* (emphasis added).

¹⁶⁶ *Id.*

¹⁶⁷ See *Guiding Principles*, NAT’L DISABILITY RTS. NETWORK, <http://www.napas.org/aboutus/gp.htm> (last visited Oct. 6, 2010).

¹⁶⁸ SUMMARY OF DISCUSSION ON PAIMI ACT IMPLEMENTATION AT THE 2001 CEO MEETING, <http://www.napas.org/aboutus/laws/PAIMIpaperAppend401.htm> (last visited Oct. 6, 2010).

¹⁶⁹ *Id.*

¹⁷⁰ See *Implementing the New PAIMI Act Authority*, *supra* note 159.

¹⁷¹ SUMMARY OF DISCUSSION ON PAIMI ACT IMPLEMENTATION AT THE 2001 CEO MEETING, *supra* note 168.

3. *The Danger of Shifting Away from Individual Representation*

Ron Honberg is an attorney and the Director of Policy and Legal Affairs for the National Alliance on Mental Illness (NAMI), which is a large, grassroots, nonprofit organization that represents approximately eleven thousand individuals with mental illness and their family members.¹⁷² Honberg says that he could “not in good faith argue that more people are getting better treatment” today than when PAIMI was enacted in 1986.¹⁷³ Indeed, reports of widespread abuse and neglect have been the focus of several federal government investigations in the past few years. These investigations reveal that patient advocates cannot afford to ignore PAIMI’s mandate to investigate individual cases of abuse.

The Civil Rights of Institutionalized Persons Act (CRIPA) allows the U.S. Attorney General and the DOJ to investigate violations of federal rights in state-run mental health institutions.¹⁷⁴ Over the past few years, the DOJ has investigated sixteen facilities in the following states: Connecticut, Georgia, New Jersey, New York, North Carolina, Oregon, Vermont, and Washington, D.C.¹⁷⁵ The Civil Rights Division of the DOJ reports that it has investigated thirty-five state or local mental health facilities under CRIPA on matters relating to the health, safety, and treatment of individuals confined in state-operated mental health facilities.¹⁷⁶ It has handled complaints about abusive staff, violent residents, unreasonable and abusive restraints, inadequate treatment, lack of protection from suicidal and harmful behavior, and unsanitary and unsafe facilities.¹⁷⁷ Considering the number of facilities that have recently been under investigation and the fact that many of these complaints are similar to the complaints Congress heard in 1986,¹⁷⁸ it is apparent that many individuals with mental illness still need protection from abuse and neglect.

¹⁷² Interview with Ron Honberg, Policy Affairs Dir., Nat’l Alliance on Mental Illness (NAMI), in Arlington, Va. (Jan. 7, 2010).

¹⁷³ *Id.*

¹⁷⁴ 42 U.S.C. § 1997(1) (2006).

¹⁷⁵ *Special Litigation Section*, *supra* note 9.

¹⁷⁶ *Mental Health Facilities*, CIV. RTS. DIVISION, U.S. DEP’T OF JUST., <http://www.justice.gov/crt/split/mh.php> (last visited Oct. 6, 2010).

¹⁷⁷ *Id.*

¹⁷⁸ *See, e.g., Joint Hearings*, *supra* note 1, at 5, 78–82, 176, 221–22, 236 (testimony of various individuals about the excessive use of physical restraints, overmedication, lack of treatment, neglect, abusive staff, prison-like conditions, and co-housing of violent and nonviolent residents).

