No. 04-4074

## IN THE UNITED STATES COURT OF APPEALS FOR THE EIGHTH CIRCUIT

IOWA PROTECTION AND ADVOCACY SERVICES, INC., Plaintiff-Appellee,

v.

TANAGER PLACE AND TANAGER, INC., Defendants-Appellants.

ON APPEAL FROM THE UNITED STATES DISTRICT COURT FOR THE NORTHERN DISTRICT OF IOWA

BRIEF OF NATIONAL ASSOCIATION OF PROTECTION & ADVOCACY SYSTEMS, INC., THE AMERICAN ASSOCIATION ON MENTAL RETARDATION, THE ARC OF THE UNITED STATES, THE FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH, THE NATIONAL ALLIANCE FOR THE MENTALLY ILL, THE NATIONAL ASSOCIATION OF COUNCILS ON DEVELOPMENTAL DISABILITIES, AND THE NATIONAL MENTAL HEALTH ASSOCIATION AS AMICI CURIAE IN SUPPORT OF PLAINTIFF-APPELLEE URGING AFFIRMANCE

Joan A. Magagna Deputy Executive Director for Legal Services National Association of Protection & Advocacy Systems, Inc. 900 Second Street, N.E., Suite 211 Washington, D.C. 20002 Tel: (202) 408-9514, Ext. 114 TTY: (202) 408-9521 Fax: (202) 408-9520

Counsel for Amicus National Association of Protection & Advocacy Systems, Inc.

Sean A. Lev Mary Ann McGrail Kellogg, Huber, Hansen, Todd, Evans & Figel, P.L.L.C. 1615 M Street, N.W., Suite 400 Washington, D.C. 20036 Tel: (202) 326-7900 Fax: (202) 326-7999

Counsel for Amici

Date: May 18, 2005

# TABLE OF CONTENTS

| TABLE OF AUTHORITIESii   |
|--|
| INTEREST OF AMICI 1  |
| SUMMARY OF ARGUMENT 5  |
| ARGUMENT   |
| <ul> <li>I. Congress Enacted PAIMI In Response To Findings Of<br/>Widespread Abuse And Neglect Of Individuals With Mental<br/>Illness Residing In Institutions</li></ul>   |
| II. The Access Authority Provided By PAIMI Has Enabled The<br>P&As To Conduct Effective Investigations And Prevent Or<br>Remedy Abuse And Neglect In Institutional Settings  |
| <ul> <li>III. The Facts Of This Case Provided An Ample Basis For The<br/>Iowa P&amp;A To Exercise Its Congressionally Mandated Powers<br/>To Ensure The Safety And Well-Being Of Individuals With<br/>Mental Illness</li></ul> |
| CONCLUSION   |

## **TABLE OF AUTHORITIES**

Page

| Cases  | 1 450     |
|--|-----------|
| Donovan v. Dewey, 452 U.S. 594 (1981)  | . 5-6, 14 |
| Iowa Prot. & Advocacy Servs., Inc. v. Gerard Treatment Programs,<br>L.L.C., 152 F. Supp. 2d 1150 (N.D. Iowa 2001)  | 16        |
| Mississippi Prot. & Advocacy Sys., Inc. v. Cotton, No. J87-0503(L),<br>1989 WL 224953 (S.D. Miss. Aug. 7, 1989), aff'd, 929 F.2d<br>1054 (5th Cir. 1991) | 17        |
| Robbins v. Budke, 739 F. Supp. 1479 (D.N.M. 1990)  | 16, 17    |
| United States v. Jamison-McKames Pharms., Inc., 651 F.2d 532<br>(8th Cir. 1981)  | 14        |

## **Constitution, Statutes, and Rules**

| U.S. Const. Amend. IV  | , 8, 14 |
|--|---------|
| Developmental Disabilities Assistance and Bill of Rights Act of 2000,<br>Pub. L. No. 106-402, 114 Stat. 1677 | 5       |
| Federal Mine Safety and Health Act of 1977, 30 U.S.C. §§ 8701<br>et seq.                                     | 6       |
| Protection and Advocacy for Individuals with Mental Illness Act,<br>42 U.S.C. §§ 10801-10851                 | 3       |
| § 10801(b)(1)  | 3       |
| § 10801(b)(2)  | 3, 14   |
| § 10801(b)(2)(A)   | 14      |
| § 10801(b)(2)(B)   | 14      |

ii

| Youth Drug and Mental | Health Services Act, F  | Pub. L. No. 106-310, |   |
|-----------------------|-------------------------|----------------------|---|
| Div. B, § 3206(a)     | , 114 Stat. 1101, 1168, | 1193-94 (2000)       | 3 |

| Fed. R. A | App. P | . 29(a) | 1 |
|-----------|--------|---------|---|
|-----------|--------|---------|---|

# **Congressional Materials**

| Care of Institutionalized Mentally Disabled Persons: Joint Hearings  |
|--|
| Before the Subcomm. on the Handicapped of the Senate Comm.           |
| on Labor and Human Resources, and Subcomm. on Labor,                 |
| Health and Human Services, Education and Related                     |
| Agencies of the Senate Comm. on Appropriations,                      |
| 99th Cong. (1985) 6, 9, 10, 23                                       |
| Appendix, Staff Report on the Institutionalized Mentally<br>Disabled |
| S. Rep. No. 99-109 (1985)  |

