United States General Accounting Office

GAO

Report to the Chairman, Subcommittee on Oversight and Investigations, Committee on Energy and Commerce, House of Representatives

September 2003

PROTECTION AND ADVOCACY AGENCIES

Involvement in Deinstitutionalization Lawsuits on Behalf of Individuals with Developmental Disabilities

GAO-03-1044

September 2003

PROTECTION AND ADVOCACY AGENCIES

Involvement in Deinstitutionalization Lawsuits on Behalf of Individuals with Development Disabilities

GAO Highlights

Accountability • Integrity • Reliability

Highlights of GAO-03-1044, a report to the Chairman, Subcommittee on Oversight and Investigations, Committee on Energy and Commerce, House of Representatives

Why GAO Did This Study

Congress established the Protection and Advocacy system in 1975 to protect the rights of individuals with developmental disabilities, most of whom have mental retardation. Protection and Advocacy agencies (P&A) use investigative and legal activities to advocate on behalf of these individuals. Deinstitutionalization has refocused delivery of care to this population over the last several decades from large public institutions to community settings. Refocusing service delivery resulted from (1) the desire to deliver care in the most integrated setting and to control costs and (2) the outcomes of deinstitutionalization lawsuits brought by P&As and others. Some parents have raised concerns that P&As emphasize these suits over other activities, inadequately inform them of family members' inclusion in the suits, and do not adequately monitor individuals after their transfer to the community. GAO was asked to review the extent to which P&As engage in lawsuits related to deinstitutionalization of these individuals, how P&As communicate with affected parents and guardians in these suits, and the role P&As have played in monitoring the well-being of individuals transferred to the community. GAO compiled a national list of lawsuits related to deinstitutionalization involving P&As and reviewed the suits and related activities in three states—California, Maryland, and Pennsylvania.

www.gao.gov/cgi-bin/getrpt?GAO-03-1044.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Kathryn G. Allen at (202) 512-7118.

What GAO Found

Lawsuits related to deinstitutionalization brought on behalf of persons with developmental disabilities are a small part of P&As' overall activities for this population. GAO identified 24 such lawsuits that P&As filed, joined, or intervened in from 1975 through 2002. During the same period, P&As filed or intervened in 6 of these lawsuits in the three states GAO reviewed—California, Maryland, and Pennsylvania. Three of the 6 were settled as class actions; the other 3 were intended, but not settled, as class actions. One is ongoing, one was dismissed, and one was settled by multiparty agreement.

P&As' communications with parents and guardians regarding the lawsuits in the three states were consistent with federal rules. For the three suits settled as class actions, P&As complied with the requirement to provide notice to all class members when a settlement agreement is proposed to the court. Such notice was not required in the other three cases, which were not class actions. Representatives of some parent groups told GAO that parents and guardians were dissatisfied with the extent of P&A communication with them before a settlement was proposed, citing problems such as not receiving notice of a family member's inclusion in the class, which the parent or guardian opposed. P&As in the three states told GAO they did not communicate with every person potentially affected by the six lawsuits before a proposed settlement agreement, although they did communicate with organizations representing some parents and guardians during that time. However, even if P&As had made such notification, under the applicable federal rule of civil procedure, an individual has no explicit right to opt out of the class in this type of case.

P&As in the three states assumed various roles in monitoring the health and well-being of individuals transferred to community settings in four of the five resolved lawsuits we reviewed, although state developmental disabilities services agencies have the primary responsibility for ensuring the quality of services provided to these individuals. P&As' roles varied with the circumstances of the lawsuits and the initiatives P&As in the three states undertook using their authority to protect and advocate the rights of individuals with developmental disabilities. For example, although the three class action settlement agreements did not specify monitoring roles, the P&As assumed roles, such as reviewing information about the quality of community services that the settlement agreements required the states to develop and reviewing care plans of individuals who had been transferred. Representatives of some parent groups told GAO that parents and guardians have been dissatisfied with the adequacy of the P&As' monitoring role in community placements, while representatives of other parent groups said they generally supported the P&A monitoring role.

The Administration for Children and Families said GAO's analysis of the three P&As' involvement in deinstitutionalization lawsuits is thorough and the P&As GAO reviewed said that the report is accurate.

Contents

Tables

Abbreviations

ACF	Administration for Children and Families
ADD	Administration on Developmental Disabilities
CMS	Centers for Medicare & Medicaid Services
DD Act	Developmental Disabilities Assistance and Bill of Rights Act of 2000
FRCP	Federal Rules of Civil Procedure
HCBS	home and community-based services
IPP	Individual Program Plan
HHS	Department of Health and Human Services
ICF/MR	intermediate care facility for the mentally retarded
OIG	Office of Inspector General
NAPAS	National Association of Protection & Advocacy Systems, Inc.
P&A	Protection and Advocacy agency
VOR	Voice of the Retarded

GAO
Accountability * Integrity * Reliability

United States General Accounting Office
Washington, DC 20548

September 30, 2003

The Honorable James C. Greenwood
Chairman, Subcommittee on Oversight
and Investigations
Committee on Energy and Commerce
House of Representatives

Dear Mr. Chairman:

Congress established the Protection and Advocacy system in the states and territories in 1975 to protect and advocate the rights of individuals with developmental disabilities, most of whom have mental retardation.[1] In fiscal year 2002, the 57 Protection and Advocacy agencies (P&A) received $35 million in federal funding for this purpose.[2] To advocate on behalf of individuals with developmental disabilities, P&As undertake a range of administrative, information and referral, investigative, and legal activities. These activities can include representing individuals with developmental disabilities in lawsuits. Some of these lawsuits have resulted in moving individuals with developmental disabilities from institutional care settings to care settings in the community such as group homes and apartments, a process that is referred to as deinstitutionalization. Some parents and legal guardians of individuals involved in these suits have supported P&A efforts in bringing these suits and implementing the settlements that have resulted. Other parents and guardians of individuals affected by these suits, however, have organized to oppose the suits and the implementation

[1]The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), Pub. L. No. 106-402, 114 Stat.1677. Predecessor acts include the Developmental Disabilities Assistance and Bill of Rights Act, Pub. L. No. 97-35, title IX, subtitle B, 95 Stat. 563 (1981) and the Developmentally Disabled Assistance and Bill of Rights Act, Pub. L. No. 94-103, 89 Stat. 486 (1975). Developmental disabilities include mental retardation, autism, and cerebral palsy. Individuals with developmental disabilities generally require lifelong residential support. For a more detailed explanation of developmental disabilities, *see* the DD Act, § 102(8), 114 Stat. 1683 (classified to 42 U.S.C. § 15002 (8)), and 45 C.F.R. § 1385.3 (2002).

[2]The Administration on Developmental Disabilities in the Department of Health and Human Services provides funding under the DD Act to P&As in the 50 states, the District of Columbia, territories, and the Native American consortium located in Shiprock, New Mexico.

of certain aspects of court-approved settlements because of concerns they have regarding the care of their family members.[3]

Deinstitutionalization of individuals with developmental disabilities has changed the way that services are provided for this population over the last several decades as states have moved their focus of care from large, public institutions to settings in the community. These large facilities are usually intermediate care facilities for the mentally retarded (ICF/MR) certified to participate in Medicaid. From 1980 through 2002, the average daily number of people with developmental disabilities living in large institutions declined from about 131,000 to about 44,000 as states downsized or closed such institutions.[4] This change occurred for several reasons, including a greater emphasis on providing services in the most integrated setting, states' desires to control costs, and the outcomes of certain lawsuits. As a result, individuals in large facilities today are mostly adults who have lived in institutions for many years because fewer individuals are being admitted to such facilities and instead are receiving their care in community settings. Care in large, public institutions for individuals with developmental disabilities is no longer provided in eight states and the District of Columbia, and the number of individuals receiving institutional care has declined in most other states.[5] Many of the former residents of institutions now receive care in group homes or other community settings as do many other individuals who were never residents of institutions. Altogether, more than 420,000 individuals with developmental disabilities were receiving care in community settings as of June 30, 2002.[6] The largest source of public funding for these institutional and community services is Medicaid, the federal-state program that

[3]Except as noted, we use the phrase "parents and guardians" to refer to parents, other family members, and legal guardians acting on behalf of their adult children or dependents in institutions. Family members may also be legal guardians. In some instances, legal guardians may not be family members.