Unfortunately, community-based treatment facilities are often far worse in their abuse and neglect of individuals than institutions.¹⁷⁹ Monitoring the many boarding homes and outpatient facilities that sometimes house and “treat” only a small number of individuals is much more difficult than monitoring a single institution that houses a large number of individuals.¹⁸⁰

One example of the deplorable conditions found in community facilities comes from California. The *Los Angeles Times* ran a series of news articles shortly before Congress expanded PAIMI to include community facilities; the articles revealed the woeful conditions in federally funded boarding homes and community facilities.¹⁸¹ At that time, there were three times as many individuals living in group homes and small community treatment facilities as there were residing in institutions.¹⁸²

In one article, a California government official said that, although some of the facility operators were caring, many community facility employees were guilty of “financial abuse[] . . . harried, inadequate psychiatric care, . . . sexual abuse and violence.”¹⁸³ This official discussed one facility in particular that had been cited 150 times by the state for “poor supervision, filth, inadequate nutrition and failure to dispense medication properly.”¹⁸⁴ Unfortunately, it was not until one resident beat another resident to death using a rock that the

¹⁷⁹ See E. Fuller Torrey, *It's a Mad, Mad World*, N.Y. POST, Sept. 13, 2009, http://www.nypost.com/p/news/opinion/opedcolumnists/it_mad_mad_world_YJgHsnCJIPggDjuoHEo9iL (stating that “many of the group homes in which patients have been placed are snake pits”).

¹⁸⁰ New York has had serious problems with larger, privately owned homes that house as many individuals as the State’s state-run institutions once did. See, e.g., Clifford J. Levy, *For Mentally Ill, Death and Misery*, N.Y. TIMES, Apr. 28, 2002, <http://www.nytimes.com/2002/04/28/nyregion/for-mentally-ill-death-and-misery.html>; Clifford J. Levy, *Here, Life is Squalor and Chaos*, N.Y. TIMES, Apr. 29, 2002, <http://www.nytimes.com/2002/04/29/nyregion/here-life-is-squalor-and-chaos.html>; Clifford J. Levy, *Voiceless, Defenseless and a Source of Cash*, N.Y. TIMES, Apr. 30, 2002, <http://www.nytimes.com/2002/04/30/nyregion/voiceless-defenseless-and-a-source-of-cash.html>. The problems at these large, private institutions mirror those that will be discussed in this section—theft of patient money, violent acts of residents that put others at risk, and lack of supervision—as well as others like Medicare and Medicaid fraud and neglect and abuse that led to a large number of patient deaths. *Id.* Unfortunately, the State, in the past, has turned a blind eye to these problems. *Id.*

¹⁸¹ See, e.g., Julie Marquis & Dan Morain, *A Tortuous Path for the Mentally Ill*, L.A. TIMES, Nov. 21, 1999, at A1.

¹⁸² *Id.*

¹⁸³ *Id.*

¹⁸⁴ *Id.*

facility was shut down permanently.¹⁸⁵ The journalists writing the article ultimately determined that “[h]ousing and treatment . . . in the community are lacking both in quantity and quality, particularly for those in need of close supervision.”¹⁸⁶ California is not the only state that has had difficulty monitoring community-based treatment facilities. More recently, Florida has seen its own share of problem facilities.

Florida has a large number of assisted-living facilities that house individuals with mental illness.¹⁸⁷ One Florida police officer who was frequently called to assist with unruly residents in these facilities stated that he “wouldn’t leave a dog in most of [them because] . . . [the] owners are simply trying to make as much money off these people as they can . . . [but] don’t do anything to really help them.”¹⁸⁸ Some of the facilities in the greater Miami area are dilapidated, unsafe, and unsanitary.¹⁸⁹ Worse, their employees do not monitor what goes on inside the facilities nor do they pay attention to the whereabouts of residents.¹⁹⁰ As a result, operators often file missing person reports, and fights between staff and patients occur frequently, as do incidents of drug abuse.¹⁹¹

Just as abuse in institutions is deplorable, conditions in these federally funded outpatient facilities are too. Patients need advocates in the community. When patient advocates resort to systematic measures, they sacrifice the individual attention that many patients need and that federal law requires.

