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

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I. Introduction

In April of 1985, a United States 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.\(^3\)

The Act created a federally-funded, national system of patient advocacy that gave lawyers, also known as "patient advocates," the authority to investigate patient allegations of neglect, abuse, and civil rights violations.\(^4\) PAIMI was also created to protect individuals with mental illness who live and receive treatment outside inpatient

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\(^1\) Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 1 (1985) (statement of Sen. Weicker, Member, S. Comm. on Labor and Human Resources).


\(^4\) 42 U.S.C.A. § 10801 (b)(1).
treatment facilities.\textsuperscript{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.\textsuperscript{6} In 2009, Congress allotted $35.8 million to patient advocacy groups to carry out these investigations.\textsuperscript{7} 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.\textsuperscript{8} It is projected that Congress will review PAIMI next year.\textsuperscript{9}

Despite this additional funding and PAIMI’s simple mandate, several problems exist with the patient advocacy system. In the past decade alone, the Department of Justice has investigated and uncovered numerous incidents of widespread neglect and abuse in hospitals and institutions around the United States.\textsuperscript{10} What was said during

\begin{itemize}
\item \textsuperscript{5} 42 U.S.C.A. §§ 10802 (3) and (4) (B) (ii), 10806, and 10841 (3)(C)(i); \textit{Connecticut Office of Protection and Advocacy for Persons with Disabilities v. Hartford}, 464 F.3d 229, 240 (2d Cir. 2006) (protecting school students from abuse or neglect within educational settings).
\item \textsuperscript{7} \textit{Id}.
\item \textsuperscript{8} The White House, President Barack Obama, Office of the Press Secretary, President Obama Commemorates Anniversary of Olmstead and Announces New Initiatives to Assist Americans with Disabilities, June 22, 2009, \url{http://www.whitehouse.gov/the_press_office/President-Obama-Commemorates-Anniversary-of-Olmstead-and-Announces-New-Initiatives-to-Assist-Americans-with-Disabilities/} (last visited on March 8, 2010). He made this declaration on the tenth anniversary of \textit{Olmstead v. L.C.}, 527 U.S. 581 (1999), a United States Supreme Court case that granted the right to community treatment for certain individuals with mental disabilities. \textit{Id}.
\item \textsuperscript{9} Interview with Andrew Sperling, Legislative Director for the National Alliance on Mental Illness (NAMI), in Arlington, VA (Jan. 7, 2010).
\item \textsuperscript{10} United States Dept. of Justice, Civil Rights Division, Special Litigation Section Documents and Publications, Investigative Findings, Mental Health Facilities Investigations, \url{http://www.justice.gov/crt/split/findsettle.php#MH%20Findings%20Letters} (last visited on March 8, 2010).
\end{itemize}
Congressional hearings 25 years ago – that "[p]rotection for these frailest of our society exists largely on paper"\(^{11}\) – 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. They have engaged in systematic advocacy efforts when they are funded and mandated to investigate individual cases of abuse, neglect, and rights violations. They have battled and even ignored the families that helped create and pass PAIMI, people who 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 might consider when it revises and re-enacts PAIMI next year. This article will begin by examining the genesis of modern-day patient advocacy and the conflicting legal theories that underlie the field of mental health law. It will then explore relevant provisions of PAIMI and its legislative intent. Finally, the article will examine the legally impermissible activities that patient advocates have

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\(^{11}\) Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 1 (1985) (statement of Sen. Weicker, Member, S. Comm. on Labor and Human Resources).
engaged in, the problems these activities present, and solutions to these problems. In the end, it is hoped that this article will hold patient advocates accountable to PAIMI, which governs their role as advocate and protector of individuals with mental illness.

II. The Genesis of Modern-Day Patient Advocacy

In order to understand why federal legislation was created 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, 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 lawyer named Morton Birnbaum.

In 1959, Dr. Birnbaum was enrolled in a post-doctorate public policy and mental health program at Harvard when he came up with a revolutionary idea to help those with mental illness. He argued that patients had a constitutional right to treatment; without treatment, hospitals took custody of patients and imprisoned them indefinitely. He asserted that when patients were confined without treatment, they essentially were given

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15 Id. at 151.
a life sentence, which violated their Fifth Amendment rights to due process and liberty.\textsuperscript{17} Dr. Birnbaum’s article was published in the \textit{American Bar Association Journal} in 1960.\textsuperscript{18}

Several weeks after his article was published, Dr. Birnbaum agreed to help a Florida man who had been civilly committed against his will.\textsuperscript{19} About the same time, the renowned D.C. Circuit Justice David Bazelon mentioned Dr. Birnbaum’s article in an opinion, which boosted the credibility of Birnbaum’s legal theory.\textsuperscript{20}

Attorneys who embraced Dr. Birnbaum’s theory and who had worked with him on cases later argued that just forcing states to treat mentally ill patients was not enough.\textsuperscript{21} Like 1960s anti-psychiatry groups that advocated abolishing the mental health care system entirely,\textsuperscript{22} early patient advocates reasoned that since medical and psychological treatment would wane once the lawsuits settled, states should simply close hospital doors rather than provide substandard treatment.\textsuperscript{23} Dr. Birnbaum disagreed with their position so strongly that he cut professional ties with them.\textsuperscript{24} 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.\textsuperscript{25}

\textbf{B. Conflicting Mental Health Legal Theories}

\begin{footnotesize}
\begin{enumerate}
\item Id.
\item Id.
\item \textsc{Pete Earley}, \textsc{Crazy} 152 (2006).
\item \textit{Id.} at 153.
\item \textit{Id.} at 155.
\item Slovenko, \textit{supra} note 12 at 643-46.
\item \textsc{Pete Earley}, \textsc{Crazy} 155 (2006).
\item \textit{Id.}
\item \textit{Id.} at 160. The Center says in its mission statement that it “envisions an America where people who have mental illnesses or developmental disabilities exercise their own life choices and have access to the resources that enable them to participate fully in their communities.” Judge David L. Bazelon Center for Mental Health Law, About the Bazelon Center for Mental Health Law, Our Mission, \textit{available at} http://www.bazelon.org/about/index.htm (last visited March 5, 2010).
\end{enumerate}
\end{footnotesize}
To this day patient advocacy is divided because of conflicting ideological views and legal theories. Some lawyers focus on the liberty of the patient, adopting a civil libertarian view, while others focus on the treatment and welfare rights of patients, adopting a treatment-oriented view.  