## **Other Materials**

Equip for Equality:

| Abuse Investigation Unit, Report: Lincoln Developmental  |    |
|--|----|
| Center – The Politics of Closing a State Institution:  |    |
| Vulnerable People Fall Victim to Special Interests,  |    |
| available at http://www.equipforequality.org/  |    |
| publications/aiu_lincoln.pdf   | 24 |
| Press Release, Equip for Equality Calls for the Closure of the<br>Choate Developmental Center (Feb. 25, 2005), available<br>at http://www.equipforequality.org/news/pressreleases/<br>february_25_2005equip_for_equa.php | 19 |

| Press Release, Equip for Equality Response to Governor Ryan's<br>Press Release (February 4, 2002) on Lincoln<br>Developmental Center (Feb. 4, 2002), available at<br>http://www.equipforequality.org/news/pressreleases/   |    |
|--|----|
| feb_4_02equip_for_equality_res.php2  | 24 |
| Special Report, Clyde Choate Developmental Center: How An<br>Archaic System Results in Tragic Consequences for<br>People with Disabilities (2005), available at<br>http://www.equipforequality.org/publications/aiu_choate.<br>pdf   | 20 |
| Expert Report of Clarence J. Sundram (Mar. 2005)   | 26 |
| Letter from R. Alexander Acosta, Ass't Attorney General, Civil<br>Rights Division, U.S. Dep't of Justice, to Gov. Arnold<br>Schwarzenegger, State of California, Re: Metropolitan State<br>Hospital, Norwalk, California (Feb. 19, 2004), <i>available at</i><br>http://www.usdoj.gov/crt/split/documents/metro_hosp_find<br>let.pdf | 25 |
| Zeke MacCormack, Advocated Gain Access to Lockup: Kerr County<br>Juvenile Facility Will Let Them Investigate Complaints, San<br>Antonio Express, Jan. 19, 2004   | 20 |
| National Association of Protection and Advocacy Systems, Inc.,<br>2004 Annual Report (2004), available at<br>http://www.napas.org/I-6/2004Report.pdf   | 22 |
| Protection and Advocacy, Inc.:   |    |
| Investigations Unit, <i>The Legal Hazard of Prone Restraint:</i><br><i>Positional Asphyxiation</i> (Apr. 2002), <i>available at</i><br>http://www.pai-ca.org/pubs/701801.pdf   | 18 |
| Newsletter Issue No. 87 (Spring 2004), <i>available at</i><br>http://www.pai-ca.org/NEWSLTRS/Issue87/<br>ISSUE87.pdf1  | 18 |

# Glenda Taylor:

| Behind Closed Doors, Kerrville Daily Times, Jan. 14, 2004 20,   | 21  |
|---|-----|
| Complaints at Juvenile Facility Investigated, Kerrville Daily<br>Times, Nov. 20, 2003   | 20  |
| Detention Center Violates State Rules, Kerrville Daily Times,<br>May 7, 2004  | 21  |
| <i>Witnesses Detail Alleged Abuse</i> , Kerrville Daily Times, Jan. 15, 2004  | 21  |
| Virginia Office for Protection and Advocacy:  |     |
| Investigation Report: An Investigation Into the Neglect of SH,<br>Case No. 02-0354 (Sept. 12, 2003), available at<br>http://www.vopa.state.va.us/Investigations/Neglect<br>%20of%20SH.pdf | -22 |
| PAIMI Program Annual Program Performance Report<br>(Dec. 30, 2003), available at http://www.vopa.state.va.<br>us/Reports/2003%20Reports/PAIMI%20Final%20%20F<br>Y%2003.pdf                | 22  |
| PAIMI Program Annual Program Performance Report<br>(Dec. 29, 2004), available at http://www.vopa.state.va.<br>us/Reports/2004% 20Reports/FY% 2004% 20% 20PAIMI<br>% 20Final.pdf           | 16  |

## **INTEREST OF AMICI<sup>1</sup>**

Amici are the National Association of Protection and Advocacy Systems, Inc. ("NAPAS"), the American Association on Mental Retardation, The Arc of the United States, the Federation of Families for Children's Mental Health, the National Alliance for the Mentally III, the National Association of Councils on Developmental Disabilities, and the National Mental Health Association.

Amici include the foremost organizations in the nation representing parents of children with serious emotional disturbance, family members of individuals with mental illness and mental retardation, children and adults with mental disabilities, and professionals who treat children and adults with mental disabilities. Amici include organizations representing the families of children who live in residential treatment centers like Tanager Place and professionals who work in such facilities.

These organizations are uniquely positioned to speak to the policy issues raised by this case. Amici have considerable experience with the abuse and neglect of individuals with mental disabilities by care providers, the need for independent advocates to investigate possible instances of abuse

<sup>&</sup>lt;sup>1</sup> Pursuant to Federal Rule of Appellate Procedure 29(a), counsel for amici is authorized to state that appellants, appellee, and intervenor United States consent to the filing of this brief.

and neglect in facilities serving individuals with mental disabilities, and the need for those advocates to have effective mechanisms to investigate abuse and neglect. As a result of this experience, amici strongly support the need to have protection and advocacy systems with the authority to gain access to facilities, residents, staff, and records, without first obtaining a warrant, in order to prevent and remedy abuse and neglect. These systems are equally necessary to protect individuals with psychiatric disabilities and developmental disabilities, as both are vulnerable to abuse and neglect. Amici believe that adoption of the positions urged by Tanager Place would have the unfortunate result of destroying the invaluable protections against abuse and neglect that have prevented needless injuries and deaths of their children, family members, patients, and fellow individuals with mental disabilities, and would bring about a return to the days when abuse and neglect of this vulnerable population were rampant and few effective means existed to address those problems.