Illinois recently passed legislation that permits the Illinois Office of the Inspector General for the Department of Human Services to investigate incidents of abuse, neglect, and financial exploitation of individuals living in community settings.¹⁹² It is not clear at this time whether Illinois did so because its P&A system has been unwilling or

¹⁸⁵ *Id.*

¹⁸⁶ *Id.*

¹⁸⁷ EARLEY, *supra* note 13, at 135–36. Most of these private boarding homes opened after deinstitutionalization began. *Id.* at 136.

¹⁸⁸ *Id.* at 137.

¹⁸⁹ *Id.* at 137–38.

¹⁹⁰ *Id.*

¹⁹¹ *Id.* at 136, 138; Marquis & Morain, *supra* note 181 (“In some board and care homes . . . patients are cheated out of pocket money, keep drugs in their rooms or simply walk off, never to return.”).

¹⁹² See Department of Human Services Act, 20 ILL. COMP. STAT. ANN. 1305/1-17 (West 2009).

unable to protect residents of such facilities or whether Illinois recognizes that patient advocates are underfunded to tackle such a large task. Regardless, it is disappointing that states have to pass legislation to protect their citizens from abuse and neglect when federally funded patient advocates have been charged with this mission.

4. *What Congress Can Do*

First, because policing the many group and privately run homes is an onerous task due to the number of those homes and the number of patients living within them, Congress should consider substantially increasing patient advocacy funds to investigate community-based treatment facilities. However, leaving the NDRN or state P&A systems to designate how they will spend federal funds is not wise. Before Congress grants any additional funds to a state P&A system, it should be sure that the advocates in that state are not shirking their responsibilities regarding individual investigations of abuse, neglect, and civil rights violations or spending funds on goals and measures that are not related to individual patient advocacy.

Second, when it revises PAIMI, Congress should be careful to clarify what it means by individual representation. Phrases like “systematic advocacy” for “systemic issues,” “systematic reform,” and even “systematic education” should be expressly prohibited if Congress determines that individual representation is still the primary focus of the advocate’s role.

Third, Congress should consider de-monopolizing the P&A system altogether. In the past, it was suggested that NAMI support state governors in designating attorneys as patient advocates.¹⁹³ If these attorneys were selected on a competitive basis, the protection and advocacy system might improve.¹⁹⁴ If nothing else, patients would have a choice of lawyers, which is something most clients seeking legal representation are afforded. Congress should look at outsourcing P&A funds to lawyers who are trained in mental health law, especially in those states where the P&A system has failed to safeguard patient rights and safety.

¹⁹³ Memorandum from Dick Greer to Laurie Flynn, former Exec. Dir., NAMI (Jan. 1991) (on file with author).

¹⁹⁴ *Id.*

C. Family Battles That Exist Outside of PAIMI's Intent

According to PAIMI, patients' family members are vital to their care and protection.¹⁹⁵ The family members who testified before Congress in an effort to get PAIMI enacted wanted to see their loved ones and their rights protected. Their accounts before Congress were heartbreaking.¹⁹⁶ The reports today are equally heartbreaking.¹⁹⁷ According to many families of those who are mentally ill, the abuse and neglect still exists; their loved ones are still ill and in desperate need of treatment, yet the family is shut out of the civil commitment and treatment process altogether. Families have no voice and often no knowledge about what is happening to their loved ones.¹⁹⁸ Many family members do not even know that patient advocates exist.¹⁹⁹ PAIMI is a family-friendly piece of legislation, yet families are no more a part of the process now than when PAIMI was enacted twenty-four years ago.

1. PAIMI and Congressional Views of Family Involvement

Family members of individuals with mental illness played a large part the enactment of PAIMI. There were several families who attended or supplied statements or testimony during PAIMI's congressional hearings.²⁰⁰ In fact, the first people to testify before the initial congressional committee that sought to enact PAIMI were the parents of a young man named Chris Cockerham, who lost his hearing because of the repeated abuse he sustained while he was institutionalized.²⁰¹ In 1991, when PAIMI was being reauthorized

¹⁹⁵ 42 U.S.C. § 10801(a)(2) (2006) ("Congress finds that . . . family members of individuals with mental illness play a crucial role in being advocates for the rights of individuals with mental illness . . .").