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.” Civil commitment laws also contain divisive theories: protection of the individual versus protection of the community. Each case requires courts and lawyers to delicately balance these interests. 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 express their objections to it. These courts reason that patients have “a due process-protected liberty interest in not being medicated against their

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29 Id.
will.”  

Patient advocates use a number of legal theories to advance the claims they raise on behalf of their clients. Though due process concepts are favored by patient advocates, they have also used 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 of 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.

It is only when the state’s compelling interest overrides the patient’s liberty interest that due process gives way to involuntary treatment.  

In sum, the area of mental health law includes many competing ideological and legal claims.

III.  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. These cases, 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.

31 Id.
32 Id. at 525-26.
33 Id. at 526-27.
34 Doe v. Gallinot, 657 F.2d 1017 (9th Cir. 1981).
35 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) (employees at the Willowbrook State School in New York garnered national attention for neglecting and abusing their residents, who were mentally retarded).
36 Id. at 959-63.
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. This Act required States to create a protection and advocacy (P & A) system to protect individuals with developmental disabilities and to investigate allegations of abuse and neglect. Ten years later, after numerous accounts of abuse and neglect surfaced in the mental health and state hospital settings, Congress passed the Protection and Advocacy for Individuals with Mental Illness Act of 1986 (PAIMI) to ensure that the rights of individuals with mental illness were protected. PAIMI was supported by legal advocates for the mentally ill, individuals with mental illness, and their family members. By establishing and funding state-governed P & A systems to monitor mental health treatment facilities and the patients within, Congress hoped that the incidents of abuse and neglect would decrease.

B. Congressional Findings and PAIMI’s Intent

Congress found that persons with mental illness who were institutionalized were particularly susceptible to inadequate nutrition and clothing, substandard mental health treatment, deficient general health care, nonexistent patient discharge plans, and poorly trained staff. Congress sought not only to prevent these forms of neglect, but also to

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37 Id. at 959.
38 Id. at 959-60.
41 Bowman, supra note 35, at 959-63.
42 42 U.S.C.A. § 10801 (a) (3) and 10802 (5).
prevent abuse. It defined patient abuse as physical or sexual abuse and included abuse through the use of chemical and bodily restraints.43

During Congressional hearings, Senators heard from individuals who testified about patients who had been raped,44 employees who had been violent,45 and widespread neglect that resulted in death.46 Most of these accounts were ignored and never investigated by hospital administrators.47 There was also substantial testimony about civil rights violations,48 under-trained and inadequate staff,49 and a lack of treatment behind institutional walls.50 Congress identified two significant problems with patient protection: states often did not monitor institutions and they failed to protect the rights of patients.51 Congress created P & A systems to protect patients’ civil rights and to police state mental health facilities.

43 42 U.S.C.A. § 10802 (1) (a)-(d).
44 See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 78-79 (1985) (statement of Carol Sands, Assistant Deputy Public Advocate for the State of New Jersey).
45 See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 5, 67 (1985) (statement of Harold Cockerman, son of Chris Cockerman, a young man who was beaten so severely that he lost his hearing during his institutionalization).
46 See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 67, 72 (1985) (account of patient Mark Jones, who drowned in a bathtub due to inadequate training and supervision of staff).
47 See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 78-82 (1985) (statement of Carol Sands, Assistant Deputy Public Advocate for the State of New Jersey).
48 See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 78-82, 176-77 (1985) (statement of Carol Sands, Assistant Deputy Public Advocate for the State of New Jersey).
50 See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 78-82 (1985) (statement of Carol Sands, Assistant Deputy Public Advocate for the State of New Jersey).
51 42 U.S.C.A. § 10801 (a) (4).
PAIMI encourages advocates to meet with and discuss treatment options and patients’ rights. PAIMI permits patient advocates to monitor and have access to patients and patient records at schools, mental health institutions, hospitals, penal institutions, and nursing homes. It also protects patients in community-run programs like outpatient facilities, boarding homes, homeless shelters, and homes. PAIMI applies equally to state and private treatment facilities, even facilities that do not receive federal funds.

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. Courts are divided as to whether the P & A system or its supervising court is the final arbiter of probable cause. Nevertheless, probable cause is the legal standard that is required to begin an investigation into patient abuse or neglect.

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52 42 U.S.C.A. § 10802 (3) and (4) (B) (ii).
54 42 U.S.C.A. § 10806. HIPAA does not prevent patient advocates from accessing patient records.
57 42 U.S.C.A. § 10802 (3) and (4) (B) (ii).
58 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. United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Protection and Advocacy, Center for Mental Health Services, Division of State and Community Development Systems, State Planning and Systems Development Branch, Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program, available at http://mentalhealth.samhsa.gov/cmhs/p&a/about.asp (last visited March 8, 2010).
59 Wisconsin Coalition 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).
C. Federal Funding and PAIMI in Action

PAIMI provides federal funds to state P & A systems so they can provide services to persons with mental illness.\(^{61}\) PAIMI grants are used by state P & A systems “to pursue administrative, legal (individual and class action litigation), systematic and legislative activities, or other appropriate remedies to redress complaints of abuse, neglect, and civil rights violations.”\(^{62}\) However, the federal government has also declared that these program grants are not intended to accomplish systematic reform of the mental health system.\(^{63}\) In return for federal funding, the government requires each state to establish a P & A system to provide advocacy services and to protect individuals with mental illness.\(^{64}\)

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. Citing the inadequacy of State-created advocacy systems,\(^{65}\) Congress provides the Substance Abuse and Mental Health Services Administration (SAMHSA), which is a division of the United States Department of Health and Human Services (HHS), with funding to assist each state in creating its own P

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\(^{61}\) Bowman, supra note 35, at 956.

\(^{62}\) United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Protection and Advocacy, Center for Mental Health Services, Division of State and Community Development Systems, State Planning and Systems Development Branch, Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program, http://mentalhealth.samhsa.gov/cmhs/p&a/about.asp (last visited March 8, 2010).

\(^{63}\) Id.

\(^{64}\) Bowman, supra note 35, at 956.

& A system. Currently, forty-five states have non-profit organizations running their P & A systems whereas the remaining five have created state-run agencies or departments to provide advocacy services.