NAPAS is the voluntary national membership association of protection and advocacy agencies ("P&As") and client assistance programs ("CAPs"), which are federally authorized and located in all 50 states, the District of Columbia, Puerto Rico, and the federal territories. The P&A/CAP system comprises the nation's largest provider of legally based

advocacy services for persons with disabilities. Congress established the P&A system to provide advocates for this vulnerable population. Through a series of federal acts, including, among others, the Protection and Advocacy for Individuals with Mental Illness Act, 42 U.S.C. §§ 10801-10851 ("PAIMI"),<sup>2</sup> Congress gave substantial support to each state that set up a P&A agency to protect the rights of individuals with disabilities so that these individuals may live a secure and stable life. See, e.g., 42 U.S.C. 10801(b)(1), (2) ("The purposes of this chapter are . . . (1) to ensure that the rights of individuals with mental illness are protected; and (2) to assist States to establish and operate a protection and advocacy system for individuals with mental illness"). Amici file this brief in furtherance of those federal policies and to ensure that P&As continue to be able to fulfill this crucial, congressionally established mission.

The American Association on Mental Retardation ("AAMR") is the nation's oldest and largest interdisciplinary organization of professional and other persons who work exclusively in the field of mental retardation. The AAMR multidisciplinary membership is comprised of special educators and

<sup>&</sup>lt;sup>2</sup> Both Tanager Place and the district court refer to the statute by its previous name, the Protection and Advocacy for Mentally III Individuals Act of 1986 ("PAMII"). The statute was renamed in 2000. *See* Youth Drug and Mental Health Services Act, Pub. L. No. 106-310, Div. B, § 3206(a), 114 Stat. 1101, 1168, 1193-94 (2000) (renaming PAMII the "Protection and Advocacy for Individuals with Mental Illness Act").

college professors, physicians, attorneys, nurses, social workers, speech pathologists and communication therapists, occupational and physical therapists, recreation therapists, gerontologists, members of the clergy, nutritionists and dieticians, rehabilitation and employment specialists, and administrators.

The Arc of the United States, through its nearly 900 state and local chapters, is the largest national voluntary organization in the United States devoted solely to the welfare of the more than seven million children and adults with mental retardation and related disabilities and their families.

The Federation of Families for Children's Mental Health is a national organization devoted to helping children with mental health needs and their families achieve a better quality of life. Consisting primarily of family members, the Federation provides leadership to a nationwide network of state and local chapters that promote change in mental health systems' responses to the needs of these children and their families through guidance, training, support, and personal advocacy.

The National Alliance for the Mentally III, the largest national organization comprised principally of family members of individuals with mental illness, leads a national grassroots effort to transform America's mental health care system, eliminate stigma, support research, and attain

adequate health insurance, housing, rehabilitation, jobs, and family support for millions of Americans living with mental illnesses.

The National Association of Councils on Developmental Disabilities is a national, member-driven organization consisting of 55 State and Territorial Developmental Disabilities Councils. These Councils are established pursuant to the Developmental Disabilities Assistance and Bill of Rights Act of 2000 to promote the interests and rights of people with developmental disabilities and their families.

The National Mental Health Association, with its more than 340 affiliates run by individuals with mental illness and their family members, is dedicated to promoting mental health, preventing mental disorders, and achieving victory over mental illness through advocacy, education, research, and services.

#### SUMMARY OF ARGUMENT

Amici file this brief to make three points.

*First*, in investigating possible abuse and neglect of children with mental illness, plaintiff/appellee Iowa Protection and Advocacy Services, Inc. ("Iowa P&A") is serving what Congress has determined to be a highly significant public interest, a fact that is directly relevant to any Fourth Amendment analysis undertaken by the Court. *See, e.g., Donovan v. Dewey*,

452 U.S. 594, 602 (1981) (upholding warrantless inspections required by the Federal Mine Safety and Health Act of 1977 because, among other things, "there is a substantial federal interest in improving the health and safety conditions in the Nation's underground and surface mines").

Congress enacted PAIMI because it concluded, based on an enormous record, that people with mental illness, a particularly vulnerable group of citizens, are often subject to abuse and neglect – the details of which are frequently shocking and repulsive. In conjunction with congressional hearings,<sup>3</sup> Senate staff conducted an investigation into conditions at institutions for those with mental illness, documenting multiple areas of abuse and neglect, including "kicking or otherwise striking patients, sexual advances and rape, verbal threats of injury and other forms of intimidation."<sup>4</sup>

A key component of Congress's response to that problem was the creation of P&As with sufficient investigative powers to root out and deter abuse of people with disabilities. Each state's P&A is intended to provide effective and vigorous advocacy for the rights and well-being of individuals

<sup>3</sup> Care of Institutionalized Mentally Disabled Persons: Joint Hearings Before the Subcomm. on the Handicapped of the Senate Comm. on Labor and Human Resources, and Subcomm. on Labor, Health and Human Services, Education and Related Agencies of the Senate Comm. on Appropriations, 99th Cong. (1985) ("Senate Hearings").

<sup>&</sup>lt;sup>4</sup> Senate Hearings, App., *Staff Report on the Institutionalized Mentally Disabled* at 2 ("Weicker Report").

with mental illness. *See* S. Rep. No. 99-109, at 7 (1985) ("The Committee bill reflects the need for an effective system to provide protection and advocacy for mentally ill persons. . . . The purpose of S. 974 is to facilitate the establishment of a system in each State to provide protection and advocacy to mentally ill persons."). In fulfilling that congressionally established mission, the P&As serve a public interest of the highest order.