¹⁹⁶ See *supra* notes 48–54 and accompanying text.

¹⁹⁷ See, e.g., Judd, *supra* note 78; Judd & Miller, *supra* note 77 (counting an alarming number of suspicious deaths in Georgia's state hospitals for the mentally ill); Shapiro, *supra* note 77 (detailing abuse by forcing patients to fight one another at a state hospital for the "entertainment" of hospital employees).

¹⁹⁸ Interview with Ron Honberg, *supra* note 172.

¹⁹⁹ Telephone Interview with Joe Bruce (Feb. 8, 2010) (Mr. Bruce's son, William, suffers from schizophrenia.).

²⁰⁰ See, e.g., *Joint Hearings*, *supra* note 1, at 5, 17, 67, 179, 369, 551 (Parents who were present at the hearing, provided testimony, or submitted statements to Congress included Harold Cockerham, Wilbur M. Savidge, Maureen Kelly, Barbara A. Thompson, and Robert Bruggeman.).

²⁰¹ *Id.* at 5 (statement of Harold Cockerham, father of Chris Cockerham, Fort Worth, Tex.).

after its initial enactment, Senator Ted Kennedy submitted a report stating that the reviewing committee believed family members needed to be involved in order for PAIMI to be successful and that their “involvement should be welcomed and encouraged.”²⁰²

In the current version of PAIMI, the phrase “family member” is mentioned nine times.²⁰³ Before PAIMI even addressed the purpose of the Act, the role of the patient advocate, or the dangers that individuals with mental illness face, Congress established that family members play an important role in the lives of those who are suffering from mental illness.²⁰⁴ Not only did the Act consider family members to be the patients’ central advocates, but it made assurances that each P&A staff would include someone who is trained to provide assistance to family members.²⁰⁵

Families are given several rights in addition to the right to receive information and assistance from patient advocates. Family members are given the authority to help individuals file grievances against treatment facilities.²⁰⁶ PAIMI also instructs advocates to consult with family members on agency priorities in part by reserving space on each P&A system’s governing board and advisory council.²⁰⁷

PAIMI acknowledges that families broadly represent the interests of the mentally ill and that they are knowledgeable about the needs of the consumers served by the system.²⁰⁸ In NAMI’s 2009 report on mental health consumers’ and their families’ satisfaction with mental health services, several consumers recognized the strength of family advocacy.²⁰⁹ For instance, a consumer stated that had his “mother . . . not fought . . . on [his] behalf, [he] most likely would have committed suicide.”²¹⁰ In a *Los Angeles Times* article, a mother of a schizophrenic daughter explained the financial toll the illness had on the family: “We lost our retirement, our savings—everything. . . .

²⁰² S. REP. NO. 102-114, at 3 (1991).

²⁰³ See 42 U.S.C. §§ 10801(a)(2), 10804(a)(2), 10805(a)(6)(B)–(C), (a)(9), (c)(1), 10821(a)(2), (b) (2006).

²⁰⁴ *Id.* § 10801(a)(2).

²⁰⁵ *Id.* § 10821(a)(2), (b).

²⁰⁶ *Id.* § 10805(a)(9).

²⁰⁷ Heilman, *supra* note 81, at 261.

²⁰⁸ 42 U.S.C. § 10805(c)(1)(B)(ii).

²⁰⁹ NAT’L ALLIANCE ON MENTAL ILLNESS, GRADING THE STATES 2009: A REPORT ON AMERICA’S HEALTH CARE SYSTEM FOR ADULTS WITH SERIOUS MENTAL ILLNESS (2009) [hereinafter GRADING THE STATES 2009].

²¹⁰ *Id.* at 75.