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. Patient advocates are legally authorized to intervene on behalf of individuals who meet the above qualifications during their treatment, up to 90 days after they have been released from inpatient care, if they die in a facility, if they are reported missing from a facility, or if they are involuntarily confined to a detention facility for a noncriminal matter. In other words, the primary responsibility of patient advocates is to

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66 United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Protection and Advocacy, Center for Mental Health Services, Division of State and Community Development Systems, State Planning and Systems Development Branch, Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program, http://mentalhealth.samhsa.gov/cmhs/p&a/about.asp (last visited March 8, 2010).
67 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.A. §10804 (a).
68 United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Protection and Advocacy, Center for Mental Health Services, Division of State and Community Development Systems, State Planning and Systems Development Branch, Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program, http://mentalhealth.samhsa.gov/cmhs/p&a/about.asp (last visited March 8, 2010).
69 42 U.S.C.A. § 10805 (a)(1)(C)(ii). But see Doe v. Stincer, 175 F.3d 879, 887-88 (11th Cir. 1999) (failure to make a specific allegation regarding a particular person whose rights were violated within the 90-day period of time resulted in lawsuit’s dismissal).
70 United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Protection and Advocacy, Center for Mental Health Services, Division of State and Community Development Systems, State Planning and Systems Development Branch, Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program, http://mentalhealth.samhsa.gov/cmhs/p&a/about.asp (last visited March 8, 2010). 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 35, at 958-65. As a result, many 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.
protect individuals at or about the time they are institutionalized or are receiving treatment.\textsuperscript{71}

Since PAIMI was passed in 1986, lawyers have sought to protect countless people who are mentally ill from abuse and neglect with the help of federal dollars and statutory authority. As much as the public would like to believe that this kind of protection is not warranted anymore, tragic news reports suggest that the patient advocate is just as necessary now as in 1986, when PAIMI was first enacted.\textsuperscript{72} Indeed, between 2002 and 2006, investigative journalists discovered 115 suspicious deaths in Georgia mental health facilities.\textsuperscript{73} Unaware that investigating deaths in treatment facilities is a role PAIMI entrusts to patient advocates,\textsuperscript{74} 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 have neglected their primary job and instead have

\textsuperscript{71} Woodside & Legg, supra note 40, 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. Georgia Advocacy Office, Inc. v. Camp, 172 F.3d 1294, 1297 (11th Cir. 1999) (individual who refuses visits with advocate protected from P & A involvement); Advocacy, Inc., v. Brown Schools, Inc., 2001 WL 1910563, *2-4 (W.D. Tex. 2001) (parents of minor child who died in mental health facility won right to prevent P & A access to child’s medical and patient records).


\textsuperscript{73} Alan Judd, System was Deaf to Pleas; Mother Died, ATLANTA J.-CONST., June 28, 2009, available at http://www.ajc.com/services/content/printedition/2009/06/28/mental06281.html.

\textsuperscript{74} United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Protection and Advocacy, Center for Mental Health Services, Division of State and Community Development Systems, State Planning and Systems Development Branch, Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program, http://mentalhealth.samhsa.gov/cmhs/p&a/about.asp (last visited March 8, 2010).
focused on other activities, which take them away from their core mission. These secondary activities are the subject of this article.

IV. Advocates Are Operating Outside the Scope of PAIMI

While some critics disagree with patient advocacy ideology, which sometimes takes a strong civil-libertarian, anti-treatment approach, everyone agrees their core mission, which is to protect patients from abuse and neglect, is a legally permissible and honorable one. However, some activities that advocates have participated in are legally impermissible. This section will examine those activities, which appear to violate PAIMI, the Act’s legislative intent, or other federal regulations.

A. Prohibited Lobbying Efforts

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. In the past decade, their lobbying efforts have focused on preventing assisted outpatient treatment laws from being enacted in numerous states across the country. Unfortunately, these activities have actually hurt patients by eliminating a less restrictive alternative to institutionalization, which is a right granted to

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individuals with mental illness. This section will analyze the laws that prohibit patient advocate lobbying and examine a few recent lobbying efforts.

1. Anti-Lobbying Legislation

Though PAIMI is silent about patient advocate lobbying, Congress explicitly prohibits any funding that it provides to any HHS agency, which includes SAMHSA, to be used in attempts to influence legislation. This means that patient advocates must not use federal monies for lobbying efforts before State or Federal legislatures. While SAMHSA permits using “legislative remedies” to correct confirmed incidents of abuse, neglect, and rights violations in treatment facilities, it has never authorized efforts to change or defeat proposed legislation.

Though P & A systems are federally funded, they may also be funded by both state funds and private donations. However, even at the state level, legal aid offices are often prohibited from using state funding for lobbying. 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. The same is true for P & A systems.

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76 See e.g., In re D.Z., 649 N.W.2d 231, 234 (N.D. 2002); In re Brown, 640 N.W.2d 919, 924 (Minn. 2002).
77 See e.g., H.R. 3293 Title 5, § 503 (2010).
78 Id.
79 United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Protection and Advocacy, Center for Mental Health Services, Protection and Advocacy, http://mentalhealth.samhsa.gov/cmhs/P&A/ (last visited March 8, 2010).
80 See e.g., 42 U.S.C.A. § 2996 (d) (4) (“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.”).
81 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*

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.\(^{82}\) Known as the least restrictive alternative, the underlying legal theory is “the state may restrict the exercise of fundamental liberties only to the extent necessary to effectuate the state’s interest.”\(^{83}\) In other words, 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.\(^{84}\) In fact, the United States Supreme Court has noted that many individuals with mental illness prefer to be treated in the comfort of their own home rather than in an institution.\(^{85}\) Being treated in an outpatient setting is one way of ensuring that a patient gets to reside at home rather than in an institution.\(^{86}\)

3. *Assisted Outpatient Treatment Laws*

“Under the [least restrictive alternative] concept, any feasible alternative must be implemented in lieu of involuntary hospitalization.”\(^{87}\) 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.\(^{88}\) 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

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\(^{82}\)Slovenko, *supra* note 12, 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)]”).

\(^{83}\) *Id.*


\(^{86}\) Slovenko, *supra* note 12 at 648.


\(^{88}\) Slovenko, *supra* note 12, at 648.
health and criminal justice systems to their own as well as their fellow citizens’
detriment.\textsuperscript{89} Inpatient treatment requires a person to be in crisis before getting help.\textsuperscript{90}
Outpatient treatment has become a better option for many who need early intervention to
prevent a crisis. Mental health observers note that the era of involuntary civil
commitment may eventually be replaced with an outpatient model.\textsuperscript{91}

Currently, forty-three of the fifty states have AOT laws;\textsuperscript{92} however, passing these
laws and implementing them 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 states.’”\textsuperscript{93}
However, advocates who have lobbied against assisted outpatient treatment or who have
delayed legislation have actually harmed their clients by forcing many into involuntary
commitment because no less restrictive alternative was available.

