
2002

Semi-
Annual

Report

October 1, 2001 to March 31, 2002



The Georgia Advocacy Office

The Protection and Advocacy System for Georgia

What is the Georgia Advocacy Office?

The Georgia Advocacy Office has had the official designation from each Governor since Governor Busbee in 1977 to be Georgia's protection and advocacy organization (P&A). P&As are empowered by Congress to provide advocacy and protection for individuals living with disabilities or mental illness. Every state has a P&A.

Individuals call the GAO to request help on issues of abuse or neglect either for themselves or someone else. Staff who do intake first instruct callers on self-advocacy techniques. When that is not possible, staff connect callers with someone who can advocate directly - either someone at the GAO or someone at another organization.

Some individuals call because they live segregated lives and long to be connected to their community. A person calling for this reason would best be served by being included in a relationship with someone in his or her community who is willing to share his or her time voluntarily on an ongoing basis.

After 25 years, the GAO continues to fulfill our legal mandates while following our Vision, Mission, Values and Principles. •

Our Vision Statement

A Georgia where all people have value, visibility and voice; where even the most difficult and long-lasting challenges are addressed by ordinary citizens acting voluntarily on behalf of each other; and where the perception of disability is replaced by the recognition of ability.

Our Mission Statement

To organize our resources and follow our values and legal mandates in ways which substantially increase the number of people who are voluntarily standing beside and for

people in Georgia who have significant disabilities or mental illness.

Our Values

The first and highest value is the value of people themselves who have disabilities or mental illness. The GAO will work to demonstrate this value.

The second value is the value of personal protection and advocacy freely given by ordinary people. The GAO will actively pursue advocacy connections, protective relationships, and vigorous representation by people who are and who can continue beyond what professionals can do to be neighbors and family to people with disabilities.

Our Principles

Independence

- remain free from conflicts of interest

Loyalty to the individual

- individualized efforts based on a person's interests

Positive interpretations and imagery

- surround people with positive and highly valued images, including language and associations

Least possible harm

- choose our actions consciously

Range of remedies

- begin with least aggressive approaches first

Values emphasis

- understand the inherent value of people

Economy

- focus on the greatest benefit, highest quality, most long-lasting protection and advocacy

Citizen participation

- seek to involve ordinary citizens

Civility

- build a better society for everyone

In some states federal funds are funneled through state entities to the P&A. In Georgia, the GAO is a private, non-profit organization, not a part of the state government.

Our Work

Access

The ability of the Georgia Advocacy Office to see and speak to or obtain information about an individual is key to the effectiveness of our advocacy. We spend much of our time visiting hospitals and community residences in an attempt to get to know individuals and their circumstances, usually in response to a complaint about abuse or neglect. Access enables us to review and evaluate an individual's situation and to investigate potential violations of laws, rules or regulations. We cannot advocate effectively for someone without access.

Even though the authority to access individuals and facilities or programs is clearly set out in the federal law, we continue to be challenged with delays or denials. We have spent much of our time clarifying our authority to the system through discussion and/or correspondence. We will not name publicly the state departments, divisions or offices denying us information. The disputes are in negotiation. Those access issues that cannot be negotiated effectively will best be resolved through court proceedings. •



Some members of the local Citizen Advocacy Staff

One example of strong advocacy is David Nelson, who cut through the job search process that his friend of six years, Al Cissel, was not able to navigate on his own. This advocacy resulted in employment at a local supermarket. An added benefit of citizen advocacy is that the advocate will stay involved over the years, able to help with any problems that arise in the future.

Citizen advocacy

There are eight citizen advocacy offices located throughout Georgia, each of which is independently governed by local citizens in their own communities. Citizen advocacy is a relationship form of protection and advocacy. Currently there are 650 people actively involved in citizen advocacy relationships around the state.

Citizen advocacy occurs when a private citizen, free from conflict, voluntarily represents the interests and concerns of a person with a developmental disability as if they were their own. Some relationships have lasted over 24 years, such as Nick O'Conner and Gail Walker. Their story was recently published in several newspapers through the Associated Press. Mr. O'Conner has performed many protection and advocacy roles on behalf of Ms. Walker and her family. He has prevented exploitation, financial and otherwise. He has helped Ms. Walker make important life decisions around housing, the education of her child, and the health of the

family and assisted her in solving problems in all of these areas. He continues to do so to this day.