You'll do anything. You'll sell your soul for one night of your child's safety."²¹¹ Family members are the largest and most dedicated group of caregivers to those living with mental illness.

2. *The Family as Caregiver*

In his 1991 report to Congress, Senator Ted Kennedy recognized that "family members frequently assume significant responsibility for overseeing the care and treatment of family members with mental illness."²¹² The U.S. Supreme Court has recognized that families are vital to helping individuals with mental illness survive safely and independently outside of mental health institutions.²¹³

Approximately fifty percent of chronically mentally ill adults live with family members.²¹⁴ Eighty percent of these caregivers are parents who are at least fifty years old.²¹⁵ Many caregivers live alone with their mentally ill family members.²¹⁶ Studies reveal that while some family members have difficulty understanding their loved one's illness,²¹⁷ many "are as able as [mental health] professionals to correctly identify the psychopathology that should necessitate involuntary treatment."²¹⁸ In other words, families are as educated as mental health professionals because they frequently assume the caregiving role.

3. *Exclusion of Family Members from Commitment and Treatment Decisions*

One of the primary complaints that parents expressed during PAIMI's congressional hearings was the feeling that they were kept in

²¹¹ Marquis & Morain, *supra* note 181.

²¹² S. REP. NO. 102-114, at 3 (1991).

²¹³ O'Connor v. Donaldson, 422 U.S. 563, 567 (1975).

²¹⁴ Tina Marshall & Phyllis Solomon, *Professionals' Responsibilities in Releasing Information to Families of Adults with Mental Illness*, 54 PSYCHIATRIC SERVICES 1622, 1622 (2003).

²¹⁵ Krishna Vaddadi, *Stress of Caregiving for the Chronically Mentally Ill*, 26 PSYCHIATRIC ANNALS 766, 767 (1996).

²¹⁶ *Id.* at 766.

²¹⁷ *Id.* at 770.

²¹⁸ June R. Husted & Alexis Nehemkis, *Civil Commitment Viewed from Three Perspectives: Professional, Family, and Police*, 23 BULL. OF THE AM. ACAD. OF PSYCHIATRY & THE LAW 533, 542 (1995).

the dark about what was happening inside the institution's walls.²¹⁹ While PAIMI may have allowed the advocate access to the patient and his records, family members are excluded from the civil commitment and treatment process, sometimes by the treating facility but more often by the advocate and the court. If anything, families are now more isolated than they were in 1986 when PAIMI was enacted.

Because the U.S. Supreme Court has refused to grant family members the right to act as parties in civil commitment cases,²²⁰ many families are kept from knowing that their loved one is even facing civil commitment. One former patient advocate from California stated that many family members are not notified about the commitment process by the court or advocate and are often kept from visiting relatives who are committed.²²¹ Only when the family is "sophisticated, assertive . . . and really engaged"²²² with the patient, is it possible for the family to gather information from the lawyer or hospital.

Ron Honberg says that family members are sometimes treated with arrogance and hostility by patient advocates.²²³ Over the years, he has heard parents complain that when their mentally ill children are in crisis and they are physically or mentally unable to contact an advocate, the response the parents get when they contact an advocate is "We don't represent families. Ask your child to call and talk to us."²²⁴ It is not always possible for the patient to contact the advocate, especially when the patient is severely and chronically mentally ill. Ignoring the family's pleas for protection and advocacy has extremely adverse effects on the patient whom the advocate is charged with protecting.

A former patient advocate from California said that most advocates believe that, because family members are not the client, there is no

²¹⁹ See, e.g., *Joint Hearings*, *supra* note 1, at 5–7 (statement of Harold Cockerham, father of Chris Cockerham, a young man who was beaten so severely that he lost his hearing during his institutionalization).

²²⁰ *Heller v. Doe*, 509 U.S. 312, 317 (1993) (granting party status only to family members of individuals who are mentally retarded).