4. Specific Instances of Prohibited Lobbying

Though there are numerous examples of lobbying efforts to prevent or stall
proposed legislation, this section will highlight just a few. In February of 2002, Ellen
Piekalkiewicz, then Deputy Director of Operations for Florida’s P & A, testified against

\textsuperscript{89} Brakel & Davis, \textit{supra} note 30, at 569.
\textsuperscript{90} Milton L. Mack, Jr., \textit{Involuntary Treatment for the Twenty-First Century}, 21 QUINNIPIAC PROB. L. J. 294,
\textsuperscript{91} Id. at 295.
\textsuperscript{92} Treatment Advocacy Center, New Jersey is 43rd State to Adopt Assisted Outpatient Treatment, \textit{available at}
http://www.treatmentadvocacycenter.org/index.php?option=com_content&task=view&id=1431&Itemid=2
(last visited March 8, 1010).
\textsuperscript{93} Brakel & Davis, \textit{supra} note 30, at 569-70, n. 370-71 (humorously describing the many efforts of patient
advocates to discredit the assisted outpatient treatment trend).
Senate Bill 2030, which was Florida’s proposed AOT law.\textsuperscript{94} During her testimony, she stated that the law “impinge[d] upon the rights of individuals with mental illness.”\textsuperscript{95} Though Piekalkiewicz no longer serves as the director for Florida’s P & A, she is now a registered lobbyist in the State of Florida for another mental health non-profit organization.\textsuperscript{96}

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.\textsuperscript{97} After identifying her employment position and that her group was federally supported, she said the law was coercive, violated a patient’s Constitutional rights, and had “no intrinsic benefits.”\textsuperscript{98} In her testimony before the Pennsylvania legislature, Horowitz said that AOT laws are “ineffective because forced treatment does not work.”\textsuperscript{99} In making this statement, she relied upon her own experiences as the mother of a child with mental illness.\textsuperscript{100} 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 would have been successful.

\textsuperscript{94} Testimony on Senate Bill 2030, Presented by Ellen Piekalkiweicz, Deputy Director of Operations for the Advocacy Center for Persons with Disabilities, Inc., Florida’s Protection and Advocacy Programs, February 20, 2002 (on file with author).
\textsuperscript{95} Id.
\textsuperscript{96} Florida Legislature—2010 Registrations by Lobbyist Name, available at http://www.leg.state.fl.us/data/lobbyist/Reports/Lobbyist_LEG_2010.pdf (last visited March 8, 2010).
\textsuperscript{98} Id.
\textsuperscript{99} Id.
\textsuperscript{100} Id.
Only two states have kept data about AOT statistics: New York\textsuperscript{101} and North Carolina.\textsuperscript{102} Both have demonstrated that AOT laws can be extremely effective in guaranteeing a continuing course of treatment among consumers and that these consumers experience fewer problems with the criminal justice system and shorter hospitalizations.

In 1999, researchers in North Carolina determined that when patients participated for six months in court-ordered outpatient services at least three times a month, hospital admissions decreased by fifty-seven percent and the length of hospital stays were reduced by twenty days compared with individuals who were not subject to court-ordered treatment.\textsuperscript{103} The results were even better for individuals with schizophrenia and other psychotic disorders: hospital admissions were reduced by seventy-two percent and the length of hospital stays decreased by twenty-eight days compared to individuals who were not subject to court-supervised treatment.\textsuperscript{104}

Most of these consumers, when they began their treatment, believed they were not mentally ill or in need of treatment.\textsuperscript{105} However, several studies have shown that consumers’ perceptions changed dramatically after treatment and that most were thankful for it.\textsuperscript{106} One individual interviewed, named Carl, was especially thankful after he sought

\textsuperscript{103} Marvin S. Swartz & Jeffrey W. Swanson, et al., Can Involuntary Outpatient Commitment Reduce Hospital Recidivism?, AM. J. OF PSYCHIATRY, 156:1968-75 (1999).
\textsuperscript{104} Id.
\textsuperscript{105} Id.
\textsuperscript{106} See e.g., William Gardner & Charles Lidz et al., Patients’ Revisions of their Beliefs about the Need for Hospitalization, 156:9 AM. J. PSYCHIATRY 1385, 1387 (1999) (seventy-six percent of all patients surveyed believed they needed to be hospitalized and fifty-two percent of patients who believed upon commitment
pharmacological treatment, stating he “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.”

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. In 2009, New York published the result of Kendra’s Law, which was enacted a decade earlier. 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.” Kendra’s Law has accomplished this goal, according to the study. After six months of AOT, consumers were as motivated to take part in their treatment as individuals who voluntarily sought treatment on their own. After a year of AOT, consumers were more motivated than voluntary patients to continue their course of treatment.

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

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109 Id.
110 Id.
111 Id.
an increased desire to continue pharmacological treatment.\textsuperscript{112} Those consumers who participated for more than a year in the program were likely to continue their treatment successfully without any supervision.\textsuperscript{113}

The study also disproved pessimistic advocate predictions that AOT laws would deplete or prevent community services for those who did not qualify for them.\textsuperscript{114} Kendra’s Law, after its first five years of operation, increased community services for those not in its program.\textsuperscript{115} Without as many individuals in mental health crisis and with 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, nor has it stopped the National Disability Rights Network (NDRN), which is a “federal interagency project” that receives federal funds for training patient advocates across the nation, from gloating over the defeat of potential AOT legislation in other states.\textsuperscript{116}

In its 2006 annual report, the NDRN stated that the New Mexico P & A “devoted considerable time and effort to educating state legislators about the problems with [New

\textsuperscript{112} Id.
\textsuperscript{113} Id.
\textsuperscript{114} See e.g., Testimony on Senate Bill 2030, Presented by Ellen Piekalkiweicz, Deputy Director of Operations for the Advocacy Center for Persons with Disabilities, Inc., Florida’s Protection and Advocacy Programs, February 20, 2002 (on file with author) (“[F]orced outpatient treatment will detract from the necessity of funding assertive outreach programs, housing, and other basic community services….”); Testimony of Carol Horowitz, Managing Attorney for the Disability Rights Network of Pennsylvania, on Senate Bill 226, http://www.senatorerickson.com/health/2007/100207/horowitz.pdf (last visited on March 8, 2010) (AOT “simply covers up the real problem relating to the lack of funding for services and the unnecessary fragmentation of the mental health system.”).
Mexico’s AOT bill.\footnote{117} It then boasted that even though changes had been made to the bill in large part because of the advocates’ concerns, the bill ultimately died.\footnote{118}