[4]See Kathryn Coucouvanis et al., "Current Populations and Longitudinal Trends of State Residential Settings (1950-2002)," in R.W. Prouty, Gary Smith, and K.C. Lakin, eds., *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2002* (Minneapolis, Minn.: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, 2003), 7.

[5]As of June 30, 2002, Alaska, the District of Columbia, Hawaii, Maine, New Hampshire, New Mexico, Rhode Island, Vermont, and West Virginia no longer operated large institutions for persons with developmental disabilities.

[6]See K. Charlie Lakin et al., "Utilization of and Expenditures for Medicaid Institutional and Home and Community Based Services," in *Residential Services for Persons with Developmental Disabilities*, 104.

finances health care coverage for certain low-income and disabled populations. State developmental disabilities services agencies administer most of the services provided to this population and have primary responsibility for monitoring these services in institutions and in community settings.

In advocating on behalf of individuals with developmental disabilities in institutions, P&As and others[7] have filed, joined, or intervened in lawsuits relating to deinstitutionalization. Some of these lawsuits have been class action lawsuits on behalf of classes of individuals. Deinstitutionalization lawsuits brought against large, public institutions have alleged inappropriate care and treatment, including abuse and neglect of residents, and breaches of statutory and constitutional rights. Some of these suits have lasted for years, and the courts' decisions have sometimes taken additional years to implement after the cases have been decided. Some parents opposing these P&A efforts have expressed concerns that P&As emphasize deinstitutionalization lawsuits over other activities; that P&As do not adequately communicate with parents and guardians of individuals potentially affected by these lawsuits, such as notifying them of the inclusion of their family members in the suits; and that P&As do not assume adequate monitoring roles for the health and well-being of individuals moved from institutions to community settings in such suits.

Because of these concerns, you asked us to review certain P&A activities. We examined (1) the extent to which P&As engage in litigation related to deinstitutionalization on behalf of individuals with developmental disabilities, (2) how P&As have communicated with parents and legal guardians in deinstitutionalization lawsuits, and (3) the role, if any, that P&As have played in monitoring the health and well-being of individuals transferred from institutions to community settings within the context of these lawsuits.

To examine the extent to which P&As engage in litigation related to deinstitutionalization on behalf of individuals with developmental disabilities, we analyzed several data sources and consulted with national and state organizations because there is no single, national source of information on P&A litigation activities. We contacted the Administration

[7]Litigation focusing on the legal rights of institutionalized persons with developmental disabilities also has been filed by attorneys working for public legal assistance programs, such as public interest law centers and legal aid societies, as well as by private attorneys and the Department of Justice.

on Developmental Disabilities (ADD), within the Administration for Children and Families (ACF), Department of Health and Human Services (HHS), which administers the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act); the National Association of Protection & Advocacy Systems, Inc. (NAPAS), which represents P&As; the National Association of State Directors of Developmental Disabilities Services, which represents state developmental disabilities services agencies; and representatives of family advocacy organizations including Voice of the Retarded (VOR) and the Arc of the United States.[8] From these sources, we compiled a national list of lawsuits related to deinstitutionalization that P&As filed, joined, or intervened in on behalf of individuals with developmental disabilities from 1975 through 2002. To examine P&A activities more closely, we chose three states—California, Maryland, and Pennsylvania—that national organizations we consulted indicated are among the states with P&As that are more active in deinstitutionalization litigation. We examined all six lawsuits regarding deinstitutionalization in these three states that were in the national list of lawsuits we developed. To obtain information on P&A communication with parents and guardians in these three states, we interviewed P&A officials, representatives of state developmental disabilities services agencies, and representatives of parent groups. In addition, we reviewed federal and relevant state rules of civil procedure[9] concerning notification of class members in class action lawsuits. To obtain information on P&A roles in monitoring the health and well-being of individuals in the community, we interviewed P&A officials, analyzed settlement agreements and other documents related to the six lawsuits, and interviewed representatives of state developmental disabilities services agencies and parent groups. We did not independently verify the extent of P&As' monitoring activities or assess their effectiveness. We did our work from October 2002 through September 2003 in accordance with generally accepted government auditing standards. (See app. I for more details on our scope and methodology.)

[8]Formerly known as the Association for Retarded Citizens, the organization changed its name to the Arc of the United States in 1992.

[9]These rules govern the conduct of civil actions in federal district or state courts.

Results in Brief

Lawsuits related to deinstitutionalization that are brought on behalf of individuals with developmental disabilities are a small part of P&As' activities for this population, both nationwide and for P&As in the three states reviewed. Nationwide, we identified 24 lawsuits that P&As filed, joined, or intervened in related to deinstitutionalization from 1975 through 2002. Most, but not all, were intended to be class actions against large public institutions providing services to persons with mental retardation and related developmental disabilities. From 1975 through 2002, P&As in the three states we reviewed—California, Maryland, and Pennsylvania—filed or intervened in six lawsuits related to deinstitutionalization. Three of the six were settled in 1993 or 1994 as class action lawsuits. Three were not settled as class action lawsuits. Litigation in one of these suits is ongoing, the second was dismissed in 1999 after the institution concerned was closed, and the third was settled in 2001. For some of the lawsuits we reviewed, implementation of court decisions regarding deinstitutionalization continued for years after settlement. P&As in the three states reported that they used litigation of all types, including litigation related to deinstitutionalization, in 1.5 percent of client problems they addressed from fiscal years 1999 through 2001. These P&As reported that they addressed the vast majority of client problems through negotiation, technical assistance, and other assistance rather than through litigation.

P&As in the three states communicated with parents and guardians as required by federal rules in the lawsuits we reviewed. In the three cases settled as class actions, P&As provided notice to all class members at the time settlement was proposed to the court, as required by federal rules. Two of these three lawsuits were certified in federal court and the third was certified in a state court that followed federal rules regarding notification of class members. Such notice was not required in the other three cases we reviewed that were not class action lawsuits. Representatives of some parent groups told us that they believed the P&As should have communicated with parents and guardians in the six lawsuits we examined before filing or intervening in the lawsuits, and prior to class certification by the court, even though P&As were not required to do so. P&As in the three states indicated that they did not try to communicate with all individuals potentially affected by the six lawsuits, including parents and guardians, during these stages of the lawsuits but that they did undertake some communication with organizations representing some parents and guardians of affected individuals during the lawsuits. However, even if P&As had made such notification to all potentially affected individuals, under the applicable federal rule of civil procedure,

an individual has no explicit right to opt out of the class in this type of case.

P&As in the three states assumed various roles in monitoring the health and well-being of individuals transferred from institutions to community settings in four of the five deinstitutionalization lawsuits we reviewed that have been resolved, although state developmental disabilities services agencies have the primary responsibility for monitoring the quality of services provided to individuals with developmental disabilities. P&As assumed these roles even though not required to do so in the settlement agreements resulting from the lawsuits. For example, in the three class action lawsuits we examined, the P&A role has been to monitor some or all class members involved in settlement agreements. This monitoring role included reviewing information that the settlement agreements required states to develop about the quality of community services provided, conducting site visits, and reviewing plans of care. In the fourth case we reviewed in which the P&A had a monitoring role, the P&A reported that it had a role to assist families that experienced problems in community placements. Representatives of some parent groups told us that parents and guardians have been dissatisfied with the adequacy of P&As' monitoring role in community placements, while representatives of other parent groups told us they generally supported the P&A monitoring role.

