

Advocate

The Georgia Advocacy Office...securing protection and advocacy for individuals with disabilities or mental illness throughout the state...now in our 26th year

**THE GEORGIA
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HOME IS WHERE THE HEART IS

Anna Santiago



Brenda Guess is glad to be back in her own home after spending many months recuperating in a nursing home.

Brenda Guess of Cobb County expected to go into a nursing home for only “a couple of months” for rehabilitation after surgery for a broken ankle. But with more surgery needed for her ankle, and perhaps partly due to her muscular dystrophy, those couple of months slowly turned into eight.

While Ms. Guess was in the nursing home, she had many visitors, including people from her church. Her friend Tim brought her meals on Wednesdays from the weekly church supper. “I was so fortunate to have a loyal group of family and friends from the church who came to see me,” said Ms. Guess. Her sisters also came to visit often and supported her both physically and emotionally.

But as the months passed, Ms. Guess came close to losing her Section 8 housing voucher because she was away from home for more than six months. The nursing home social worker, hoping to help save her apartment, had already put Ms. Guess in touch with the Georgia Advocacy Office.

I met with Ms. Guess and the people who had gathered around her. Together we mapped out a plan for her to leave the nurs-

Please see HOME, page 2

HOW DO YOU MEASURE LOYALTY?

LOYALTY IMPLIES A FIRM RESISTANCE TO ANY TEMPTATION TO DESERT OR BETRAY. MERRIAM-WEBSTER DICTIONARY

Olwyn DeMarco

William Gregory (not his real name) is in his early 30s. Today he is waiting in a sunny kitchen for his supper. He knows a lot about waiting.

Throughout school, William waited for bus services; he waited for promotions or transfers due to “limited seats” in education programs. After high school, he waited years at home until a workshop position opened for him. It finally came, and everything was good. Then William, who has Down syndrome, was diagnosed with Alzheimer’s.

“Before William got Alzheimer’s, he was very independent,” said Margaret, his mother. “Every day when I went to work, I left him a list of chores. When I came home, he would have every chore done and checked off the list.” William used to go to a community workshop. “He enjoyed making his lunch and laying out his clothes the night before. He loved it,” she said.

Several years ago, Margaret knew William couldn’t remain at home by himself safely. She had put his name on waiting lists for services years before, but now she was told there were no services available. She gave up her job to care for William 24-hours a day, until a nursing home placement came up. Finally, William moved into a nursing home nearby.

There were problems from the beginning. “Nursing homes like families to come on

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“Brenda is a woman with an inner strength and determination that is inspiring.”

ing home and get the help she needed to live in her own home again. I provided her with information about waivers and Section 8 policies which Ms. Guess and her family used to apply for a Medicaid waiver. Next, I spoke with the housing authority and asked that a reasonable accommodation be provided by extending the length of Ms. Guess' voucher. When Ms. Guess called and asked for the extension, she got it.

After that, things moved quickly. Tim and her sister Robin helped her find an accessible apartment in which she could fit her new wheelchair. Her sisters helped with packing and cleaning her old apartment. Even without Medicaid supportive services, Ms. Guess took a risk and moved to her new home with limited visits from home health nurses. One nurse helped her to get an emergency CCSP waiver, and a personal assistant arrived within two weeks. Her name is Rita.

“Rita brings me a cup of coffee and a newspaper and asks me what I want for

breakfast. And now I can have what I want [for breakfast] every day,” said Ms. Guess.

Being able to make decisions about when and what she can eat, when she can go outside, or even if she can go outside, is what Ms. Guess sees as the main difference between living in a nursing home and living in her own home. “I had to give up my right to privacy, modesty, dignity, and decision-making in the nursing home,” said Ms. Guess. In order to get the staff to help her with a simple activity, it took a meeting with the charge nurse, the therapist and the social worker. “In the nursing home, everything takes a committee,” she said.

Ms. Guess is a woman with an inner strength and determination that is inspiring. She is an avid reader with a diverse taste in literature. Bookshelves line the walls of her home. An entire bedroom is filled with boxes of books which she is eagerly unpacking. She looks forward to the day when her personal library is arranged on her shelves.