As a result of citizen advocacy, there are private citizens around Georgia spending hundreds of hours each month voluntarily on behalf of others. We continue to offer over two hundred Georgians an opportunity to advocate for and protect our fellow citizens with developmental disabilities each year. Much of the care and response that has traditionally existed in community life is being driven out and replaced by professional services. Citizen advocacy tips the scales back toward personal response and community responsibility. •

Children in facilities

In response to the large numbers of people 22-years-of-age or younger who live in settings like regional psychiatric hospitals, nursing homes, private intermediate care facilities, juvenile justice facilities and private psychiatric hospitals:

1. Advocates helped over 278 young individuals, some in such facilities.
2. Advocates began to make contacts in several cities for the purpose of building a community response to youngsters who are isolated by their segregation and congregation in such facilities.
3. Citizen advocates have been recruited across the state to provide protection and advocacy for 53 youngsters.

As an example, a baby was placed in one of Georgia's state institutions. A citizen advocate was recruited to ensure that this little one did not languish there. The advocate spent time being with the baby for the year that it took to get the child back in the community. She made numerous phone calls and attended meetings, constantly reminding and challenging "the system" to find a home and do the right thing on behalf of this baby. •

Community living

Several of our Objectives and Priorities focus on getting to know people who are currently living in institutions and helping them move to the community whenever that is their choice. One useful tool is the very important

U.S. Supreme Court decision in the *L.C. and E.W. (Olmstead)* case rendered three years ago this June, based on the Americans with Disabilities Act. We have focused some of our energy on trying to advocate with this tool in two main ways.

First, in May 2001, we filed a group Office of Civil Rights (OCR) complaint with several partners (Georgia Legal Services, Atlanta Legal Aid, and the Disability Law and Policy Center of Georgia). The complaint asked OCR to investigate our allegations that the State is violating the civil rights of individually named complainants and more than 3000 similarly situated individuals by keeping them unnecessarily institutionalized. Since filing the complaint, some of the individually named complainants have gotten out of institutions. We are visiting these individuals to learn about their new living situations and whether they are receiving appropriate services. We continue to add additional people to the complaint as we get to know them.

Second, we focused some concentrated energy on informing the State's efforts to develop a comprehensive, effective working plan (*Olmstead* plan) for serving people with disabilities in the most appropriate integrated setting. Some of us attended the *Olmstead* Planning Committee work group meetings and offered input on what should be included in the State's plan and what principles should guide this plan.

Many of our comments are captured in the latest version of the *Olmstead* plan that was ready for acceptance in November 2001. We are unsure of the fate of this draft plan and know the best plan means nothing if not owned in the hearts of Georgia's leaders. To date, the State has not approved this plan or any other plan. We are waiting for action by the State as are the people who are institutionalized and not even counted or listed on a waiting list for services, making it easy for them to be invisible and forgotten. •

Death investigations

Every year, individuals with disabilities or mental illnesses are put at risk of abuse and

neglect or sometimes die while in the care of the state. At present, a team of staff members of the GAO is conducting a number of ongoing investigations. Each takes several months to complete. The investigative team is comprised of a leader, an attorney, an investigator and an advocate. Advocates are assigned based on the type of investigation and the expertise of the advocate. The investigative process is similar regardless of the circumstances. The team has had and continues to seek out opportunities for specialized investigation training and skill enhancement.

In December of 2001, the *Atlanta Journal-Constitution* ran a series of articles about Georgia citizens living with developmental disabilities and/or mental retardation who died while in community residential placements.

As in all investigations, the first step was to gather facts. A request was made to DMHMRS for all records in their possession relating to the individuals. For approximately one month, the team reviewed the reports available at the Division offices and determined that the deaths of many individuals will need continued investigation.

Team members researched the laws, rules, regulations and standards that applied. They determined whether or not compliance and best practice standards were present and being followed. They also enlisted the help of outside experts for their perspective and knowledge. The team has worked to uncover facts for three months. In this investigation, as in the others, the work is ongoing.