In commenting on a draft of this report, ACF said it was a thorough analysis of the three P&As' involvement in deinstitutionaliation lawsuits for the population examined. P&A officials in the three states that we reviewed said that the report is accurate and also provided technical comments.

Background

The Protection and Advocacy system was established in 1975 and was most recently reauthorized in 2000 for 7 years. P&A activities on behalf of individuals with developmental disabilities include legal representation; information and referral services; training and technical assistance in self-advocacy; short-term assistance, mediation and negotiation assistance to obtain benefits and services such as medical care and housing, transportation, and education; representation in administrative appeals; and investigation of reports of abuse and neglect, sexual harassment, inappropriate seclusion and restraint, and other problems. The 57 P&As include 46 that are private, nonprofit agencies; the other 11 are state

agencies. P&A staffing typically includes management, investigators, advocates, attorneys, and administrative staff.[10] The P&A in one state we reviewed also contracted with another organization to conduct lawsuits on its behalf.

ADD provides annual funding to P&As, the amount of which is determined by a formula that uses several measures, including state population weighted by relative per capita income in the state and a measure of the relative need for services by individuals with developmental disabilities. In fiscal year 2003, ADD funding for P&As was set at $36.3 million, a $1.3 million increase over fiscal year 2002. Funding amounts to states ranged from $345,429 to $2,978,192 for fiscal year 2003. For P&As in California, Maryland, and Pennsylvania, these amounts were $2,978,192, $468,934, and $1,388,495, respectively. P&As also may receive funding from other sources to serve individuals with developmental disabilities, including state and private funds. In addition, P&As often serve populations other than individuals with developmental disabilities and receive separate funding for that purpose.[11]

Although state developmental disabilities services agencies are primarily responsible for arranging for the provision of services and oversight of quality for services received by individuals with developmental disabilities, the DD Act authorizes P&As to play an important role in monitoring these services. The DD Act authorizes P&As to investigate allegations of abuse and neglect when reported or if there is probable cause to believe that incidents occurred and to pursue legal, administrative, and other appropriate remedies or approaches on behalf of individuals with developmental disabilities. The act grants P&As access to individuals with developmental disabilities and to their records, including reports prepared by agencies or staff on injuries or deaths. Under this authority, P&As typically undertake monitoring efforts to review the adequacy of services that individuals receive in institutions and in community settings and to

[10]According to a 2002 survey conducted by the HHS Office of the Inspector General (OIG), in which 49 of 57 P&As responded, the average P&A full-time-equivalent staff level was 31 employees in fiscal year 2001. P&A staffing size ranged from 6 employees at the smallest P&A to 179 employees at the largest. See *State Protection and Advocacy Programs for Persons with Developmental Disabilities*, OEI-07-02-0090 (Washington, D.C.: April 2003).

[11]Other populations served by P&As include individuals with mental illness, individuals with traumatic brain injury, individuals receiving Social Security benefits who wish to return to work, and individuals with any type of disability seeking access to assistive technology.

examine state oversight of quality assurance and regulatory compliance for residential services providers.

Many individuals with developmental disabilities for whom P&As advocate are eligible to receive publicly financed residential services through Medicaid, which is the largest source of funds for services for individuals with developmental disabilities. State developmental disabilities services agencies have primary responsibility for monitoring the quality of services provided to individuals with developmental disabilities, including those services funded by Medicaid. In 2002, Medicaid financed 77 percent ($26.8 billion) of the total $34.7 billion in total long-term care spending on individuals with developmental disabilities.[12] Medicaid spending was about $10.9 billion for ICF/MR residents including those living in large institutions;[13] about $12.9 billion for individuals with developmental disabilities receiving home and community-based services (HCBS) under Medicaid waivers; and an additional $2.9 billion for other services provided in community settings, such as personal care.[14]

Residential choices for individuals with developmental disabilities vary by state since states choose whether to offer these individuals services in ICF/MRs, which is an optional rather than a mandatory benefit in Medicaid, and whether to provide services in community settings through HCBS waivers. States may apply to the Centers for Medicare & Medicaid Services (CMS) for waivers under section 1915(c) of the Social Security Act to provide HCBS services as an alternative to institutional care in ICF/MRs and waive certain Medicaid requirements that would otherwise apply, such as statewideness, which requires that services be available throughout the state, and comparability, which requires that all services be available to all eligible individuals.[15] For both the ICF/MR and waiver

[12]See M.C. Rizzolo et al., University of Colorado Department of Psychiatry and Coleman Institute for Cognitive Disabilities, *The State of the States in Developmental Disabilities: 2003 Study Summary* (preliminary data) (Boulder, Colo.: University of Colorado, in press).

[13]ICF/MRs include both large institutions and smaller residential settings. Smaller ICF/MRs, in the form of community group homes, may have as few as four residents. Regardless of size, all ICF/MRs are required to follow similar rules regarding the provision of care and oversight of quality.

[14]These numbers do not add to the total of Medicaid long-term care spending on individuals with developmental disabilities cited above because of rounding.

[15]42 U.S.C. § 1396n(c)(2000).

programs, protecting the health and welfare of Medicaid-covered individuals receiving services is a shared federal-state responsibility. Under the ICF/MR optional benefit program, states annually inspect institutions to ensure that they meet federal quality standards. Under Medicaid waivers, states must include assurances to CMS that necessary safeguards are in place to protect beneficiaries.

In pursuing legal remedies on behalf of individuals with developmental disabilities, P&As have represented individuals as well as groups or classes of individuals in lawsuits. All such lawsuits are subject to rules of procedure that govern proceedings in the relevant court. Many of these cases take place in federal court, where the Federal Rules of Civil Procedure (FRCP) apply. FRCP Rule 23 establishes procedural requirements for class action lawsuits in federal district court, including the circumstances under which individuals must be notified of their inclusion in a class prior to class formation, referred to as certification by the court, and notified of proposed settlements of lawsuits on their behalf. The requirements vary depending upon whether the suit is for injunctive relief or monetary damages. Lawsuits for injunctive relief seek a court order requiring another party to do or refrain from doing a specified act. For suits seeking injunctive relief, the type of class action suit P&As generally bring, the rule does not require notification of individuals' inclusion in a class prior to class formation.[16] The rule does, however, require notification of class members at the time of proposed settlement. By contrast, for class action suits seeking monetary relief, the rule requires that individuals be notified of their inclusion in a class prior to its formation.

[16]A 2001 proposed revision to the FRCP Rule 23 that would have required notice to all potential class members in lawsuits for injunctive relief resulted in comments from many civil rights groups indicating that mandatory notice could impair many class actions. Memorandum to the Honorable Anthony J. Scirica, Chair, Standing Committee on Rules of Practice and Procedure, from Honorable David F. Levi, Chair, Advisory Committee on the Federal Rules of Civil Procedure, dated May 20, 2002, Re: Report of the Civil Rules Advisory Committee. The proposal was not adopted.