*Second*, two decades of experience have shown that, just as Congress intended, the investigative authority granted to P&As is a highly effective tool to protect this extremely vulnerable population. In case after case, P&As have used that authority, including the authority to obtain access to residents of treatment facilities, to uncover abuse and neglect, and thus to improve the lives and well-being of people with mental illness. Each year, P&As "respond[] to tens of thousands of complaints of abuse, neglect, and civil rights violations in a variety of settings," resulting in the "protection of individuals with disabilities from serious harm – and, in some cases, saved lives." National Association of Protection and Advocacy Systems, Inc., 2004 Annual Report at 5 (2004) ("NAPAS 2004 Annual Report"), available at http://www.napas.org/I-6/2004Report.pdf. The access authority at issue in this case thus serves a vital public interest in just the manner that Congress intended.

*Third*, the facts that led the Iowa P&A to exercise its congressionally granted PAIMI authority in this instance are similar in key respects to the facts of prior cases where there was serious abuse and neglect. There was thus ample basis for the Iowa P&A to conclude that there was sufficient probable cause to exercise the powers that Congress granted to it to ensure the safety and well-being of individuals with mental illness.

#### ARGUMENT

## I. Congress Enacted PAIMI In Response To Findings Of Widespread Abuse And Neglect Of Individuals With Mental Illness Residing In Institutions

In this appeal, appellants claim that the access authority granted by PAIMI presents a Fourth Amendment issue. Assuming that such an issue even exists, there has been no violation of the Fourth Amendment for the reasons discussed in the Iowa P&A brief. Amici will not repeat those reasons in this brief, but will instead focus on one aspect of the issue – the paramount public interest served by the congressionally granted access authority at issue here. The evidence presented to Congress prior to passing PAIMI amply demonstrates this significant public interest.

Congress enacted PAIMI because it found that, for the many individuals with mental illness residing in institutions in the United States, there was a need to "affirm and enforce the[ir] rights" and expand "the advocacy efforts available to [them] in residential facilities." S. Rep. No. 99-109, at 3.

Congress made those findings after an extensive investigation showed widespread abuse and neglect of people with mental illness. During days of hearings, Congress heard extensive testimony about the pervasive and systemic abuse and neglect of individuals living in mental health facilities. For instance, witnesses discussed a psychiatric hospital in New Jersey where a resident reported that "she had been raped by six or seven inmates from a local prison who were working in the hospital cafeteria. The hospital police were notified the day of the incident, but they did not see to it that the young woman was medically examined." Senate Hearings at 79.

In another case, a mother described the abuse and neglect suffered by her schizophrenic son in a New Mexico state hospital. The son was often attacked by other residents and, in his effort to escape the abuse, attempted to run away from the hospital 30 times in nine months. *See id.* at 411-13. "[H]is sister later told us [he] had tried to fall, to do away with himself, since life had become unbearable." *Id.* at 413. He succeeded in running away six times, occasionally in cold weather, with few clothes. The hospital responded to these instances of escape by placing him in restraint and

seclusion. *See id.* Residents of another treatment center were allowed to run away because the staff fell asleep while on duty. *See id.* at 454.

In conjunction with these hearings, Senate staff conducted a ninemonth investigation of state-run institutions for people with mental illness and developmental disabilities and issued a 246-page report detailing the findings of that investigation and discussing the often daunting problems and challenges faced by individuals with mental illness and developmental disabilities living in these institutions. See Weicker Report. The Senate staff investigation consisted of visits to 31 facilities in 12 states – and the examination of documents and taking of interviews of individuals from several other states – exploring the conditions and the physical health and safety of the residents of state mental hospitals. See id. at 7. The Senate investigation found that, especially in psychiatric hospitals, "where some of society's most severely disabled patients live in a volatile daily mix with some of the health-care profession's most undertrained staff," the conditions were "intolerable." Id. at 2.

Indeed, *all* of the institutions providing information to the Senate staff investigation reported incidents of physical abuse of residents. *See id.* at 39. In one instance, a staff member at a psychiatric hospital in New Jersey beat a patient. During the ensuing investigation, it emerged that, despite the fact

that the staff member had admitted the abuse, which appears to have been routine at this facility, he had been cleared of any wrongdoing by both the facility and local police. *See id.* at 100-02.

An advocate at another institution for people with developmental disabilities told a Senate staff member that she had observed an employee snatch a resident by the hair, fling him on a chair, and jump onto the resident to hold him. *See id.* at 42. Earlier on the same day, the advocate had observed another employee shove the same resident "across the room into the steel springs of a bed frame." *Id.* 

Among other things, the Weicker Report documented the extensive use of seclusion and restraint as a means to control the behavior of residents. "In one facility, [a] Senate staff member observed an adolescent in four point restraint lying on his back in a bed in the middle of a crowded unit hallway." *Id.* at 72-73. And the report told the story of a "patient [who] died while in a coma after being placed in seclusion." *Id.* at 21. This resident's autopsy concluded that the resident died of strangulation, under circumstances that indicated that "excessive force had been used in restraining the patient." *Id.* at 21-22 (internal quotation marks omitted).

The Weicker Report likewise documented in great detail the grossly inadequate living conditions found in many facilities. *See*, *e.g.*, *id.* at 2-3.

Residents themselves were often observed to be filthy, smelling of urine and cigarettes, wearing soiled and torn institutional clothing, and sleeping on bathroom floors. *See id.* at 3-4. "One Senate staff member was told that when the units at a Connecticut facility were sprayed for roach control, the residents who were lying on the floor were also sprayed." *Id.* at 61. "When asked, facility administrators and state officials say living conditions are in the process of being corrected. Ward staff, however, take a cynical view of these 'plans.' In several cases, ward staff said newspaper and television news accounts of these living conditions result in improvements, albeit temporary." *Id.* at 12.