Our ideal is to prevent the death of an individual before it happens, not investigate after it is too late. Tragically, individuals with disabilities and mental illness continue to die of abuse and neglect in segregated, isolated settings. •

Drug studies

In 1997, two doctors associated with the Medical College of Georgia in Augusta were arrested and convicted after it was revealed that they had cheated the State of millions of dollars and put thousands of people in harm's way by cutting corners in drug studies they were conducting. GAO continues to follow up on the harm caused to



Filing the OCR complaint

As people with disabilities continue to wait for Georgia to listen to the U.S. Supreme Court, another legislative cycle passes without serious attention given to the more than 5500 people institutionalized in state hospitals and nursing homes and thousands of others waiting for services on the community waiting lists.

individuals who were seeking help for mental illness and is investigating to see if anything can be done to recompense them.

It has been an arduous struggle contacting former patients in the face of the State's resistance to reveal their names and addresses. In the process, new case law developing protection and advocacy system access rights has been created. A court order approving a method for GAO to proceed was issued just before this fiscal year. GAO sent letters to nearly 1,000 individuals who participated in the drug studies, while another 768 individuals did not have addresses listed on the information provided to GAO from the State.

Over time, GAO received 107 responses, and 345 letters were returned as undeliverable. A few responses indicated that the individual had died; many indicated some of the doctors' improprieties but reported little injury. A handful of individuals experienced some substantial harm, while fewer called to express that they had no complaint.

The next task is to review the records of individuals who reported problems and then to review the records of individuals who died. GAO will also request a limited review of other files in order to obtain more addresses. •

Education

Education issues have always generated and continue to generate a large number of calls to our office. All children are entitled to a free, appropriate, public education in the least restrictive environment. What that means for children in Georgia has been a matter of hot debate for many years.

During Fiscal Year 2001, we advocated on behalf of many children with developmental and other disabilities who were being denied an appropriate education. We provided direct advocacy to 158 individuals on issues such as lack of IEP/IFSP planning, development or implementation, failure to provide an inclusive setting, and other violations of IDEA. We provided information and referral on education issues to hundreds more callers.

One typical example involves a student named Mindy (not her real name). Mindy is seven years old and receives educational

services at home because of her disability. After her family relocated from one Georgia county to another, Mindy's mother requested school services for her daughter. The school failed to provide the services, and Mindy's mom called our office. The school agreed to work things out. GAO's attorney requested some evaluations be done, and Mindy's IEP meeting was held. As a result, Mindy's teacher and her physical, speech, and occupational therapists all visit her home weekly. The school also purchased some equipment which will enhance the quality of Mindy's life. Mindy and her family love her new opportunities for learning.

Also in our last fiscal year, staff trained 471 individuals in 19 sessions about their rights and those of their children with disabilities in the public schools. Our most requested publication, the booklet "Advocating for Your Child's Education," was updated and is now in the process of being translated into Spanish. Last year we mailed approximately 1500 of the education booklets to parents and others in search of a thorough, informative self-advocacy tool. •

Guardianship

In response to abuse or neglect of individuals who have guardians or who are at risk of being forced to have an unneeded guardian:

1. Staff provided advocacy for 72 individuals in 2001.
2. The GAO brochure "Guardianship and its Alternatives in Georgia" was updated. The brochure emphasizes options and highlights the preference for limitations on guardianships.
3. GAO coordinated an Institute for Continuing Legal Education (ICLE) seminar on guardianship in Albany for over 80 advocates, attorneys, probate court judges, family members and human service workers. The ongoing impact of this seminar is highlighted by a call the GAO received two months after the seminar was held, from a probate court judge. After reading all of the materials distributed during the seminar and calling the GAO for options, this judge concluded (in a guardianship proceeding) "neither party is likely to offer the person a decent



The Guardianship seminar in Albany, Georgia

IEP - Individual Education Plan

IFSP - Individual Family Service Plan

IDEA - Individuals with Disabilities Education Act

quality of life.”

4. Citizen advocacy programs across the state have recruited individuals to act as formal guardians for people with developmental disabilities when that has been appropriate. •

Model waivers

The Model Waiver is a home and community based program that allows children with severe disabilities to receive nursing care in the home as an alternative to being in a nursing home or other institution. For several years, the GAO has supported a group of parents of children who receive the Model Waiver in their efforts to get appropriate quantity and quality of services. A GAO staff attorney has attended numerous hearings and parent meetings.