Lawsuits Related to Deinstitutionalization Are a Small Part of P&A Activities

Nationwide and for the three states reviewed, lawsuits related to deinstitutionalization on behalf of individuals with developmental disabilities constitute a small part of overall P&A activities. We identified 24 lawsuits nationwide that P&As filed, joined, or intervened in related to deinstitutionalization from 1975 through 2002. P&As filed or intervened in six of these suits in the three states we examined—California, Maryland, and Pennsylvania—during this same period. Three of the six suits were settled as class actions. The three other suits were intended but not settled as class action lawsuits. P&As in these three states reported that they used litigation of all types, including litigation related to deinstitutionalization, in 1.5 percent of client problems they addressed from fiscal years 1999 through 2001.

P&As Filed, Joined, or Intervened in Few Lawsuits Relating to Deinstitutionalization

National data sources indicate that, from 1975 through 2002, P&As filed, joined, or intervened in approximately 24 lawsuits related to deinstitutionalization on behalf of individuals with developmental disabilities. (See app. II.) Most but not all of these lawsuits were intended to be class actions against large public institutions for persons with mental retardation and other developmental disabilities. Moreover, P&As reported that, relative to other activities, they spent a small proportion of staff time on filing class action lawsuits on behalf of individuals with developmental disabilities. Nationally, P&As reported spending about 2 percent of their staff time for this purpose in 2001.[17]

From 1975 through 2002, P&As in the three states we reviewed filed or intervened in six lawsuits related to deinstitutionalization on behalf of individuals with developmental disabilities. (See table 1.) Of the six lawsuits, four were brought in federal court and two were brought in state court. Three of these suits were settled as class action lawsuits. The other three suits were intended as class actions but not certified as such by their respective courts. Of these three, one in Maryland was dismissed by mutual agreement of the parties, one in California was settled by a multiparty agreement, and another in California is pending. Although most of the suits were settled a number of years ago, the impact of the suits can be ongoing. For example, the *Nelson v. Snider* suit in Pennsylvania was

[17]This information is from a national survey of 57 P&As in fiscal year 2001 in which 44 provided information about staff time spent on filing class action lawsuits on behalf of individuals with developmental disabilities. See HHS OIG, *State Protection and Advocacy Programs for Persons with Developmental Disabilities*.

settled in 1994 but was part of the impetus for closing the Embreeville Center in 1998.

Table 1: Lawsuits Related to Deinstitutionalization That P&As Filed or Intervened in on Behalf of Individuals with Developmental Disabilities in California, Maryland, and Pennsylvania, 1975–2002

Lawsuit	Federal/ state court	Date filed	P&A actions	Class certified by court?	Status of case	Examples of actions required by settlement
California						
Coffelt et al. v. California Department of Developmental Services et al. (various institutions and regional centers named among defendants)[a]	State	February 1990	Initiated lawsuit seeking class action certification.	Yes.	Class action settlement approved January 1994.	Required state officials to reduce the number of individuals with developmental disabilities living in large state developmental centers by 2,000 over 5 years and provide services to them in community-based settings, and engage in system improvement activities.
Richard S. et al. v. California Department of Developmental Services et al.[b]	Federal	March 1997	In a lawsuit initiated by plaintiffs seeking class action certification, P&A intervened to seek injunction against state policy allowing family members or guardians (referred to as conservators in California) to veto community placement decisions made by a member of the Individual Program Plan (IPP) team.	No.	Court issued permanent injunction in April 2000. Multiparty settlement agreement approved in January 2001.	Injunction overturned state policy permitting family member or guardian veto of community placement decisions for adult developmental center residents. Settlement instituted policy ensuring that when a member of the IPP team for the individual with developmental disabilities objects to community placement, a hearing may be requested in state court on the individual's proposed community placement.

Lawsuit	Federal/ state court	Date filed	P&A actions	Class certified by court?	Status of case	Examples of actions required by settlement
Capitol People First et al. v. California Department of Developmental Services et al. (various regional centers named among defendants)	State	January 2002	Initiated lawsuit seeking class action certification.[c]	No court decision as of August 4, 2003.	Lawsuit is ongoing.	Not applicable.
Maryland						
Hunt et al. v. Meszaros et al. (state-operated institution named is Great Oaks Center)	Federal	September 1991	Initiated lawsuit seeking class action certification.	No.	Lawsuit dismissed by mutual agreement March 1999.	Not applicable.[d]
Pennsylvania						
Richard C. et al. *v. Snider et al.* (state-operated institution named is Western Center)[e]	Federal	September 1989	Initiated lawsuit seeking class action certification.	Yes.	Class action settlement approved June 1993.	Defined activities for state officials in planning and implementing phased community placement and establishing a quality assurance program.
Nelson et al. v. Snider et al. (state-operated institution named is Embreeville Center)[e]	Federal	January 1994	Initiated lawsuit seeking class action certification.	Yes.	Class action settlement approved November 1994.	Phased community placement and closure of the Embreevillle Center by September 30, 1997.[f] Defined state activities for planning and implementing a quality assurance program.

Sources: California, Maryland, and Pennsylvania P&As and settlement agreements for the lawsuits.

[a]Regional centers named in lawsuit include San Andreas, Golden Gate, East Bay, and North Bay.

[b]The P&A intervened in a multiparty suit that included individual plaintiffs from Fairview Developmental Center. Both the permanent injunction and the settlement agreement as approved by the court apply statewide to institutions for developmentally disabled individuals.

[c]Complaint proposes a class of "all Californians with developmental disabilities … who are or will be institutionalized, and those who are or will be at risk of being institutionalized, in either public or private facilities including, but not limited to, the Developmental Centers (DCs), Skilled Nursing Facilities (SNFs), Intermediate Care Facilities — Developmentally Disabled (ICF-DDs), large congregate Community Care Facilities (CCFs), psychiatric hospitals, or children's shelters."

[d]Although not required as a result of the lawsuit, the Great Oaks Center closed in June 1996.

[e]The Pennsylvania P&A contracted with the Disabilities Law Project in Philadelphia, Pennsylvania, to file this suit.

[f]The center closed in 1998.

Complaints brought in these lawsuits included allegations of inappropriate care and treatment in state institutions, including abuse and neglect, and violations of constitutional due process rights as well as rights under the Rehabilitation Act of 1973 and the Americans with Disabilities Act. The three class action suits resulted in court-ordered settlements requiring state officials to take a variety of actions, including placing of individuals with developmental disabilities in community settings, downsizing or closing of state institutions, and establishing and overseeing of certain quality assurance standards.

P&As in Three States Used Litigation to Address a Small Percentage of Client Problems

P&As in California, Maryland, and Pennsylvania used litigation infrequently to address client problems according to available data from fiscal years 1999 to 2001. In their annual reports to ADD, P&As in these states reported using litigation to address 272 client problems over the 3-year period, or about 1.5 percent of all problems addressed. (See table 2.) This included litigation on behalf of named plaintiffs in deinstitutionalization litigation, such as class action lawsuits, and other litigation, such as litigation filed on behalf of individuals. By contrast, P&As reported using other services to address 17,947 client problems, more than 98 percent of all problems addressed. These services include contacting state officials for individuals in need of services such as health care, negotiation and mediation help, technical assistance in self-advocacy, and representation at administrative hearings.

Table 2: P&A Services Used to Address Problems of Individuals with Developmental Disabilities in California, Maryland, and Pennsylvania, Fiscal Years 1999–2001

	Assistance provided through litigation (number of client problems)	Assistance provided through other services[a] (number of client problems)	Total	Percentage of total client problems addressed through litigation	Percentage of total client problems addressed through other services
California Protection & Advocacy, Inc.					
2001	16[b]	1,002	1,018	1.6	98.4
2000	9	3,281	3,290	0.3	99.7
1999	28	4,586	4,614	0.6	99.4
Pennsylvania Protection and Advocacy, Inc.					
2001	65	2,451	2,516	2.6	97.4
2000	89	2,672	2,761	3.2	96.8
1999	39	3,661	3,700	1.1	98.9
Maryland Disability Law Center (Maryland P&A)					
2001	0	178	178	0	100.0
2000	11	68	79	13.9	86.1
1999	15	48	63	23.8	76.2
Total	**272**	**17,947**	**18,219**	**1.5**	**98.5**

Source: ADD.