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.\footnote{119} Shortly thereafter, New Mexico’s P & A and the ACLU sued the city to prevent it from enforcing the law.\footnote{120} After a federal judge struck down Albuquerque’s ordinance,\footnote{121} the State legislature attempted in 2007 to enact another AOT law only to have it defeated again by New Mexico’s P & A system.\footnote{122} Last year, for the third time, a new AOT law was proposed in the New Mexico legislature.\footnote{123} New Mexico will have to wait and see if its P & A system will attempt to kill the legislation once again; based upon their aggressive efforts in the past, it is almost certain it will.

California’s Laura’s Law, its AOT program, has faced similar hurdles. Only two Californian counties currently enforce Laura’s Law;\footnote{124} this is because California’s P & A

lobbied against the law and then filed a lawsuit to prevent the counties who attempted to enforce it from implementing it.\textsuperscript{125}

One of the problems with these lawsuits is that PAIMI specifically discourages advocates from initiating lawsuits. Congress hoped that advocates would pursue a “nonlitigative approach to advocacy and dispute resolution” by urging advocates to pursue administrative remedies before initiating lawsuits.\textsuperscript{126}

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 & A’s watchdog status.”\textsuperscript{127} 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 the laws need to be challenged, other mental health advocacy groups can get involved.

Proposed AOT laws are not the only ones susceptible to aggressive patient advocate lobbying. Many other proposed mental health laws have been challenged by advocate lobbyists. For example, the Disability Rights Center in Maine, which is Maine’s P & A system, has lobbied against laws that would allow families and law enforcement officers to petition a court to initiate civil commitment proceedings.\textsuperscript{128} It has also lobbied against laws in Maine that would loosen patient confidentiality restrictions for family members and that would allow patient medication over

\begin{flushleft}
\textsuperscript{125} \textit{Id.}  \\
\textsuperscript{127} Bowman, \textit{supra} note 35, at 958-65.  \\
\textsuperscript{128} Memorandum from Helen Bailey to Senator Joseph Brannigan, Representative Anne Perry, and the Joint Legislative Committee on Health and Human Services (April 28, 2009) (on file with author); E-mail from Joe Bruce to Amanda Peters, Assistant Professor of Law, South Texas College of Law (August 19, 2009) (on file with author).
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objection. And advocates in Maryland have lobbied against proposed changes to Maryland’s civil commitment criteria.

Though federal law prohibits federal patient advocates from lobbying, some academics believe that advocates can educate legislatures about proposed legislation. Suggesting that advocates are uniquely qualified to voice concerns to legislatures because of their repeat contact with individuals with mental illness, one scholar believes that “patient advocates can work at the local, county, and state levels to make policy changes benefiting clients.” However, patient advocates are forbidden from lobbying. Unless and until Congress permits them to petition proposed legislation, these lawyers must follow federal law, which does not authorize them to lobby on behalf of mental health patients.

Patient advocacy groups acknowledge time and time again that their funds are limited. With limited resources, they should be following the strict letter of the law and assisting patients who have suffered abuse and neglect, not taking on additional and legally impermissible responsibilities. For every legislative hearing that an advocate testified at, for every dollar spent on travel expenses to that hearing, and for every hour

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129 Id.
130 Letter from Laura Cain, Staff Attorney for the Maryland Disability Law Center, to Clarence Blount, Chairman for the Education, Health, and Environmental Affairs Committee regarding Senate Bill 645 (letter not dated) (on file with author).
131 Woodside & Legg, supra note 40, at 44 (suggesting that the crux of patient advocacy policy changes may center around how services are provided or delivered); 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).
132 Woodside & Legg, supra note 40, at 44.
133 See e.g., New Jersey’s 2006-2007 Ledger, 3, (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.”); National Disability Rights Network, Annual Report of the P & A System, 1996-97, 11 (“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.”).
spent on the lawsuits involved in preventing legislation from being enforced after it was enacted, patient advocates could have been investigating individual cases of abuse, neglect, and rights violations.

5. What Congress Can Do

Congress has been effective at preventing 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 non-profit legal aid organization serving the nation’s indigent population.\(^{134}\)

Legal Services Corporation was created by Congress in 1974 with the specific purpose of providing legal aid services to needy individuals.\(^{135}\) Since its creation, federal law has prohibited Legal Services Corporation’s employees from lobbying.\(^{136}\) 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.”\(^{137}\) This prevents these 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

\(^{134}\) Legal Services Corporation, What is LSC?, available at http://www.lsc.gov/about/lsc.php (last visited March 8, 2010).

\(^{135}\) Id.

\(^{136}\) See e.g., 45 C.F.R. § 1612.3 (a)(1) (2006) (preventing members from influencing the passage or defeat of any legislation); 45 C.F.R. § 1612.4 (2006) (preventing members from engaging in grassroots lobbying).

insulate the Corporation from the political influence, abuses, and criticisms that had characterized … previous … program[s].” Other reasons include the fact that nonprofit, federally-funded lawyers have little funding and much responsibility and may use the funds to get around their legislatively-mandated responsibilities.

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

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.

139 See also Rand, supra note 81, at 550-51 (“[A]torneys 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.”)
143 Memorandum from Laurie Tarantowicz, Assistant Inspector General and General Counsel for Legal Services Corporation to Kirt West, Inspector General for Legal Services Corporation, 5-7 (April 24, 2007) available at https://www.oig.lsc.gov/gov/OIG%202007%20regulatory%20recommendations.pdf; Legal Servs. Corp. v. Velazquez, 531 U.S. 533, 547-49 (2001) (stating that individuals affected by proposed legislation have the opportunity to challenge the legislation even if their legal aid attorney cannot).
The only effective way of preventing lobbying is to do as Congress has done with
the Legal Services Corporation: consider passing additional regulations 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 un-fund 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.” Mental health consumers, their family members, and other non-profit
and grassroots organizations who are involved in the causes that affect individuals with
mental illness are not prevented from lobbying. Because patient advocates are
prohibited, lobbying should be left to these individuals and groups.