²²¹ Interview with Aileen Kroll, Legislative & Policy Counsel, Treatment Advocacy Ctr., in Arlington, Va. (Jan. 6, 2010).

²²² Interview with Ron Honberg, *supra* note 172.

²²³ *Id.*

²²⁴ *Id.*

reason to involve them in the process.²²⁵ As an example of this viewpoint, Helen Bailey, a current patient advocate in Maine, has stated that some families are “nasty” and should have limited voices in the patient’s treatment plan.²²⁶ Unfortunately, this antifamily sentiment began shortly after PAIMI was enacted, and it has persisted.²²⁷

Where families usually want to see their relative’s mental health restored, advocates usually want to see that the individual’s legal rights—most often, the right to refuse treatment—are preserved. As one psychologist-turned-law-student said after working as a patient advocate,

Often, the feelings of helplessness of the family in watching their significant other living a life which is demeaning are ignored by the advocates. The family is perceived as an adversary to the goal of the advocate, which is to prevent hospitalization at all costs, even when hospitalization is a temporary treatment, as in the case of alcoholism, or when the hospitalization may be beneficial to assist the client in moving out of a demeaning situation, as in a life of homelessness, into a life with dignity.²²⁸

Court proceedings are mostly unkind to family members. In some states, families have no right to testify during the civil commitment hearing.²²⁹ If the patient has expressed to her advocate that she does not want to be committed or that she wants to refuse treatment, the patient advocate will refuse to call a disagreeing family member to testify.²³⁰ One study found that “families are cynical and pessimistic about the feasibility of commitment under current laws—a probable

²²⁵ Interview with Aileen Kroll, *supra* note 221.

²²⁶ Elizabeth Bernstein & Nathan Koppel, *A Death in the Family*, WALL ST. J., Aug. 16–17, 2008, at A1 (statement by patient advocate Helen Bailey that “[t]here are some God damn nasty families out there” who should not be involved in decisions that affect the patient).

²²⁷ See, e.g., *Protection and Advocacy for Mentally Ill Individuals Act: Hearing Before the Subcomm. on the Handicapped of the S. Comm. on Labor & Human Res.*, 100th Cong. 24 (1988) (statement of Joseph A. Rogers, President, National Mental Health Consumers’ Association) (“[W]e need changes in the law to encourage real consumer and family involvement in some P&As that are actively or passively resisting their legal obligations.”); Memorandum from Dick Greer to Laurie Flynn, *supra* note 193, at 2 (discussing his “displeasure if not anger with the anti-psychiatry, anti-science, anti-family viewpoint so rampant in the P&As and their professional associations”).

²²⁸ Gutierrez, *supra* note 26, at 79.

²²⁹ Interview with Aileen Kroll, *supra* note 221.

²³⁰ *Id.*

outcome of past experience with ‘the system,’ and repeated failures to obtain needed intervention.”²³¹

Not only do families face barriers to both participation and information in the legal setting, they also experience them from mental health facilities. Often family members, if they are able to determine where their loved one is being treated after the civil commitment hearing, leave the hospital feeling demoralized because their efforts at educating those who are making treatment decisions fail²³² and the patient’s care is therefore inconsistent.²³³ One mental health consumer stated that the “[I]ack of continuity from one provider to the next [is the worst part of the system].”²³⁴ Families can help here; they are often more aware than the patient of the patient’s treatment history and which treatments have been successful. Families should, at a minimum, be given the right to discuss prior treatment, and whether it was effective or not, with medical professionals.