Note: GAO analysis of ADD data. Percentages may not add to 100 because of rounding. Client assistance data are calculated on the basis of the number of client problems reported by individuals that are addressed and closed each year. These data do not include individuals who are being assisted but whose problems are not yet addressed and closed—that is, they do not include active cases.

[a]Other services include short-term assistance to obtain needed services, technical assistance in self-advocacy, mediation/negotiation, and administrative hearings.

[b]Includes two of the named plaintiffs in the *Coffelt* lawsuit but does not include unnamed class members.

P&As' Communications in Three States Were Consistent with Federal Rules but Not as Comprehensive as Some Parents Desired

P&As in the three states communicated with parents and guardians as required by federal rules in the lawsuits we reviewed. In the three cases settled as class actions, P&As provided notice to all class members at the time settlement was proposed to the court, as required by federal rules. Such notice was not required in the other three cases we reviewed, which were not class actions. Even though P&As provided the notice required by federal rules in the lawsuits we examined, representatives of some parent groups told us they believed that P&As should have communicated with parents and guardians before filing or intervening in these lawsuits and prior to class certification by the court. P&As in the three states reviewed indicated that they did not try to communicate with all individuals potentially affected by the six lawsuits, including parents and guardians, but did communicate with organizations representing some parents and guardians during these stages of the lawsuits. However, even if P&As had provided notification during the stages specified by the parents and guardians, under the applicable federal rule of civil procedure an individual has no explicit right to opt out of a class in this type of case.

P&As Complied with Requirement to Provide Notice to All Class Members Prior to a Court's Approval of a Settlement Agreement

In the three class action lawsuits we reviewed, P&As complied with FRCP Rule 23, which requires communication with all class members prior to settlement. Two of these lawsuits were filed and settled in federal district court, where the FRCP applied directly, and one lawsuit was filed and settled in California superior court, where, under prevailing law at that time, the judge applied the FRCP.

FRCP Rule 23 does not require notification of class members prior to class certification in lawsuits seeking injunctive relief, the type of lawsuits generally brought by P&As, although such notice is required in class action lawsuits seeking monetary damages. However, FRCP Rule 23 does require notification at the time of proposed settlement for all class action lawsuits—including those seeking injunctive relief. It specifies that such notice "shall be given to all members of the class in such manner as the court directs."[18] This notice guarantees that unnamed class members will receive notice of any proposed settlement and have an opportunity to

[18]FRCP Rule 23(e). Federal judicial guidance for providing such notice provides that, among other things, it should describe the essential terms of the proposed settlement; disclose any special benefits provided to the named class representatives; provide information regarding attorney's fees; and indicate the time and place of the hearing to consider approval of the settlement and the method for objecting to the settlement. Federal Judicial Center, *Manual for Complex Litigation*, § 30.212 (Third Ed., West 1995).

register objections with the court, thereby assisting the court in determining whether the proposed settlement is fair, adequate, and reasonable.[19] We confirmed that such notice was provided in each of the three cases. Such notice was not required in the other three cases we reviewed, which were not class action lawsuits.

P&As' Communication Was Not as Comprehensive as Some Parents Desired

P&As' communication before a settlement was proposed to the court was not as comprehensive as some parents desired in the lawsuits we reviewed. Representatives of some parent groups told us they were not satisfied with the extent of P&A communication because they believed that P&As should have communicated with parents and guardians in the six lawsuits we examined before filing or intervening in the suits and prior to class certification by the court. P&A officials in California, Maryland, and Pennsylvania told us that they did not try to communicate with all individuals, including parents and guardians, potentially affected by the six lawsuits until a settlement was proposed to the court. However, P&As were not required to provide such communication. In a discussion with NAPAS, the national organization representing P&As, an official told us that for P&As to attempt to contact all such individuals would require considerable time and expense, which would make providing such notice extremely difficult. Furthermore, he said that P&As would not generally wish to provide such notice unless required to do so because this could provide defendants with information they might use to oppose litigation.

Nevertheless, P&A officials said that they met or attempted to meet with organizations representing some parents and guardians of affected individuals during the lawsuits.[20] The context of the meetings varied with the circumstances of the six lawsuits. For example, a California P&A official indicated that, both before and after filing the *Coffelt* lawsuit in 1990, the P&A met with organizations representing the parents and guardians of residents of at least three of the institutions affected. In the other two California lawsuits, *Richard S.* (1997) and *Capitol People First* (2002), a California P&A official indicated that the P&A met with and represented organizations whose members included the families of institutional residents, and met with individual family members before and

[19]James Moore and Kevin Shirey, *Moore's Federal Rules Pamphlet*, Part 1, § 23.14 Matthew Bender, 2003.

[20]We did not determine the number of P&A meetings with family members and guardians or the number of attendees for any of these lawsuits.

during the litigation. The P&A did not, however, meet with parent organizations specifically associated with the institutions. In both of those lawsuits, the organizations specifically associated with the institutions were or are involved as parties, thus complicating direct communication between the P&A and parents and guardians who might belong to these organizations.[21] A Maryland P&A official told us that, before filing the *Hunt v. Meszaros* litigation in 1991, the P&A met with an organization representing parents and guardians of residents of the affected facility—the Great Oaks Center. A Pennsylvania P&A official told us that the P&A met with a parent group representing Embreeville Center residents during the *Nelson v. Snider* litigation (1994)—both before filing the lawsuit and after the court's certification of a class action. These efforts were complicated by the fact that this organization had already filed another lawsuit against the state.[22] A Pennsylvania P&A official said that the P&A tried unsuccessfully to meet with an organization representing parents and guardians of Western Center residents prior to filing the *Richard C. v. Snider* lawsuit (1989) and that such efforts were complicated by another lawsuit filed against the P&A by that organization. Representatives of some parent groups, however, told us that P&A communication concerning the lawsuits with parents and guardians of affected individuals was limited.

Three of the six lawsuits we examined—*Nelson v. Snider*, *Richard. C. v. Snider*, and *Coffelt v. California Department of Developmental Services*—were certified by the courts as class actions. The P&As indicated that they did not attempt to notify all prospective class members prior to certification of their classes by the court for the reasons discussed above. P&As told us they maintained regular contact with all named plaintiffs in the lawsuits. Representatives of some parent groups said that parents and guardians of individuals affected as unnamed class members in the lawsuits had insufficient opportunity to express their views about the inclusion of their adult children in the class and were not notified that their children might be included until the settlement was proposed to the court. As a result, some individuals may have been included in class

[21]Generally, counsel will avoid direct communication with parties to a lawsuit represented by others. *See* ABA Model Code of Professional Responsibility, Canons 7 and 9, DR 7-104 (1980).