The group, led by parent Judith Johnson, has met with State representatives recently in a seemingly successful attempt to convince them to replace the Model Waiver Program with one that is more effective. Over the past seven or eight months, the Division of Medical Assistance has worked to implement its replacement, under the nomenclature the GAPP (Georgia Pediatric Program) model. It is to be administered by the Medical College of Georgia, but at last report, the Division of Medical Assistance has rejected three proposals submitted by the College.

When the Model Waiver parent group formed, GAO filmed a video featuring them and their children entitled “Living With...Whatever It Takes to Keep Your Child at Home.” That video was just updated to include new footage and will be distributed to all P&As by the National Association of Protection and Advocacy Systems (NAPAS). The video received its first award in March 2002, a Bronze Telly Award. The Telly Awards was founded in 1980 and has become a well-known, highly respected national competition for film and video productions. •

Visible lives

The VISIBLE LIVES project was proposed to discover and implement ways to counteract the invisibility of people who live in the

disabilities service system. Its goal is to increase the safety of people with disabilities who are isolated and to decrease the possibility of abuse and neglect. The objective is to increase the membership of people previously disconnected from civic life in community associations.

Our objective was written as a result of a GAO funded visit in 2001 by John McKnight of Northwestern University. McKnight spoke to 160 people at four different venues in Georgia.

With the consultation of McKnight, a plan called “United We Stand” has been formulated. Simply stated, the steps are to:

- (a) identify a community with cohesiveness and vitality which is close enough to the study group to be easy to get to;
- (b) identify at least one community leader;
- (c) explain the project to the community leader, and, if favorably received, ask if she or he is interested in proceeding by inviting friends who are also active in community associations to join him or her in the project;
- (d) help this small group identify someone who is disconnected who has an interest in being included in an association with one of the members of the leadership group;
- (e) help this member include and foster the giving of the gift(s) of the new person on a permanent basis;
- (f) repeat steps (d) through (f).

The Board of Directors accepted a proposal on December 1, 2001, to investigate the likelihood of initiating successful projects in one or more Georgia communities. The study group chose to begin exploration in Elberton, Newnan, Hartwell, Dahlonega and Cartersville. One or more visits to each community have been made, and community leaders have been identified in all but Dahlonega. Initial explanations have been favorably received, and steps of the proposal are being followed. •

John McKnight is the Director of the Assets Based Community Development Institute and Associate Director of the Center on Urban Policy and Research at Northwestern University.

McKnight's motive as a community organizer is to build stronger communities. The GAO's motive as a protective and advocacy organization is to build safety and freedom into people's lives.



John McKnight in Georgia

Issues and Funds for Fiscal Year 2001

October 1, 2000 to September 30, 2001

Individuals Served Statewide

One-to-One Advocacy	Information and Referral	Training
726	4,820	4,364

Programs and Issues

Issues	PADD*	PAIMI	PAIR	PAAT	PABSS	Total
Abuse	43	124	12	0	0	179
Neglect	45	99	29	0	0	173
Education	69	1	88	0	0	158
Housing	26	0	20	0	0	46
Assistive Technology	14	0	0	19	0	33
Employment	5	0	17	0	3	25
Other Rights Violations	74	49	84	0	3	210
Total	276	273	250	19	6	794

Note: Some individuals had more than one issue

*PADD-Protection and Advocacy for Developmental Disabilities; PAIMI-Protection and Advocacy for Individuals with Mental Illness; PAIR-Protection and Advocacy for Individual Rights; PAAT-Protection and Advocacy for Assistive Technology; PABSS-Protection and Advocacy for Beneficiaries of Social Security

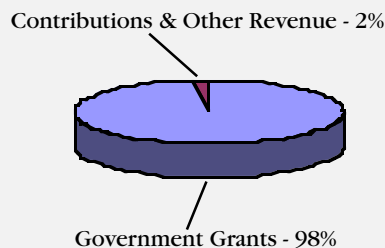
The Georgia Advocacy Office is the Protection and Advocacy System for Georgia and receives funding through:

- US Dept. of Health and Human Services/ Administration on Developmental Disabilities (PADD);
- Georgia Dept. of Community Affairs (Citizen Advocacy);
- US Dept. of Health and Human Services/Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (PAIMI);
- US Dept. of Education/ Rehabilitation Services (PAIR);
- US Dept. of Education/ Nat'l. Instit. on Disability and Rehab. Research (PAAT);
- US Social Security Administration (PABSS);
- Donations from Individuals and Corporations.