Finally, the investigation documented that residents often received little in the way of treatment in these facilities beyond medication. *See id.* at 66. Leaving aside the extensive problems observed in the prescribing and administration of medicine to these individuals, the report noted that, "[p]articularly in psychiatric institutions, control appears to be the treatment goal, and medication the chief method of achieving control." *Id.* at 68; *see id.* at 69-70.

The Weicker Report further found that state systems for monitoring the conditions of these facilities vary widely. *See id.* at 4. Internal advocates were often unable to investigate complaints adequately and,

frequently, there was no disciplinary action taken against people who were found to be abusive to residents. *See id.* at 76-79. There was no stable funding for advocacy efforts. Moreover, the "limited authority of advocates to investigate certain complaints under state definitions of abuse and neglect" severely hampered the ability of the advocacy systems currently in place to protect individuals with mental illness. S. Rep. No. 99-109, at 2-3. By contrast, under PAIMI, state P&As have the power to access institutions and records and to conduct full investigations in a way that an individual advocate cannot.

The Weicker Report also found that the voluntary review to which many of these facilities submitted consisted of little more than predictable reviews and paperwork. Federal reviews conducted by the Health Care Financing Administration of facilities participating in the Medicare and Medicaid programs also contained many weaknesses: audits were infrequent, and there were no federally mandated deadlines for correcting any deficiencies that were found. *See id.* at 4-5. Most states did not (and still do not) have independent agencies to investigate allegations of abuse and neglect. This problem is compounded by the fact that it is often a state agency accused of wrongdoing that is then charged with investigating the allegations against itself.

In response to the Senate staff investigation and the testimony given at the hearings, Congress identified a need for an advocacy system, *independent* of service providers and state agencies, with authority to obtain access to records, facilities, residents, and staff of mental health facilities under appropriate circumstances.

Congress thus enacted PAIMI "to assist States to establish and operate a protection and advocacy system for individuals with mental illness." 42 U.S.C. § 10801(b)(2). Congress intended for the P&As to "protect and advocate the rights of such individuals through activities to ensure the enforcement of the Constitution and Federal and State statutes" and to "investigate incidents of abuse and neglect of individuals with mental illness if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred." *Id.* § 10801(b)(2)(A), (B).

In sum, Congress found that the protection of these vulnerable individuals through a P&A system with adequate powers to root out and deter abuse and neglect serves a highly significant public interest, a fact that is directly relevant to any Fourth Amendment analysis. *See, e.g., Donovan,* 452 U.S. at 601-02; *United States v. Jamieson-McKames Pharms., Inc.,* 651 F.2d 532, 537 (8th Cir. 1981) (holding that significant public-health interests

were served by regulation of the drug-manufacturing industry by means of warrantless administrative searches).

## II. The Access Authority Provided By PAIMI Has Enabled The P&As To Conduct Effective Investigations And Prevent Or Remedy Abuse And Neglect In Institutional Settings

The access authority that Congress granted to P&As has worked much in the way the legislature intended. In case after case, the P&As have served the public interest by using their access authority responsibly to investigate incidents of abuse and neglect and to advocate for people with mental illness. As the examples that follow demonstrate, the P&As' use of this authority has led directly to improvements in the lives of many individuals with disabilities.

Indeed, a P&A's investigation into an incident involving one individual has resulted in improvement in the quality of life for all residents of a facility. For instance, the Virginia P&A in 2004 conducted an investigation into a death at a state hospital. The investigation revealed numerous instances of abuse and neglect, including the improper administration of psychotropic medication, improper monitoring of the individual while in seclusion, and problems of staffing. *See* Virginia Office for Protection and Advocacy, *PAIMI Program Annual Program Performance Report* at 22 (Dec. 29, 2004), *at* http://www.vopa.state.va.us/ Reports/2004% 20Reports/FY% 2004% 20% 20PAIMI% 20Final.pdf. As a result of the formal complaint filed by the P&A, the hospital made substantial changes in policy and procedures and implemented a schedule for staff training. *See id*. The P&A is monitoring the hospital's compliance with the training program, a program that will affect approximately 400 residents. *See id*.

In another case, the Iowa P&A investigated the case of a young boy who was suffocated while staff restrained him. The P&A attempted to access the boy's records and interview other juveniles at the facility. The facility resisted, and the P&A filed suit and moved for a preliminary injunction. The district court granted the injunction and permitted the P&A access to patients and records pursuant to the PAIMI Act. *See Iowa Prot.* & *Advocacy Servs., Inc. v. Gerard Treatment Programs, L.L.C.*, 152 F. Supp. 2d 1150 (N.D. Iowa 2001).

Similarly, a district court in New Mexico ruled that the New Mexico P&A was entitled to an injunction to permit it access to patients and records after a facility reacted to a negative report on its practices by making access by the P&A to patients and records extremely difficult. *See Robbins v. Budke*, 739 F. Supp. 1479 (D.N.M. 1990). In granting that relief, the court specifically emphasized the importance of the P&A's ongoing oversight of troubled institutions. *See id.* at 1487 ("P&A has a legitimate reason to see patients at [Las Vegas Medical Center] by virtue of the Act . . . [and] should be accessible on a regular basis to those patients who desire information about their rights"); *see also Mississippi Prot.* & *Advocacy Sys., Inc. v. Cotten*, No. J87-0503(L), 1989 WL 224953 (S.D. Miss. Aug. 7, 1989) (ordering a facility to allow P&A to visit and speak to residents after investigations into a five-day lockdown of a resident without a mattress or toilet and the death of another resident who was being restrained), *aff d*, 929 F.2d 1054 (5th Cir. 1991). In each of these cases, court-ordered access proved essential to the P&A's investigations of alleged abuse of persons with mental illness, which, in turn, fostered reform of abusive practices.