[22]This case was eventually consolidated with the P&A's own case on behalf of residents of the Embreeville Center and resulted in the settlement agreement discussed in this report. *See* 160 F.R.D. 46 (E.D. Pa. 1994).

actions even though they or their parents or guardians opposed their inclusion. As a matter of law, however, these individuals would have had limited influence even if they had been able to express their views. In class action suits seeking injunctive relief, such as the three we examined, the court focuses on the circumstances of the class as a whole as opposed to those affecting individual members.[23] In such suits, under the rules governing such litigation, an individual has no explicit right to opt out of a class as certified by the court. By contrast, there is an explicit right to opt out of a class in class action lawsuits that seek monetary compensation.[24]

P&As in the Three States Assumed Various Roles in Monitoring Individuals Transferred to Community Settings

P&As assumed various roles in monitoring the health and well-being of individuals with developmental disabilities transferred from institutions to community settings in four of five lawsuits we reviewed in California, Maryland, and Pennsylvania that had been resolved. (See table 3.) No P&A monitoring role has been established in the sixth suit we reviewed, in which litigation is ongoing. In these three states, P&A roles and responsibilities varied with the circumstances of the lawsuits and initiatives P&As undertook as part of their general role to protect and advocate the rights of individuals with developmental disabilities. State developmental disabilities services agencies, however, continue to have the primary responsibility for ensuring the health and well-being of individuals, including monitoring these individuals when they receive services in the community. Representatives of some parent groups told us that parents and guardians have been dissatisfied with the adequacy of P&As' monitoring role in community placements, while representatives of other parent groups told us they generally supported the P&A monitoring role.

With respect to the three lawsuits filed and settled as class actions, the settlement agreements did not specify a monitoring role for the P&As, but the P&As assumed specific roles in monitoring individuals transferred to the community. Regarding the other three lawsuits not settled as class actions, the P&A also undertook a role in monitoring affected individuals

[23]To maintain a class action for injunctive relief, one must establish that (1) the party opposing the class has acted or refused to act on grounds generally applicable to the class and (2) final injunctive or corresponding declaratory relief is appropriate with respect to the class as a whole. *See, e.g.*, Carl Aron et al., Class Actions Law and Practice, § 1:05 (1991 ed. Callaghan) (citing Rule 23(b)(2) of the Federal Rules of Civil Procedure).

[24]*See* Aron at § 3:12; Steven T.O. Cottreau, Note: *The Due Process Rights to Opt Out of Class Actions, 73 N.Y.U. L. Rev. 480, 483* (1998).

in one of these suits. P&As are not playing a monitoring role in the other two suits—in one because of the nature of the suit, and in the other because litigation is ongoing.

Table 3: Roles P&As Assumed in Monitoring Individuals Affected by Lawsuits Reviewed in California, Maryland, and Pennsylvania

Lawsuit (status)	Examples of P&A monitoring roles
California	
Coffelt et al. v. California Department of Developmental Services et al.[a] (settled 1994)	The P&A assumed the role of monitoring class members transferred to community settings using information the state was required to develop as part of this settlement agreement (e.g., annual reports about various aspects of the well-being of individuals and consumer and family satisfaction with the quality of life in community settings, and quarterly reports about client placement in community settings, crisis intervention and emergency services).[b] As of June 2002, the number of persons with developmental disabilities moved to community settings as a result of the settlement exceeded 2,200 persons. The P&A's responsibilities for monitoring the lawsuit's 11 named plaintiffs included communication with these individuals, who needed a variety of services, such as behavior intervention, medical services, and assistance in crises.
Richard S. et al. v. California Department of Developmental Services et al. (settled 2001)	The P&A did not undertake a monitoring role as a result of this lawsuit.
Capitol People First et al. v. California Department of Developmental Services et al. (ongoing)	No role; this lawsuit is ongoing.
Maryland	
Hunt et al. v. Meszaros et al. (Great Oaks Center; dismissed 1999)	Although this lawsuit was dismissed, the P&A undertook a role with the Arc of Maryland to provide affected families with information about community placement processes. In addition, P&A officials told us that the P&A assumed responsibility for monitoring some former Great Oaks Center residents identified as having problems, based on P&A reviews of complaints and provider incident reports. When this lawsuit was filed in 1991, 205 individuals resided at this center, according to the Maryland P&A.
Pennsylvania	
Richard C. et al. v. Snider et al.[a] (Western Center; settled 1993)	The P&A assumed the role of monitoring each class member. This role included conducting site visits to community facilities, reviewing records to determine whether class members were receiving services consistent with their "person-centered" discharge plans, interviewing residents and provider staff, following up on noncompliance issues, and participating in the Western Center Human Rights and Behavior Management Review Committees. A P&A official told us the P&A role included face-to-face interaction with individuals while they were at the Western Center and after they were placed in the community. The court certified the class of 384 individuals in February 1992, including approximately 360 who resided at the Western Center, according to a P&A official.

Lawsuit (status)	Examples of P&A monitoring roles
Nelson et al. v. Snider et al.[a] (Embreeville Center; settled 1994)	The P&A assumed the role of monitoring 50 class members who had no family members to assist them. Monitoring responsibilities for these individuals prior to their discharge from the center included reviewing plans of care and examining community facilities. After community placements, the P&A role encompassed visiting homes and day programs, and attending treatment meetings for up to 1 year. A P&A official also reported the role of monitoring 15 to 20 class members who had problems with community placements by contacting the appropriate entity such as the provider, the county, court monitor, and/or the state developmental services agency. Examples of problems in community settings included absence of adaptive equipment or day activities, inadequate staffing, inadequate dental service, and failure to properly implement behavior management plans. P&A monitoring responsibilities for the lawsuit's six named plaintiffs included conducting site visits and reviewing case managers' reports.[c] There were 260 individuals with developmental disabilities living in the Embreeville Center when the court certified the class in April 1992, according to a P&A official.

Sources: California, Maryland, and Pennsylvania P&As, state developmental disabilities services agencies, and settlement agreements for the six lawsuits.

Note: GAO analyzed settlement agreements and information related to the lawsuits provided by P&As and state developmental disabilities services agency officials.

[a]Settled as a class action lawsuit.

[b]The *Coffelt* settlement agreement required that the state contract with an independent expert to prepare an annual report that contains certain quality dimensions, including general health and safety, behavioral support services, psychoactive medication usage, quality of home and work settings, independence, productivity, social integration, and opportunity for choice and control. This requirement became part of section 4418.1 of the California Welfare and Institutions Code. A California P&A official stated that the expert's assessment is based on visits to persons who moved as a result of the settlement, interviews with these persons, and records review.

[c]Case managers are responsible for assessing individuals' needs, developing a plan of care, arranging for delivery of services, monitoring individuals, and periodically reassessing individuals' needs to modify the care plan as appropriate.

For the three lawsuits settled as class actions—*Coffelt* (California), *Richard C.* (Pennsylvania), and *Nelson* (Pennsylvania)—the P&As assumed the role of monitoring some or all class members transferred to community settings. As a result of the *Coffelt* settlement in 1994, the California P&A has undertaken the role of monitoring individuals using information that the state was required to provide, such as annual reports about quality of life in community settings, based on consumer and family surveys. P&A monitoring responsibilities for *Coffelt's* 11 named plaintiffs involved regular communication with these individuals. For *Richard C.*, a Pennsylvania P&A official told us that the P&A role included hiring an advocate to monitor services[25] provided to all class members while they

[25]The Pennsylvania developmental disabilities services agency reimbursed the P&A for this advocate's services.

were still living at the Western Center and after their placement in community settings. This advocate was expected to visit each class member discharged from the Western Center after 1994 at least once. A P&A official said that monitoring included face-to-face interaction with class members living at the Western Center or in the community. The P&A has ongoing responsibility for monitoring several individuals who were moved from the Western Center to the Ebensburg Center, another state facility for individuals with mental retardation. For the *Nelson* lawsuit settled in 1994, the P&A undertook the responsibility to follow 50 class members who did not have involved family members, in addition to monitoring six named plaintiffs. P&As have assumed a role in monitoring state development and implementation of quality assurance mechanisms established by all three settlement agreements to improve services provided in community settings and evaluate services delivered in the community. Thus, these agreements have long-lasting implications for state and P&A monitoring activities because implementation of the settlement agreements may take years to complete.

