

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**





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.

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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.