I asked Ms. Guess if she would be going back to church. “I hadn't thought about going back to church. I can go to church now. I'd like to go shopping, or go to the grocery store, or to the movies. I haven't been to the movies in years.” •

GLOSSARY OF TERMS

Waiver – Because Federal and state money for long-term health services for people with low incomes typically goes to institutions like nursing homes, a person who needs help with personal support and/or nursing care for daily living tasks must get a “waiver” (“exception”) if he or she wants the care given at home. There are currently several waivers in Georgia with different names, and a person's situation has to match the requirements of a particular waiver in order to get that waiver's services.

CCSP – Community Care Services Program is the name of one waiver meant for people who have a disability. It provides household and personal assistance and home health service.

Section 8 Voucher – Federal laws provide a variety of ways for people with low incomes to rent or own their own homes or apartments. A housing program known as Section 8 provides financial subsidy for a person who wants to live in an ordinary place (not a housing project) but needs extra rent money to afford it. A voucher (like a coupon) is issued by the local Housing Authority. The voucher is dated and must be used within a certain time period.

Housing Authority – Each city and county has a division of their government called the housing authority, such as the Atlanta Housing Authority. This government agency implements all the different government assisted ways to help residents with low incomes have a place to live.

Reasonable Accommodation – This term comes from the American with Disabilities Act (ADA) and covers all the possible reasonable ways owners, employers, and public buildings and services can (and in some cases, must) make things accessible to people with disabilities.

FREEDOM'S JUST ANOTHER WORD

Tom Kohler



Gary Foss celebrates his 60th birthday this year with friends and citizen advocate Sheldon Tenenbaum.

When Sheldon Tenenbaum met Gary Foss in 1980, Gary had a room in Savannah. Needing help doing things his cerebral palsy made it impossible for him to do, Gary was paying too much for the help he received.

Sheldon met Mr. Foss with hopes of helping him get control of his finances. No sooner had these two men met, than Gary needed another place to live and soon. Sheldon helped him find a rent subsidy apartment. Sheldon, as his payee, restructured debt, pushed creditors back and generally got Gary's finances in some order.

Gary met an older man, Mr. Martin, at the apartment complex who helped him out each day. These were the good years. In 1985, Gary's asthma became acute and he began to have heart problems. These things made his day-by-day life harder. In 1986, Mr. Martin's health failed and he died. Gary was crushed and without the practical help and emotional support from Mr. Martin, Gary had to be hospitalized.

Sheldon wrote to local churches, lobbied local and state Department of Human Resources officials for in-home care services. None appeared and Gary had to be discharged from the hospital into a nursing home.

From 1986 to early 1992, Gary lived in several different nursing homes. He kept telling Sheldon to get him out, to get him back into his apartment. Sheldon contacted local legislators, DHR Commissioner Ledbetter, and everybody in between. This went on for years. He also continued to be

Gary's payee, a regular visitor and faithful friend.

Then Sheldon and Gary attended a workshop held in Savannah. Speakers talked about an idea called supported living. Among the handouts was a declaration by the Department of Human Resources describing their commitment to a quality lifestyle for people with disabilities.

Sheldon wrote DHR Commissioner James Ledbetter again and asked about the state living up to its written word. He reminded the Commissioner that this was not the first time he had tried to get practical help for Gary. Sheldon asked the Commissioner to send a planning team to Savannah to meet with him and Gary and several other people that Gary knew. Sheldon's letter also suggested two progressive-thinking human service workers who could be asked to do this planning.

Commissioner Ledbetter responded. These two human service workers were sent to Savannah and on a Saturday morning, they, Sheldon, Gary, two people from Gary's church, two of Gary's friends and several Savannah human service workers met to map out Gary's exit from the nursing home. Six months after this meeting, Gary, with the help of two friends, packed up his belongings and moved into his own apartment. That was 10 years ago, and Gary is living in the same apartment that he moved into at that time, with hired personal assistants.

Mr. Foss recently celebrated his 60th birthday with a party. Several of the people attending were at the Saturday morning meeting 10 years ago. In an interview given after the party, Sheldon acknowledged that there have been problems to solve with the paid assistants and with new health issues that come up. But Gary continues to get around town on his own in his electric wheelchair after the early morning assistance.