Family members also are prevented from discovering the status of their loved one’s treatment due to confidentiality laws.²³⁵ Researchers found that ninety-five percent of mental health providers were overly cautious about confidentiality laws, believing the laws were “more restrictive than even the most conservative legal interpretation.”²³⁶ As a result, families were prevented from knowing even the most basic information, such as the symptoms of the mental illness with which their loved one had been diagnosed.²³⁷

Patient advocacy has always focused on the rights of the patient; but over the years, as families have become more and more alienated during the treatment process, families have begun to demand their own rights.²³⁸ Many families are demanding that a family advocate be available at hospitals to educate family members about their rights and the rights of the patient.²³⁹ As one commentator stated: “The families of chronic patients are protesting. In the 1950s and 1960s,

²³¹ Husted & Nehemkis, *supra* note 218, at 542.

²³² Interview with Aileen Kroll, *supra* note 221.

²³³ Vaddadi, *supra* note 215, at 770.

²³⁴ GRADING THE STATES 2009, *supra* note 209, at 143 (second alteration in original).

²³⁵ Marshall & Solomon, *supra* note 214, at 1625.

²³⁶ *Id.* at 1626.

²³⁷ *Id.* at 1625.

²³⁸ Woodside & Legg, *supra* note 39, at 47.

²³⁹ See, e.g., E-mail from Joe Bruce to Priscilla Hanley, Office of Senator Collins, Me. (Oct. 1, 2008) (on file with author).

they were loosely organized, but today they have formed political action associations with chapters in virtually every state.”²⁴⁰ Perhaps this is, in part, because they have been excluded by an advocacy system that was designed to include them and because states across the nation have failed to provide quality care for those who suffer from mental illness.

4. *What Congress Can Do*

Congress has the authority to empower family members and parents—particularly those who act as caregivers to individuals with chronic and severe mental illness. It can accomplish this in several ways: it can relax confidentiality laws for family members, grant family members better access to advocates, and create a better monitoring system with a right for family members to file grievances against patient advocates who fail to carry out PAIMI provisions.

a. *Relax Confidentiality Laws for Families*

Families have fewer rights now than they once did due to confidentiality laws, like the Health Insurance Portability and Accountability Act (HIPAA).²⁴¹ Not only does HIPAA shield families from knowing about the patient’s diagnosis and treatment plan, but it also shields the family from knowing about the existence of the patient advocate and what he or she has accomplished in the mental health facility. Many “families are not only unaware of the activities of the P&A, the[y] are unaware even of their existence.”²⁴² As one parent of a young man with schizophrenia suggested:

To apply the same standards of confidentiality to someone lacking the capacity to make the positive decisions needed to have a successful life is not in the best interest of the individual, the families, or the community. Families have always been the true caregivers of the mentally ill, and always will be. There is not a single mental institution in the country that will list indefinite hospitalization as its goal. The families are the ones with the best interest of the mentally ill at heart. They carry the greatest burden. They have the most at stake in the process, and yet they are totally left out of the process.²⁴³

²⁴⁰ Slovenko, *supra* note 11, at 660.

²⁴¹ See, e.g., 45 C.F.R. § 164.501 (2009).

²⁴² E-mail from Joe Bruce to Priscilla Hanley, *supra* note 239, at 2.

²⁴³ *Id.* at 3.

With PAIMI, Congress attempted to create accountability between attorneys and families so that individuals would be protected. However, while it has given attorneys the ability to see what happens inside the hospitals' walls, families cannot be assured that their loved ones are being treated or that the advocate has performed her job adequately. Family members need to have better access to the institutions and the advocates.

Loosening confidentiality laws for families who will in all likelihood be taking care of their loved ones upon release from treatment can further safeguard the patient from abuse, neglect, and rights violations. It can also help families know what to expect when their loved one is released. Unfortunately, families who have no access to information while their loved one is being treated do not know what condition their family member will be in when he returns home. This alone presents huge problems for families.²⁴⁴

Maine is one state that has proposed legislation to loosen confidentiality laws for family members.²⁴⁵ Congress could loosen confidentiality laws without violating the patient's right to receive or refuse treatment. Relaxing confidentiality laws, particularly for caretakers of individuals with chronic and severe mental illness, would assist family members in discovering both the patient's treatment plan and the role the patient advocate is playing in the life of the patient. Loosening confidentiality laws would also act as a "measure of oversight."²⁴⁶

b. Create Family Grievance and Monitoring Systems

According to PAIMI, family members should be decision-makers on state boards, and P&A employees should be trained in counseling and communicating with family members.²⁴⁷ However, even if the family is aware of the advocate's existence, it is often ignored by the advocate.