In other cases, a P&A's investigation of abuse and neglect has resulted in the passage of legislation that will benefit thousands of individuals with mental illness across a state. In 2003, the California P&A sponsored legislation designed to help reduce improper restraint and seclusion. *See* NAPAS 2004 Annual Report at 9. This legislation was enacted after several years during which the P&A published reports about injuries and deaths resulting from unregulated restraint and seclusion. *See*, *e.g.*, Protection and Advocacy, Inc., Investigations Unit, *The Lethal Hazard of Prone Restraint: Positional Asphysiation* (Apr. 2002), *available at* 

http://www.pai-ca.org/pubs/701801.pdf. The statute requires comprehensive training for staff in order to avoid the use of restraint and seclusion, "implementation of safeguards to protect patients in restraint from injury or death[,] and publication of data about a facility's use of restraint and seclusion." NAPAS 2004 Annual Report at 9; *see also* Protection & Advocacy, Inc., Newsletter Issue No. 87, at 17 (Spring 2004), *available at* http://www.pai-ca.org/NEWSLTRS/Issue87/ISSUE87.pdf.

Moreover, the specific form of access at issue here – the ability to speak to the victims of or witnesses to abuse and neglect without the presence of institutional staff – has often led to significant improvements in the lives and well-being of individuals with mental illness. The Weicker Report itself indicated the problems associated with having the employees of these facilities present at resident interviews: "Hospital staff say patients can and do ask the staff to contact the patient representative for them. Patients, however, told Senate staff that it was awkward, intimidating and rare for a patient to ask hospital staff to contact a patient representative so that he or she may file a complaint." Weicker Report at 78.<sup>5</sup>

<sup>&</sup>lt;sup>5</sup> The Weicker Report also described the resident complaint systems of several states, including the California system in which residents in some facilities had to telephone a representative from a pay phone on the residents' unit. Because of the limitation on the number of calls permitted to

Experience since PAIMI's enactment has proven that to be true. For example, the Illinois P&A recently called for the closure of a developmental center housing 200 people with disabilities. See Equip for Equality, Press Release, Equip for Equality Calls for the Closure of the Choate Developmental Center (Feb. 25, 2005), available at http://www.equip forequality.org/news/pressreleases/february\_25\_2005equip\_for\_equa.php. The P&A drafted a report documenting incidents of abuse and neglect ranging from the excessive use of restraint and seclusion to sexual abuse to a failure to provide adequate healthcare. In its report, the P&A stated that "[d]iscussions with residents revealed a culture of fear in which residents are afraid to exercise rights or express their needs for fear of retaliation or being 'tied up.'" Equip for Equality, Special Report, *Clyde Choate Developmental Center:* How An Archaic System Results in Tragic Consequences for People with Disabilities at 5 (2005), available at http://www.equipforequality. org/publications/aiu\_choate.pdf.

The residents' fears had a sound basis in reality. In 2002, staff at the center found a resident with bruises all over his body. Three days later, the center staff interviewed residents and staff regarding the incident and

each unit, residents on average were permitted less than two phone calls total per month. *See* Weicker Report at 77-78.

learned from three residents that "a staff person hit [the resident] repeatedly with a pole and metal part of a dust mop." *Id.* at 24.

Last year, the staff of Advocacy Inc., the Texas P&A, requested access to a juvenile justice facility that had been the subject of numerous complaints made by former employees regarding mistreatment of juveniles with mental disabilities. *See* Glenda Taylor, *Complaints at Juvenile Facility Investigated*, Kerrville Daily Times, Nov. 20, 2003 ("Taylor, *Complaints at Juvenile Facility*"); Glenda Taylor, *Behind Closed Doors*, Kerrville Daily Times, Jan. 14, 2004 ("Taylor, *Behind Closed Doors*"). Citing the confidentiality of the juveniles and concern about the role of Advocacy Inc., the facility repeatedly blocked the P&A's access to the facility, despite ongoing investigations of the facility by the state. *See* Taylor, *Complaints at Juvenile Facility*; Taylor, *Behind Closed Doors*.

Advocacy Inc. gained access to the facility in January 2004 and opened an investigation that included interviewing witnesses and potential victims within the facility. *See* Zeke MacCormack, *Advocates Gain Access to Lockup: Kerr County Juvenile Facility Will Let Them Investigate Complaints*, San Antonio Express, Jan. 19, 2004. Both the state's and Advocacy Inc.'s investigations continued throughout the spring. The alleged violations at the facility included claims of medical neglect and improper restraint. In one case, a former employee claimed that two girls had boils under their arms, which were not treated. In response to a complaint, the "supervisor said the boils were from the deodorant, and then said that this wasn't the Hilton and the girls needed to get over it." Taylor, *Behind Closed Doors* (internal quotation marks omitted).<sup>6</sup> Ultimately, the executive director of the facility, who had initially opposed Advocacy Inc.'s access, resigned and the Texas Juvenile Probation Commission publicly released findings that the facility had violated state rules. *See* Glenda Taylor, *Detention Center Violates State Rules*, Kerrville Daily Times, May 7, 2004.