Of the three other lawsuits we reviewed, one was settled, one was dismissed, and the third is ongoing litigation. In the settled suit, *Richard S.* (California), the P&A did not undertake a monitoring role as a result of this lawsuit. In this suit, the P&A intervention was intended to overturn California state policy permitting family member or guardian veto of community placement decisions, an outcome that did not lead to a P&A role in monitoring individuals affected by this suit. However, California P&A officials reported that the P&A had the role of monitoring the well-being of all individuals who moved from institutions to the community, including individuals affected by the *Richard S.* suit, based on the role assumed by the P&A in the *Coffelt* case. In the dismissed suit *Hunt* (Maryland), the P&A undertook a certain role to monitor plaintiffs and other affected individuals. The *Hunt* lawsuit was dismissed in 1999 following closure of the Great Oaks Center in 1996. However, the P&A and Arc of Maryland officials reported having a role in assisting families of individuals who had problems with community placements. Finally, California's *Capitol People First* (filed in 2002) is in the early stages of litigation and has not yet addressed a P&A monitoring role.

Parent groups we interviewed had differing views about the role P&As played in monitoring individuals in the five resolved lawsuits we reviewed. Representatives of some parent groups were generally dissatisfied with the adequacy of P&As' efforts to monitor the health and well-being of individuals transferred to community settings, while representatives of other parent groups, who were generally in favor of these lawsuits, supported P&As' monitoring approaches. Those parent groups that were dissatisfied said that in supporting states' "rapid" deinstitutionalization efforts, P&As disregarded parents' concerns about service quality deficiencies in community settings and the needs of individuals with severe developmental disabilities, who tend to be medically fragile.[26] They also stated that P&A staff did not adequately monitor individuals who were moved to community settings. In contrast, representatives of other parent groups generally supported the P&A role in monitoring community placements. For example, a representative of one parent group said that the Maryland P&A collaborated with this group in developing a family guide to community programs for people affected by the *Hunt* lawsuit. Other parent groups said the Pennsylvania P&A was instrumental in establishing consumer and family satisfaction teams to monitor the quality of services provided to individuals and families affected by the *Nelson* lawsuit.

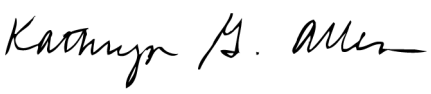
Agency and Other Comments

We provided a draft of this report to ACF and to the California, Maryland, and Pennsylvania P&As for their review. ACF said it was a thorough analysis of the three P&As' involvement in deinstitutionaliation lawsuits for the population examined. ACF's written comments are in appendix III. The three P&As stated that the report is accurate, and provided technical comments. We incorporated technical comments as appropriate.

[26]We recently reported on the need to improve federal and state quality assurance systems for home and community-based Medicaid long-term care services for the elderly. See U.S. General Accounting Office, *Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened*, GAO-03-576 (Washington, D.C.: June 20, 2003).

As agreed with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days after its issue date. At that time, we will send copies to the Assistant Secretary for Children and Families and the Commissioner of the Administration on Developmental Disabilities in the Department of Health and Human Services, interested congressional committees, and other parties. We will also make copies available to others on request. In addition, the report will be available at no charge on the GAO Web site at http://www.gao.gov. If you or your staff have any questions about this report, please call me at (202) 512-7118. Another contact and key contributors are listed in appendix IV.

Sincerely yours,



Kathryn G. Allen
Director, Health Care—Medicaid
and Private Health Insurance Issues

Appendix I: Objectives, Scope, and Methodology

We examined (1) the extent to which Protection and Advocacy agencies (P&As) engage in litigation related to deinstitutionalization on behalf of individuals with developmental disabilities, (2) how P&As have communicated with parents and legal guardians in deinstitutionalization lawsuits, and (3) the role, if any, that P&As have played in monitoring the health and well-being of individuals transferred from institutions to community settings within the context of these lawsuits.

To determine the extent to which P&As engage in litigation related to deinstitionalization on behalf of individuals with developmental disabilities, we compared data from several sources and consulted with national and state organizations because there is no single, national source of information on P&A litigation activities. We analyzed information from two key studies that provide extensive information on deinstitutionalization lawsuits,[1] interviewed the authors of these studies, and examined information on lawsuits provided by the National Association of Protection & Advocacy Systems, Inc. (NAPAS) and Voice of the Retarded (VOR). We also interviewed officials from the Administration on Developmental Disabilities (ADD) in the Administration for Children and Families in the Department of Health and Human Services (HHS), NAPAS, the National Association of State Directors of Developmental Disabilities Services, and the VOR; representatives of several other family advocacy organizations, including the Arc of the United States; and P&A officials in the three states. From these sources, we compiled a national list of 24 deinstitutionalization lawsuits confirmed by NAPAS or state P&As that P&As filed, joined, or intervened in on behalf of individuals with developmental disabilities from 1975 through 2002. (See app. II for a list of all 24 cases identified.) From the national list we identified six lawsuits in three states—California, Maryland, and Pennsylvania—to study in more detail. National organizations that we consulted indicated that these states' P&As are more active in deinstitutionalization litigation. In addition, we analyzed research on national trends in litigation for institutionalized individuals with developmental disabilities, consulted individuals knowledgeable about P&A deinstitutionalization lawsuits, and examined

[1]See Mary F. Hayden, "Civil Rights Litigation for Institutionalized Persons with Mental Retardation: A Summary," *Mental Retardation* (February 1998) and Gary A. Smith, *Status Report: Litigation Concerning Medicaid Services for Persons with Developmental and Other Disabilities* (Tualatin, Ore.: Human Services Research Institute, Jan. 16, 2003).

aggregate and state-specific ADD data from 1999 through 2001 on P&A litigation services provided to this population.[2]

To determine how P&As communicated with parents and legal guardians of individuals with developmental disabilities in deinstitutionalization lawsuits, we focused on the six lawsuits in California, Maryland, and Pennsylvania. We reviewed class action notification requirements for plaintiffs in federal and state courts and analyzed settlement agreements and other documents related to the six lawsuits. We also discussed the extent of P&A communication with individuals potentially affected by class action litigation with P&A officials and parent representatives in these states.

Finally, to determine the role P&As play in monitoring individuals who have been moved from institutions to community settings, we reviewed the authority P&As have under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 to protect and advocate the rights of individuals with developmental disabilities. We interviewed P&A officials in the three states about their roles and responsibilities and reviewed applicable deinstitutionalization settlement agreements and related documentation that they provided. We also interviewed officials from these states' developmental disabilities services agencies who have primary responsibility for ensuring the quality of services provided to individuals with developmental disabilities.[3] We did not attempt to assess the effectiveness of P&A and state agencies' quality monitoring efforts nor to generalize our study findings to P&As nationwide. We did our work from October 2002 through September 2003 in accordance with generally accepted government auditing standards.

[2]ADD does not tabulate the number of client case problems addressed through class action litigation separately from other types of litigation services. Nonlitigation services ADD tracks include activities such as mediation, technical assistance, and administrative hearings.

[3]The state agencies with these responsibilities are the California Department of Developmental Services, Maryland Developmental Disabilities Administration, and Pennsylvania's Department of Public Welfare, Office of Mental Retardation.