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” v. 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 affect this
goal. However, when Congress recently authorized greater funds to accomplish a larger
mission in non-institutional settings, advocates turned from individual representation to

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systematic representation. As a result, they have abandoned their role as protector and advocate to countless individuals living in the community 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 the institution’s closed door. Senators also heard that many institutions were doing everything possible to prevent investigations and to destroy or hide evidence from patients’ families and from lawyers. Consequently, PAIMI gave advocates full authority to enter those doors to access any and all materials and persons necessary to their investigation.

SAMHSA is the government agency that oversees federally-funded patient advocates. SAMHSA’s website says 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. Therefore, PAIMI and SAMHSA advocates are required to investigate individual cases of abuse and neglect and 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 towards

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145 See infra, notes 45-51 and accompanying text.
146 See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 66 (1985) (statement of Harold Cockerham, father of Chris Cockerham, a young man who was abused in the institution where he lived).
147 See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 80-82 (1985) (statement of Carol Sands, Assistant Deputy Public Advocate for the State of New Jersey).
148 United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Protection and Advocacy, Center for Mental Health Services, Division of State and Community Development Systems, State Planning and Systems Development Branch, Protection and Advocacy for Individuals with Mental Illness (PAIMI) Program, available at http://mentalhealth.samhsa.gov/cmhs/p&a/about.asp (last visited March 8, 2010).
systematic advocacy. 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. But with that increase in funding, advocates saw an increase in responsibility: for the first time ever, they were required to investigate cases of abuse and neglect in community treatment facilities. 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 who were being treated in boarding homes, outpatient facilities, and elsewhere within the community.

The National Disability Rights Network (NDRN) is the organization that acts as the collective voice for each state’s P & A system. It gets two percent of PAIMI’s budget for training all patient advocates. Through its training, the NDRN sets the agenda for national advocacy and patient advocate groups. In 2001, the NDRN contemplated its new funding and new role in a document addressed to advocates across

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150 Id.
151 The National Disability Rights Network used to be called the National Association of Protection and Advocacy Systems. See Wiser Earth: Connecting You to Communities in Action, available at http://www.wiserearth.org/organization/view/72f128d1a2517074d995437d2d1d1454 (last visited March 8, 2010).
153 Id.
the nation entitled, “Implementing the New PAIMI Act Authority: Where Do We Go from Here?”\textsuperscript{154} In it, the NDRN recommended that patient advocacy groups use the increased funding and responsibility to “focus on systematic advocacy approaches to address community-based issues for people with mental illness, but [to] continue to pursue individual cases \textit{to the extent possible}.”\textsuperscript{155} The NDRN advised advocates to turn their attention away from investigating individual allegations of abuse, neglect, and rights violations and instead to “systemic issues” that affect those living in the community.\textsuperscript{156} “Systematic issues” has never been defined by the NDRN. However, it is important to note that none of the advocacy goals or client “issues” mentioned on the NDRN’s website relate to investigating allegations of abuse, neglect, or rights violations.\textsuperscript{157}

At a 2001 P & A Executive Directors meeting, those in attendance expressed concerns about how to spend the newly allocated community funds.\textsuperscript{158} They contemplated enhancing investigation capacity, strengthening their advocacy role, and serving new, previously un-served mental health consumers,\textsuperscript{159} including those living in nursing homes.\textsuperscript{160} However, after this meeting, the NDRN reported that P & A systems were to focus on systematic advocacy of issues within the community and to focus on individual cases of abuse and neglect only if time and resources allowed.\textsuperscript{161}

\textsuperscript{155} \textit{Id}.
\textsuperscript{156} \textit{Id}.
\textsuperscript{159} “Consumers” is the term used to describe individuals who require mental health services.
Executive Directors acknowledged that P & As 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.”162

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, non-profit organization that represents approximately 11,000 individuals with mental illness and their family members.163 Honberg says that he could “not in good faith argue that more people are getting better treatment” today than when PAIMI was enacted in 1986.164 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 United States Attorney General and the Department of Justice (DOJ) to investigate violations of federal rights in state-run mental health institutions.165 Over the past few years, the DOJ has investigated sixteen facilities in the following states: Georgia, New Jersey, New

163 Interview with Ron Honberg, Policy Affairs Director for the National Alliance on Mental Illness (NAMI), in Arlington, VA (Jan. 7, 2010).
164 Id.
York, Oregon, Connecticut, Washington D.C., Vermont, and North Carolina. The Civil Rights Division of the DOJ reports that it has investigated thirty-five states under CRIPA on matters relating to the health, safety, and treatment of individuals confined in state-operated mental health facilities. It has handled complaints about abusive staff, violent residents, unreasonable and abusive restraints, inadequate treatment, a lack of protection from suicidal and harmful behavior, and unsanitary and unsafe facilities. 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, it is apparent that individuals who are institutionalized still need protection from abuse and neglect.

Unfortunately, community-based treatment facilities are often far worse in their abuse and neglect of individuals than institutions. 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 larger number of individuals.

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

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168 Id.
169 See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 5, 78-82, 176, 221-22, 236 (1985) (various individuals testified about the excessive use of physical restraints, overmedication, lack of treatment, neglect, abusive staff, prison-like conditions, and the fact that violent residents and nonviolent residents were housed together).
170 E. Fuller Torrey, It’s a Mad, Mad World, N.Y. POST, Sept. 13, 2009 (“many of the group homes in which patients have been placed are snake pits”).
Congress expanded PAIMI to include community facilities; the articles revealed the woeful conditions in federally-funded boarding homes and community facilities.\textsuperscript{171} At that time, there were three times as many individuals who lived in group homes and small community treatment facilities than those who resided in institutions.\textsuperscript{172}

In one article, a California government official said that while some of the facility operators were caring, many community facility employees were guilty of “financial abuse…harried, inadequate psychiatric care, … sexual abuse and violence.”\textsuperscript{173} 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.”\textsuperscript{174} Unfortunately, it was not until one resident beat another resident to death using a rock that the facility was shut down permanently.\textsuperscript{175} 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.”\textsuperscript{176} 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.\textsuperscript{177} 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 of these people as possible.”