The Virginia P&A launched an investigation in response to a complaint from a man that his mental health care provider improperly denied him medication and proper medical care. *See* NAPAS 2004 Annual Report at 8. In addition to the review of records and expert reports, the investigation included interviews with dozens of witnesses, including the doctors whom the man complained had misdiagnosed him. *See id.* at 8-9.<sup>7</sup>

<sup>&</sup>lt;sup>6</sup> Another former employee reportedly observed a boy being "restrained with a belly chain around his waist. A piece of chain that hung down was brought through his crotch area between his legs, and connected in the back. The restraint procedure caused bruising between his legs. It was called a nut restraint." Glenda Taylor, *Witnesses Detail Alleged Abuse*, Kerrville Daily Times, Jan. 15, 2004 (internal quotation marks omitted).

<sup>&</sup>lt;sup>7</sup> The Virginia P&A's report of the investigation can be found on its website. *See* Virginia Office for Protection and Advocacy, *Investigation Report: An Investigation Into the Neglect of SH*, Case No. 02-0354 (Sept. 12, 2003),

The P&A shared its findings with the mental health provider, which sued the P&A in an attempt to keep the findings from being made public. *See id.* at 9.

After successfully contesting the suit, which the mental health provider dismissed on its own, the Virginia P&A published the report. As a result of the P&A's efforts, the service provider "has made changes in the way it treats its clients and the way it supervises its doctors." Virginia Office for Protection and Advocacy, *PAIMI Program Annual Program Performance Report* at 4 (Dec. 30, 2003), *at* http://www.vopa.state.va.us/ Reports/2003%20Reports/PAIMI%20Final%20%20FY%2003.pdf.

In sum, an important element of many successful investigations are the interviews conducted by these agencies. In order to ensure that the information provided to the investigators is accurate and credible, it is vital that investigators be able to talk to victims and witnesses in an environment in which they feel comfortable and are free to speak openly.

*available at* http://www.vopa.state.va.us/Investigations/Neglect %20of%20SH.pdf.

## III. The Facts Of This Case Provided An Ample Basis For The Iowa P&A To Exercise Its Congressionally Mandated Powers To Ensure The Safety And Well-Being Of Individuals With Mental Illness

The facts of this case fully demonstrate the significant public interest served by the access authority provided by PAIMI. The Iowa P&A undertook its investigation in order to protect an extremely vulnerable population – children with mental illness – from the potential for significant threats to their health and safety.

In particular, information that a resident has run away is significant because it is often an indication of mistreatment or neglect at a facility. As Congress heard during the PAIMI hearings, the boy who repeatedly ran away from his New Mexico state hospital in Las Vegas, Nevada, did so because he had been severely abused. *See* Senate Hearings at 413. Running away in that case was indicative of a larger problem that a P&A would have uncovered had it investigated the circumstances surrounding the young man's attempts to run away.

Likewise, in Illinois, as part of an ongoing, comprehensive investigation of a state-run developmental disabilities institution, the P&A reported a November 2000 incident in which a resident was able to wander away due to a "series of errors by multiple staff and the lack of facility procedures to address the availability of keys, securing of doors, use of

alarms, supervision of residents, and staff accountability." Equip for Equality, Abuse Investigation Unit, *Report: Lincoln Developmental Center* – *The Politics of Closing a State Institution: Vulnerable People Fall Victim to Special Interests* at 4, *available at* http://www.equipforequality.org/ publications/aiu\_lincoln.pdf.

Although the resident was returned to the home unharmed the next day, the resident's ability to run away was indicative of the systemic failures found in the home and described throughout the report. *See id.* The P&A called for the facility's closure as a result of its investigation, leading the Governor of Illinois to downsize the facility and invest substantial funds in order to build new structures at the facility. *See* Equip for Equality, Press Release, *Equip for Equality Response to Governor Ryan's Press Release* (*February 4, 2002*) on Lincoln Developmental Center (Feb. 4, 2002), available at http://www.equipforequality.org/news/pressreleases/feb\_ 4\_02equip\_for\_equality\_res.php.

But there is also a substantial risk of harm faced by individuals with mental illness who run away from treatment facilities once they leave. These individuals typically find themselves on the street without any access to needed services and without the stability gained through appropriate discharge planning. Thus, allowing these residents to run away from a

facility is often an incident of neglect itself. Indeed, in a 2004 report documenting the unlawful conditions at Metropolitan State Hospital in Norwalk, California, the United States Department of Justice ("DOJ") listed incidents of "elopement" or "attempted elopement" among the "harmful incidents" to which residents were frequently exposed. See Letter from R. Alexander Acosta, Ass't Attorney General, Civil Rights Division, U.S. Dep't of Justice, to Gov. Arnold Schwarzenegger, State of California, Re: Metropolitan State Hospital, Norwalk, California, at 37 (Feb. 19, 2004), available at http://www.usdoj.gov/crt/split/documents/metro\_hosp\_find let.pdf. The DOJ discussed elopement along with several other "risk factors" – including suicidal and homicidal tendencies – from which it determined that the hospital failed to protect its residents. Id. at 6-7, 36-37. The DOJ stated, in response to these findings, that, "[i]n general, Metropolitan lacks an adequate procedure to identify or track patterns of high-risk behavior or to establish thresholds to ensure early and timely intervention to reduce ongoing risk." Id.

The DOJ was well aware that running away poses a substantial risk of harm to residents with mental illness and noted that risk as part of its assessment of the failures of this hospital in caring for these individuals. If a P&A learns that a resident has run away from a treatment facility, then, like

the DOJ, the P&A is immediately aware that an incident has occurred from which the resident faces a risk of harm and from which the facility potentially failed to protect the resident.