Appendix II: P&A Lawsuits Related to Deinstitutionalization for Individuals with Developmental Disabilities, 1975–2002

Case name	Year filed	State
Evans v. Washington[a]	1976	District of Columbia
Garrity v. Gallen	1978	New Hampshire
Baldridge v. Clinton[a]	1983	Arkansas
Leisz v. Kavanagh	1985	Texas
Conner v. Branstad	1986	Iowa
Nicoletti v. Brown[a]	1987	Ohio
Jackson v. Fort Stanton	1987	New Mexico
Kope v. Watkins	1988	Michigan
Parrent v. Angus	1989	Utah
Martin v. Voinovich	1989	Ohio
Richard C. et al. v. Snider et al.[b]	1989	Pennsylvania
John S. v. Cuomo	1990	New York
Weston v. Wyoming State Training School	1990	Wyoming
Connecticut Traumatic Brain Injury Association v. Hogan	1990	Connecticut
Hunt et al. v. Meszaros et al.[b]	1991	Maryland
Coffelt et al v. California Department of Developmental Services et al.[b]	1990	California
Nelson et al. v. Snider et al.[b]	1994	Pennsylvania
Travis D. et al. v. Eastmont Human Services Center	1996	Montana
People First of Washington v. Rainier Residential Habilitation Center	1996	Washington
Richard S. et al. v. California Department of Developmental Services et al.[a, b]	1997	California
Brown et al. v. Bush et al.	1998	Florida
Capitol People First et al. v. California Department of Developmental Services et al.[b]	2002	California
The Arc of Delaware et al. v. Meconi et al.	2002	Delaware
McCarthy et al. v. Gilbert et al.	2002	Texas

Sources: NAPAS; VOR; P&A officials; Mary F. Hayden, "Civil Rights Litigation for Institutionalized Persons with Mental Retardation: A Summary," *Mental Retardation* (February 1998); and Gary A. Smith, *Status Report: Litigation Concerning Medicaid Services for Persons with Developmental and Other Disabilities* (Tualatin, Ore.: Human Services Research Institute, Jan. 16, 2003).

Note: GAO compiled information on the cases in which P&As filed, intervened, or joined from these sources. GAO did not include *Michigan Arc v. Smith* (1978) because even though the P&A staff did legal work on the suit, the Arc filed the case rather than the P&A.

[a]P&A intervened.

[b]Reviewed by GAO.

Appendix III: Comments from the Administration for Children and Families

DEPARTMENT OF HEALTH & HUMAN SERVICES

ADMINISTRATION FOR CHILDREN AND FAMILIES
Office of the Assistant Secretary, Suite 600
370 L'Enfant Promenade, S.W.
Washington, D.C. 20447

DATE: SEP 25 200

TO: Kathryn G. Allen
Director, Health Care-Medicaid
and Private Health Insurance Issues

FROM: Wade F. Horn, Ph.D.
Assistant Secretary
for Children and Families

SUBJECT: Comments on the GAO Draft Report, "Protection and Advocacy Agencies: Involvement in Deinstitutionalization Lawsuits on Behalf of Individuals with Developmental Disabilities" (GAO-03-1044)

Attached are the Administration for Children and Families' comments on the subject GAO Draft Report.

Should you have any questions regarding our comments, please contact Faith McCormick, Acting Director, Division of Program Operations, Administration on Developmental Disabilities at (202) 690-6590.

Attachment

COMMENTS OF THE ADMINISTRATION FOR CHILDREN AND FAMILIES ON THE GENERAL ACCOUNTING OFFICE'S DRAFT REPORT, "PROTECTION AND ADVOCACY AGENCIES: INVOLVEMENT IN DEINSTITUTIONALIZATION LAWSUITS ON BEHALF OF INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES" (GAO-03-1044)

The Administration for Children and Families (ACF) appreciates the opportunity to comment on this draft report. We note that the General Accounting Office (GAO) made no specific recommendations.

General Comments

The Administration on Developmental Disabilities (ADD) found that in the three Protection and Advocacy (P&A) agencies selected--California, Maryland and Pennsylvania--GAO has completed a thorough analysis of those agencies' involvement in the deinstitutionalization lawsuits on behalf of individuals with developmental disabilities. We found the report easily understandable; however, it is unclear how consumers and parents will react to the report in this snapshot because it does not represent the entire P&A system.

Other Comments

- Page 14, table 1; page 17, table 2; and page 23, table 3.

  Tables 1, 2, and 3 are clear and concise summaries of the major findings.

- We recommend that GAO include the following definition for "Developmental Disabilities" either in the highlight section or in the letter to the Chairman in footnote 1:

  Developmental Disability is a severe, chronic disability (e.g., mental retardation, autism, cerebral palsy) of an individual five years of age or older that (1) is attributable to a mental or physical impairment or both, (2) is manifested before age 22, (3) is likely to continue indefinitely, and (4) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency.

Appendix IV: GAO Contact and Staff Acknowledgments

GAO Contact

James C. Musselwhite, (202) 512-7259

Acknowledgments

In addition to the person named above, key contributors to this report were Anne Montgomery, Carmen Rivera-Lowitt, George Bogart, and Elizabeth T. Morrison.

Related GAO Products

Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened. GAO-03-576. Washington, D.C.: June 20, 2003.

Children with Disabilities: Medicaid Can Offer Important Benefits and Services. GAO/T-HEHS-00-152. Washington, D.C.: July 12, 2000.

Mental Health: Improper Restraint or Seclusion Use Places People at Risk. GAO/HEHS-99-176. Washington, D.C.: September 7, 1999.

Adults with Severe Disabilities: Federal and State Approaches for Personal Care and Other Services. GAO/HEHS-99-101. Washington, D.C.: May 14, 1999.

Medicaid: Oversight of Institutions for the Mentally Retarded Should Be Strengthened. GAO/HEHS-96-131. Washington, D.C.: September 6, 1996.

Medicaid: Waiver Program for Developmentally Disabled Is Promising but Poses Some Risks. GAO/HEHS-96-120. Washington, D.C.: July 22, 1996.

GAO's Mission

The General Accounting Office, the audit, evaluation and investigative arm of Congress, exists to support Congress in meeting its constitutional responsibilities and to help improve the performance and accountability of the federal government for the American people. GAO examines the use of public funds; evaluates federal programs and policies; and provides analyses, recommendations, and other assistance to help Congress make informed oversight, policy, and funding decisions. GAO's commitment to good government is reflected in its core values of accountability, integrity, and reliability.

Obtaining Copies of GAO Reports and Testimony

The fastest and easiest way to obtain copies of GAO documents at no cost is through the Internet. GAO's Web site (www.gao.gov) contains abstracts and full-text files of current reports and testimony and an expanding archive of older products. The Web site features a search engine to help you locate documents using key words and phrases. You can print these documents in their entirety, including charts and other graphics.

Each day, GAO issues a list of newly released reports, testimony, and correspondence. GAO posts this list, known as "Today's Reports," on its Web site daily. The list contains links to the full-text document files. To have GAO e-mail this list to you every afternoon, go to www.gao.gov and select "Subscribe to e-mail alerts" under the "Order GAO Products" heading.

Order by Mail or Phone

The first copy of each printed report is free. Additional copies are $2 each. A check or money order should be made out to the Superintendent of Documents. GAO also accepts VISA and Mastercard. Orders for 100 or more copies mailed to a single address are discounted 25 percent. Orders should be sent to:

U.S. General Accounting Office
441 G Street NW, Room LM
Washington, D.C. 20548

To order by Phone:
Voice: (202) 512-6000
TDD: (202) 512-2537
Fax: (202) 512-6061

To Report Fraud, Waste, and Abuse in Federal Programs

Contact:

Web site: www.gao.gov/fraudnet/fraudnet.htm
E-mail: fraudnet@gao.gov
Automated answering system: (800) 424-5454 or (202) 512-7470

Public Affairs

Jeff Nelligan, Managing Director, NelliganJ@gao.gov (202) 512-4800
U.S. General Accounting Office, 441 G Street NW, Room 7149
Washington, D.C. 20548