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\textsuperscript{172} Id.
\textsuperscript{173} Id.
\textsuperscript{174} Id.
\textsuperscript{175} Id.
\textsuperscript{176} Id.
\textsuperscript{177} Pete Earley, \textit{Crazy} 135 (2006). Most of these private boarding homes opened after deinstitutionalization began. Id. at 136.
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they can [but] don’t do anything to really help them.” 178 Some of the facilities in the greater Miami area are dilapidated, unsafe, and unsanitary. 179 Worse, their employees do not monitor what goes on inside the facilities nor do they pay attention to the whereabouts of residents. 180 As a result, operators often file missing person reports and fights between staff and patients occur frequently, as does drug abuse. 181 Just as the 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 federal law mandates these consumers receive.

4. What Congress Can Do

When it revises PAIMI, Congress should be careful to distinguish what it means by individual representation. Phrases like “systematic advocacy” for “issues,” “systematic reform,” and even “systematic education” should be expressly prohibited if Congress determines that individual representation is still the focus of the advocate’s role. Leaving the NDRN or state P & A systems to designate how they will spend federal funds is not working. Before Congress grants any annual funds to a state P & A system, it should make sure that the advocates in that state are not shirking their responsibilities with individual investigations of abuse, neglect and civil rights violations or spending funds on goals and measures that are not related to individual patient advocacy.

178 Id. at 136.
179 Id.
180 Id. at 136-37.
181 PETE EARLEY, CRAZY 135, 138 (2006); Julie Marquis & Dan Morain, The Tortuous Path to Mental Health Care, LOS ANGELES TIMES, Nov. 21, 1999, at A1 (“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.”).
Another possible solution is to de-monopolize the P & A system altogether. In the past, it was suggested that NAMI support state governors in designating attorneys as patient advocates. If these attorneys were selected on a competitive basis, the protection and advocacy system might improve. 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 has failed to safeguard patient rights and safety.

C. Family Battles

According to PAIMI, patients’ family members are vital to their care and protection. 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. Their reports today are no less so. 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

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182 Memorandum from Dick Greer, to Laurie Flynn, former Executive Director of NAMI (January 1991) (on file with author)
183 Id.
184 42 U.S.C.A. § 10801 (a)(2) (“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 ….”).
185 See supra notes 45-51.
knowledge about what is happening to their loved ones.\textsuperscript{187} Many family members do not even know that patient advocates exist.\textsuperscript{188} 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. \textit{PAIMI and Congressional Views of Family Involvement}

Family members of individuals with mental illness had a large part in getting PAIMI enacted. There were several families who attended or supplied statements or testimony during PAIMI’s Congressional hearings.\textsuperscript{189} 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 Cockerman, who lost his hearing because of the repeated abuse he sustained while he was institutionalized.\textsuperscript{190} In 1991, when PAIMI was being reauthorized 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.”\textsuperscript{191}

\textsuperscript{187} Interview with Ron Honberg, Policy Affairs Director for the National Alliance on Mental Illness (NAMI), in Arlington, VA (Jan. 7, 2010).
\textsuperscript{188} Telephone Interview with Joe Bruce, whose son William suffers from schizophrenia (February 8, 2010).
\textsuperscript{189} See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99\textsuperscript{th} Cong. 5, 17, 67, 179, 369, 551, (1985) (parents who were present at the hearing or who provided testimony or who submitted statements to Congress included Harold Cockerham, Wilbur Savidge, Maureen Kelly, Barbara A. Thompson, Robert Bruggeman, and Reese Jones).
\textsuperscript{190} Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99\textsuperscript{th} Cong. 5 (1985) (statement of Mr. Harold Cockerham, father of Christopher Cockerham, Fort Worth, TX).
\textsuperscript{191} S. REP. NO. 102-114 (1991).
In the current version of PAIMI, the phrase “family member” is mentioned nine times. 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 found that family members play an important role in the lives of those who are suffering from mental illness. Not only did the Act consider family members the patient’s central advocate, but it makes assurances that each P & A staff is trained to provide assistance to family members.

Families are given several rights in addition to the right to information and assistance from patient advocates. Family members are given the authority to help individuals file grievances against treatment facilities. 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.

PAIMI acknowledges that families broadly represent the interests of the mentally ill and are knowledgeable about the needs of the consumers served by the system. In NAMI’s 2009 “Grading the States” report on mental health consumers’ and their families’ satisfaction with mental health services, several consumers recognized the strength of family advocacy. For instance, a consumer stated had his “mother not fought … on my behalf, I most likely would have committed suicide.” In a Los

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192 42 U.S.C.A. §§ 10801 (2), 10804 (a)(2), 10805 (a)(6)(A)-(C), 10805 (a)(9), 10805 (c)(1)(B)(ii), and 10821(a)(2) & (b).
193 42 U.S.C.A. § 10801 (2).
194 42 U.S.C.A. § 10821 (a)(2) & (b).
196 Heilman, supra note 75, at 261.
199 Id. at 75.
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. You’ll do anything. You’ll sell your soul for one night of your child’s safety.” Family members comprise the largest and most dedicated group of caregivers.

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.” The United States Supreme Court has recognized that families are vital in helping individuals with mental illness survive safely and independently outside of mental health institutions.

Approximately fifty percent of chronically mentally ill adults live with family members. Eighty percent of these caregivers are parents who are at least fifty years old. Many caregivers live alone with their mentally ill family member. Studies reveal that while some family members have difficulty understanding their loved one’s illness, many are “as able as [mental health] professionals to correctly identify the psychopathology that should necessitate involuntary treatment.” Families are as

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205 Id.
206 Id. at 770.
educated as mental health professionals because they frequently assume the care-giving 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 a feeling that they were kept in the dark about what was going on inside the institution’s walls.\textsuperscript{208} 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 United States Supreme Court has refused to grant family members the right to act as parties in civil commitment cases,\textsuperscript{209} 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.\textsuperscript{210} Only when the family is "sophisticated, assertive … and really

\textsuperscript{208} See e.g., Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99th Cong. 5-7 (1985) (statement of Harold Cockerman, son of Chris Cockerman, a young man who was beaten so severely that he lost his hearing during his institutionalization).

\textsuperscript{209} Heller v. Doe, 509 U.S. 312, 317 (1993) (granting party status only to family members of individuals who are mentally retarded).