These contents are solely the responsibility of the grantee and do not necessarily represent the official views of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

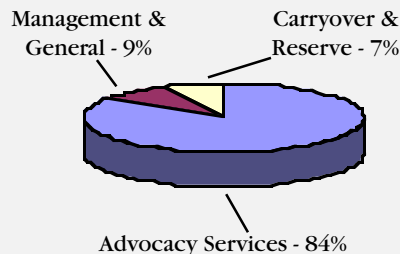
Sources of Revenue

Government Grants . . .	\$2,271,334.00
Contributions	30,125.00
Other Revenue	15,310.00
TOTAL.	\$2,316,769.00



Expenditures

Advocacy Services . . .	\$1,950,434.00
Management & General . .	202,249.00
Carryover and Reserve . . .	164,086.00
TOTAL.	\$2,316,769.00



GAO Board and Staff

GAO Board

Ray Hornbuckle
Chair, Kennesaw

Constance Curry
Atlanta

Gordon Drennen
College Park

Nancy Duncan
Chamblee

John Gamble
Milledgeville

Ernestine Hooker
Augusta

Cynthia Outman
Tucker

Jim Outman
Tucker

Deborah Poole
Atlanta

Bobby Rowan
Enigma

Rob Saxon
Macon

Denise Shaw
Atlanta

A.O. "Soji" Tinubu
Atlanta

Rafael Uzcategui
Gainesville

GAO Staff

Joyce Ringer, Ph.D.
Executive Director

Coordinators

Barbara Fischer
State Citizen Advocacy Coord.

Gillian Grable
PADD Coordinator

Stephanie McKay
PAIMI Coordinator

Attorneys

Jean Estes
PADD Attorney

Leslie Kulbersh
PAIR Attorney

Angela Lavori
PAIMI Attorney

Robert Raubach
PAIR Attorney

Bruce Roberts
PADD Attorney

Naomi Walker
PAAT Attorney

Advocates

Nann Anderson
PABSS Advocate

Rafael Lopez
PAIMI Advocate

Tobin McDaniel

PAIMI Advocate

Melody Mills
PAIMI Advocate

Denise Quigley
Short Term Advocate

Joanne Reese
PAIMI Advocate

Linda Richburg
PAIMI Advocate

Anna Santiago
PAIR Advocate

Diane Tebbel
Short Term Advocate

Support Staff

Donna Champion
Office Manager

Olwyn DeMarco
Communication Specialist

Shoshana Froman
PAIMI Assistant

Veronica Jarmon
PAIR Assistant

Teresa Johnson
PAIMI Admin. Assistant

Debbie Morgan
Accounting Assistant

Sue Sanders
Financial Officer

Citizen Advocacy

**Citizen Advocacy
Athens-Clarke**
706•549•0063
Marvin Nunnally
Coordinator

**Atlanta Citizen
Advocacy**
404•523•8849
Rob Cleveland
Coordinator

**Greater Augusta
Citizen Advocacy**
706•724•1490
Susan Johnston
Coordinator

**Baldwin County
Citizen Advocacy**
912•452•6968
Margaret Chambliss
Coordinator

**DeKalb Citizen
Advocacy**
404•373•0118
Judy Maddox
Associate Coordinator

**Gainesville Area
Citizen Advocacy**
770•536•0314
Manuela Scordino
Coordinator

**Macon-Bibb Citizen
Advocacy**
912•743•1521
Connie Flair
Coordinator

**Chatham-Savannah
Citizen Advocacy**
912•236•5798
Tom Kohler
Ashley Brown
Coordinators

Consultants

Kaytha Barton
Leigh Anne Clark
Jenny Manders
Elizabeth O'Berry
Sophia O'Brien
Douglas Satkofsky
Ed Sheehan
Lex Sheehan

The Georgia Advocacy Office

100 Crescent Centre Parkway, Suite 520
Tucker, GA 30084
404•885•1234 voice/tdd
1•800•537•2329
770•414•2948 fax
<http://www.thegao.org>
info@thegao.org

2 0 0 2

Semi-Annual

Report

October 1, 2001 to
March 31, 2002

This report is available in
alternative formats upon
request.