Sheldon summed it up this way: "The issue is freedom. To Gary it means not being told, 'You can't go out, you can't do this, you can't do that,' and 'You have to do this and you have to do that.' He's a man who loves his freedom." •

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WHY CARE? GEORGIANS AND OTHERS ANSWER QUESTION CLEARLY WITH LIVES AND WORDS

Elizabeth O'Berry

In Georgia and elsewhere, leaders and thinkers in the field of civic life ask and answer a very important question, which goes something like this: "What is a reasonable, legal and civil response by the citizenry, acting through their budgeted funds and their public servants, to people who need help to live reasonably well among us when they are also challenged by physical or mental impairments?"

This question comes up each time we read newspaper accounts such as "Dying in Darkness" and "Nursing Home Abuse" or visit people with disabilities who are isolated. Answers are in the stories of the heroic efforts made by people and their family and friends to escape from isolation and confinement (see this edition's stories) and in thoughtful written works, some of which are quoted below.

"Home is a nearly sacred concept to Americans. Home is where we can be ourselves, where we can choose our own activities. Home is where we can be with the people with whom we want to be; it is a haven from those with whom we don't want to be. Home is the foundation of our personal liberty and our pursuit of happiness. It is the center of our community participation and our independence in daily living."

John O'Brien

"The common life of North America is so segregated that the absence of experience with those who are excluded has led many citizens to imagine that these labeled people are somehow inappropriate for community life. Many have come to believe that labeled people are so incapacitated that their lives literally depend upon separate and expert attention. Having accepted this proposition, most citizens lead segregated lives in which they can only imagine labeled people. The result is that the very isolation created by services has stimulated many fantasies in the popular

mind. Many citizens imagine that human beings labeled developmentally disabled are unacceptable in everyday life and helpfully isolated by the professional care that is the only "good thing" that a "good society" can do for them.

Obviously, some people who have been excluded forge a path back into community on their own. This is often a heroic struggle that requires great commitment and persistence." (See stories in this newsletter. Ed.)

John McKnight

"Getting personalized residential and community supports and services of high quality in Georgia can be difficult and very time consuming if you have a disability or mental illness, even though the Supreme Court decision in *Olmstead v. L.C.* affirmed the fundamental premise that people with disabilities cannot be arbitrarily "served" in segregated and isolated institution-like services or programs that keep people from sharing places (in homes and neighborhoods) and from participating in significant ways (in work and school, for example) with typical citizens (Ezekiel, 1999)."

David Truran

"The real challenge is to create a durable culture of caring to protect and nurture people with developmental disabilities as they learn and develop their decision-making capacities; and to support them as they reach for the fruits of full citizenship. Bureaucrats and providers, families and advocates, co-workers and friends, frontline staff and monitors, must embrace this culture A cornerstone of this culture must be a vigilant and effective governmental role supporting a stable workforce, and in monitoring and ensuring accountability for performance by those to whom it entrusts this responsibility."

Clarence Sundram

“Of all the domains in which I have traced the consequences of social capital¹, in none is the importance of social connectedness so well established as in the case of health and well-being.”

¹Social Capital is a term used for the collective value derived from the flow of information, mutual aid and the greater good generated by being connected to each other.

Robert Putnam

“Stand up for a coherent vision of community life for everyone. Survival is not enough. Compliance with health regimens is not enough. Assisting people to discover rich lives of belonging and contributing to the life of their communities is the only sufficient goal. It is possible to try to provide a particular person or family such assistance and fail; what would be wrong is to fail to try.

- Georgia ranks 50th in terms of placement in community residences of 15 or fewer people. Only Kentucky serves fewer people per 100,000 of its population in smaller community residences. Kentucky has recently adopted a legislative initiative to remedy their service shortfall.

- 1.8% of residents in Georgia’s institutions are children aged between 1-14. The national average for this age group is less than half that, at 0.7%.

- In 1998, Georgia ranked 13th in the nation in per capita nursing home utilization for people with developmental disabilities. Georgia kept 1576 people with developmental disabilities in nursing homes, a rate of 21/100,000 population. South Carolina kept 121 people in nursing homes a placement rate of 3/100,000 (7 times lower than Georgia’s) and has a public commitment to systematically decrease this number.

- Fiscal effort measures expenditures on developmental disabilities services as a proportion of the total income of its state’s population. On this measure, Georgia’s investment in community services fell from 7th in the US in 1977 to 44th in 1998.”