\textsuperscript{210} Interview with Aileen Kroll, Legislative and Policy Counsel for the Treatment Advocacy Center, in Arlington, VA (Jan. 6, 2010).
engaged”\textsuperscript{211} 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.\textsuperscript{212} Over the years, he has heard parents complain that when their ill relative is in crisis and physically or mentally unable to contact an advocate, the response the family gets when it contacts an advocate is “We don’t represent families. Ask your child to call and talk to us.”\textsuperscript{213} It is not always possible for the patient to contact the advocate, especially when the patient is severely mentally ill. Therefore, ignoring the family's pleas for protection and advocacy have extremely adverse affects on the patient 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 reason to involve them in the process.\textsuperscript{214} To illustrate this point, 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.\textsuperscript{215} Unfortunately, this anti-family sentiment began shortly after PAIMI was enacted and has persisted.\textsuperscript{216}
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 of dignity.\(^\text{217}\)

Court proceedings are also unkind to family members. Families have no right to testify during the civil commitment hearing.\(^\text{218}\) 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 family member to testify who disagrees.\(^\text{219}\) One study found that “families are cynical and pessimistic about the feasibility of commitment under current laws – a probable outcome of past experience with ‘the system,’ and repeated failures to obtain needed intervention.”\(^\text{220}\)

Not only do families face barriers to participation and information in the legal setting, they also experience them from mental health facilities. In the rare instances when a loved one is committed, family members often have no right to advise treating staff or doctors about the effectiveness of prior medical treatment or provide facilities

\(^\text{217}\) Gutierrez, \textit{supra} note 27, at 79.

\(^\text{218}\) Interview with Aileen Kroll, Legislative and Policy Counsel for the Treatment Advocacy Center, in Arlington, VA (Jan. 6, 2010).

\(^\text{219}\) \textit{Id}.

\(^\text{220}\) Husted & Nehemkis, \textit{supra} note 207, at 542.
with the medication that is currently being used by the patient.\textsuperscript{221} Often family members, if they are able to determine where their loved one is being treated, leave the hospital feeling demoralized because their efforts at educating those who are making treatment decisions fail\textsuperscript{222} and the ill person’s care is therefore inconsistent.\textsuperscript{223} A consumer told NAMI that the “lack of continuity from one provider to the next [is the worst part of the system].”\textsuperscript{224} Families can help here; they are often more aware than the patient of the patient’s treatment history and what treatment has 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.\textsuperscript{225} Researchers found that ninety-five percent of mental health providers were overly cautious about confidentiality laws, believing they were “more restrictive than even the most conservative legal interpretation.”\textsuperscript{226} 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.\textsuperscript{227}

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,

\textsuperscript{221} Interview with Aileen Kroll, Legislative and Policy Counsel for the Treatment Advocacy Center, in Arlington, VA (Jan. 6, 2010).
\textsuperscript{222} Id.
\textsuperscript{223} Vaddadi, supra note 204, at 770.
\textsuperscript{226} Id. at 1626.
\textsuperscript{227} Id. at 1625.
families have begun to demand their own rights.\textsuperscript{228} 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.\textsuperscript{229} As one commentator stated, “The families of chronic patients are protesting. In the 1950s and 1960s, they were loosely organized, but today they have formed political action associations with chapters in virtually every state.”\textsuperscript{230} 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 are failing at providing quality care for those who suffer from mental illness.

3. 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).\textsuperscript{231} Not only does HIPAA shield families from knowing about the patient’s diagnosis and treatment plan,

\begin{itemize}
  \item \textsuperscript{228} Woodside & Legg, supra note 40, at 47.
  \item \textsuperscript{229} See e.g., E-mail from Joe Bruce to Priscilla Hanley Collins, Senator from Maine (October 1, 2008) (on file with author).
  \item \textsuperscript{230} Slovenko, supra note 12, at 660.
  \item \textsuperscript{231} See e.g., 45 C.F.R. §164.501 (2009) et seq.
\end{itemize}
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, they are unaware of their existence.”

As one parent of a young man with schizophrenia has 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.

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 goes on behind the hospitals’ walls, families cannot be assured that their loved ones are being treated or that the advocate has performed 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 their treatment facility 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

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232 E-mail from Joe Bruce to Priscilla Hanley Collins, Senator from Maine (October 1, 2008) (on file with author).
233 Id.
family member will be in when he returns home. This alone presents huge problems for families. 234

Maine is one state that has proposed legislation to loosen confidentiality laws for family members. 235 Congress could loosen confidentiality laws without violating the patient’s right to treatment or the right to refuse treatment. Relaxing confidentiality laws, particularly for caretakers of individuals with chronic and severe mental illness, would assist family members in discovering 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.” 236

b. Create Family Grievance and Monitoring Systems

According to PAIMI, family members should be decision-makers on state boards and P & A employees are supposed to be trained in counseling and communicating with family members. 237 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 a grievance with a P & A system to assure that it is operating within the confines of PAIMI. 238 However, while a system exists for patients to grieve advocates, there is not a system in place for families

234 See e.g., Elizabeth Bernstein and Nathan Koppel, A Death in the Family, WALL ST. J., August 16-17, 2008, at A1 (William Bruce, a young man with schizophrenia, 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.).
235 E-mail from Joe Bruce to Amanda Peters, Assistant Professor of Law, South Texas College of Law (August 19, 2009) (on file with author).
236 E-mail from Joe Bruce to Priscilla Hanley Collins, Senator from Maine (October 1, 2008) (on file with author).
237 42 U.S.C.A. §§ 10805 (c)(1)(B)(ii) and 10821(a)(2) & (b).
to grieve the advocate. 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.” SAMHSA has never publicly disciplined systems that fail to carry out PAIMI provisions. Some suggest that PAIMI should be amended “to include performance standards with federal sanctions for violations.” 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.

V. Conclusion

Protecting the mentally ill is a noble cause. During PAIMI’s Congressional hearings, Senator Lowell Weicker stated that one gauge of a civilized society is how it

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239 Gutierrez, supra note 27, at 58.

240 Gutierrez, supra note 27, at 96.

241 Memorandum from Dick Greer, to Laurie Flynn, former Executive Director of NAMI (January 1991) (on file with author).
treats those in need.\textsuperscript{242} Congress sought to make a difference in the way that individuals with mental illness were treated in the facilities entrusted to take care of them. However, it appears the mental health system is no 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.

\textsuperscript{242}Care of Institutionalized Mentally Disabled Persons: Hearing Before the Subcomm. on the Handicapped of the Comm. on Labor and Human Resources, 99\textsuperscript{th} Cong. 4 (1985) (statement of Sen. Lowell Weicker, Member, S. Comm. on Labor and Human Resources).