Those conclusions are confirmed by the expert report prepared by Clarence J. Sundram and recently provided to appellants in the district court proceedings. Mr. Sundram is a former Chairman and CEO of the New York State Commission on Quality of Care of the Mentally Disabled, has testified before congressional committees on the problems of patient abuse in institutions, and has served as an expert consultant for the DOJ. His report found that the report of a runaway child from Tanager, itself, "was ample, in light of the P&A's knowledge and experience, to provide 'probable cause' within the meaning of the law to authorize an investigation to determine whether abuse or neglect had in fact occurred in this case." Expert Report of Clarence J. Sundram at 8 (Mar. 2005). As Mr. Sundram explained, the report of the runaway, and his likely death as a result of leaving the facility, raised the obvious question as to how a child in "an extremely structured therapeutic environment" could have been endangered in this manner, and required thorough investigation. Id.

In sum, based on the accumulated experience of agencies charged with the responsibility of protecting a vulnerable population, the knowledge

that a resident with mental illness has run away from a treatment facility and died is indicative, and in some cases is an example, of the abuse and neglect from which Congress sought to protect these individuals when it passed PAIMI. Such information frequently sets off a P&A's investigation. Many incidents resulting in serious harm to individuals with mental illness could pass unreported and unremedied if P&As were unable to investigate facilities based on situations known to be potentially hazardous or the result of abuse and neglect.

### CONCLUSION

Because individuals with mental illness continue to be abused and neglected by the people who are entrusted with their care, PAIMI remains a vital tool for protecting the rights of these citizens. Without the access authority provided by PAIMI, the P&As would simply be unable to gather enough information adequately and effectively to document the abuse and neglect that individuals with mental illness suffer daily. For all of the reasons set forth above, amici urge this Court to affirm the decision of the district court.

Respectfully submitted,

Joan A. Magagna Deputy Executive Director for Legal Services National Association of Protection & Advocacy Systems, Inc. 900 Second Street, N.E., Suite 211 Washington, D.C. 20002 Tel: (202) 408-9514, Ext. 114 TTY: (202) 408-9521 Fax: (202) 408-9520

Counsel for Amicus National Association of Protection & Advocacy Systems, Inc.

Date: May 18, 2005

Sean A. Lev
Mary Ann McGrail
Kellogg, Huber, Hansen, Todd, Evans & Figel, P.L.L.C.
1615 M Street, N.W., Suite 400
Washington, D.C. 20036
Tel: (202) 326-7900
Fax: (202) 326-7999

Counsel for Amici National Association of Protection & Advocacy Systems, Inc., the American Association on Mental Retardation, The ARC of the United States, the Federation of Families for Children's Mental Health, the National Alliance for the Mentally Ill, the National Association of Councils on Developmental Disabilities, and the National Mental Health Association

### **CERTIFICATE OF COMPLIANCE**

Pursuant to Federal Rule of Appellate Procedure 32(a)(7)(C), the undersigned certifies that this brief complies with the applicable typevolume limitations of Federal Rule of Appellate Procedure 32(a). This brief was prepared using a proportionally spaced type (Times New Roman, 14 point). Exclusive of the portions exempted by Federal Rule of Appellate Procedure 32(a)(7)(B)(iii), this brief contains 5,750 words. This certificate was prepared in reliance on the word-count function of the word-processing system (Microsoft Word 2000) used to prepare this brief.

I also certify that the CD-ROM containing the full text of the foregoing brief has been scanned for viruses and, to the best of our ability and technology, is virus-free.

Sean A. Lev

### **CERTIFICATE OF SERVICE**

I hereby certify that, on May 17, 2005, I served the foregoing **Brief** of the National Association of Protection and Advocacy Systems, Inc., the American Association on Mental Retardation, The Arc of the United States, the Federation of Families for Children's Mental Health, the National Alliance for the Mentally III, the National Association of Councils on Developmental Disabilities, and the National Mental Health Association As Amici Curiae in Support of Plaintiff-Appellee Urging Affirmance upon counsel listed below by overnight mail to:

Sharon K. Malheiro Heather Lee Palmer Davis Brown 666 Walnut Street, Suite 2500 Des Moines, Iowa 50309 (515) 288-2500 Sharon.Malheiro@lawiowa.com

Vernon P. Suires Melissa Weets Anderson Bradley & Riley 2007 First Avenue, S.E. Cedar Rapids, Iowa 52406-2804 (319) 363-0101 vsquires@bradleyriley.com Samuel R. Bagensos Washington University School of Law One Brookings Drive St. Louis, Missouri 63130 (314) 935-9097 srbagenstos@wulaw.wustl.edu

Peter D. Keisler Charles W. Larson, Sr. Mark Stern Alisa B. Klein Attorneys, Appellate Staff Civil Division, Room 7235 U.S. Department of Justice 950 Pennsylvania Avenue, N.W. Washington, D.C. 20530-0001 (202) 514-5089 Ira A. Burnim Judge David A. Bazelon Center for Mental Health Law 1101 15th Street, N.W. Washington, D.C. 20005 (202) 467-5730

Alex M. Azar II Constance L. Foster James Murphy Stephanie Davis U.S. Department of Health & Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201 (202) 619-0257 Robert R. Gasaway Ashley C. Parrish Kirkland & Ellis 655 15th Street, N.W., Suite 1200 Washington, D.C. 20005 (202) 879-5000 rgasaway@kirkland.com aparrish@kirkland.com

2