PAIMI allows patients and prospective patients to file grievances with a P&A system to assure that it is operating within the confines of

²⁴⁴ See, e.g., Bernstein & Koppel, *supra* note 226 (discussing William Bruce, a young man with schizophrenia, who returned home from his civil commitment more psychotic than when he entered the facility. He was released in large part because of the persistence of patient advocates, who told him he was not ill. Two months after his release, he murdered his mother, Amy Bruce. A jury found him not guilty by reason of insanity.).

²⁴⁵ See E-mail from Joe Bruce to author, *supra* note 137.

²⁴⁶ E-mail from Joe Bruce to Priscilla Hanley, *supra* note 239, at 3.

²⁴⁷ 42 U.S.C. §§ 10805(c)(1)(B), 10821(a)(2), (b) (2006).

PAIMI.²⁴⁸ However, while a system exists for patients to grieve advocates, there is not a system in place for families to grieve advocates.²⁴⁹ Sometimes, due to the nature or severity of the client's mental illness, family members are the only ones who are able to comprehend the existence and extent of poor advocacy. For this reason alone, advocates should be held accountable to both the patient and the patient's family.

Congress must also consider giving SAMHSA more authority in regulating patient advocates. After all, "mental health advocacy programs are not infallible and need to be monitored in order to ensure that they are complying with the mandate to represent the interests of the client"²⁵⁰ SAMHSA has never publicly disciplined P&A systems that fail to carry out PAIMI provisions. Some suggest that PAIMI should be amended "to include performance standards, with federal sanctions for violations."²⁵¹ Though attorneys can be sanctioned by courts for failing to comply with court-imposed rules, most patient advocates operate outside of the judicial system. And, as illustrated throughout this Article, patient advocates have violated numerous provisions of PAIMI and other federal mandates with impunity. Congress and SAMHSA must do more to hold patient advocates accountable for poor advocacy and unlawful activity.

CONCLUSION

Protecting the mentally ill is a noble cause. During PAIMI's congressional hearings, Senator Paul Simon stated that one gauge of a civilized society is how it treats those in need.²⁵² Congress sought to make a difference in the way individuals with mental illness were treated in the facilities entrusted to take care of them. During the original hearings, Senator Weicker stated that he hoped that by enacting PAIMI Congress could prevent future senators from listening to the same tragedies that he and his colleagues heard.²⁵³ Sadly, it appears that, in many ways, the mental health system is no

²⁴⁸ *Id.* § 10805(a)(9).

²⁴⁹ Gutierrez, *supra* note 26, at 58.

²⁵⁰ *Id.* at 96.

²⁵¹ Memorandum from Dick Greer to Laurie Flynn, *supra* note 193, at 2.

²⁵² *Joint Hearings*, *supra* note 1, at 4 (statement of Sen. Paul Simon, Member, Subcomm. on the Handicapped of the S. Comm. on Labor and Human Res.).

²⁵³ *Id.* at 3.

different today than it was nearly twenty-five years ago when PAIMI was first enacted.

Patient advocates have lost their way. And, their clients and clients' families—the same groups that appeared before Congress in 1986—are paying the price. Patient advocates have a simple mission: to protect mental health patients from abuse, neglect, and civil rights violations. When Congress reviews and revises PAIMI next year, it needs to investigate why this mission has been abandoned and why advocates deem their extra-legislative activities more important than the security of the clients they are charged with protecting. Advocates need to be held accountable for PAIMI violations. They must be redirected and reminded that their mission is a simple, yet vital, one.