Connie Lyle O’Brien

From these and other sources, the answer would seem to be that a bed in a nursing home is not a reasonable, legal, or civil response to fellow Georgians who need help to live reasonably well among us when they are challenged by physical or mental impairments •

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GEORGIANS SERIOUS ABOUT GETTING PERSONAL ASSISTANCE AT HOME

Joyce Ringer

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Recently, a suit was filed in federal court in Atlanta (Birdsong, see *The Atlanta Journal-Constitution*, 2/7/03.) on behalf of persons with physical disabilities who now receive or are seeking to receive long-term health care services administered by the state. The suit is based on the premise that people with disabilities in nursing homes or who are at risk of nursing home placement have been unnecessarily segregated. The state is legally obligated to provide services in the most "integrated" setting – in this case, home or other community place, rather than a nursing home. Also, most people have not been informed of the community alternative to life in a nursing home.

It is clear from reading the lawsuit that Georgia public policy prefers to spend our tax dollars in nursing home care, rather than

in home and community care. According to the Georgia Department of Community Health, in FY2000, 50,004 individuals were served in nursing homes, while less than 1/3 that number (13,647) were served under the various home and community waivers.

One of the facts cited in the case concerns budget. "In 2001, Georgia spent \$1,099,000,000 (that's \$1.09 Billion) in combined state and federal funds on long-term care. Approximately 79% or \$872M of Georgia's expenditures for long-term care services goes to institutional rather than Home/Community services. More than 69% or \$760M of these institutional expenditures goes to nursing homes. Only about 6% of Georgia's overall Medicaid expenses cover Home & Community based services."

You, our readers, are citizens of Georgia. Make your voices heard. •

LOYALTY, continued from page 1

Sundays, when everything and everyone is clean and sweet smelling," Margaret said. She visited often, and what she learned about nursing home care – even in a home she calls "adequate" – was painful.

"William needed to be treated like a person. They didn't get it," said Margaret. When he refused a bath, staff wrote in his chart that he refused it, but no one made sure he eventually got a bath. "The nursing home housed him, but I gave the baths, or I paid an outsider to do it," Margaret shared. They said William "wouldn't allow" them to change his clothes or shave him. His skin, which had been healthy, soon developed serious problems.

Then William became unable to eat and nursing home staff refused to help. "Alzheimer's causes difficulties with eating," said Margaret. "His medications caused problems too." Also, William ate slowly, and staff often removed his food before he was finished. "But the real problem was that they neglected William's teeth," she said.

Margaret hired a private attorney and called the Georgia Advocacy Office. The attorney clarified William's legal rights. "I felt

then that he needed to be out. But where would he go?" she asked. "I had to work, and my whole family was worried about my mental and physical health."

"Gillian, from the Georgia Advocacy Office, urged me to try again for a community placement," said Margaret. Gillian provided support, giving her the courage to try the system once more. Once Margaret saw the home – not a nursing home – where William could live, she helped him fill out an application to move into it. One question on the application asked, "What three things are you looking forward to doing in the coming year?" William responded, "Bowling, going to a social club, and getting up." (He has trouble getting out of bed.) It doesn't seem like too much to ask after the long years of waiting.

William moved into his home last month. He has a roommate, and someone is there 24-hours a day to provide the care he needs. He is looking forward to spending his days being productive. More than anything, he wants to spend time with his friends again.

"William has family and wonderful friends who care about him," said Margaret. "His new home is five minutes away. That's good." •

DIFFERENT THINKING, DIFFERENT ACTION CALLED FOR BY GEORGIANS

Elizabeth O'Berry

Based on the stories in this newsletter and on the papers quoted, it seems evident that a different level of thinking and acting in Georgia is needed in order for us to all live together. The Georgia Advocacy Office is offering the following workshops which support that aim.

VALUED SOCIAL ROLES (SRV)

This workshop exposes devaluation of people with disabilities so that we can see it in many of its most prevalent forms. Devaluation as a force which can override our good intentions thrives on our unconsciousness. In this workshop, much evidence is presented in lectures and slides to help overcome our disbelief that we really have these habits. Other time is spent in small groups to see what our own experience can teach us and to help each other see more clearly. The second day and a half are spent on a different vision and a set of principles that with diligence and practice can keep us on a higher road. Other workshop attendees can be a set of allies for you as you try to separate yourself, your family member or the person on whose behalf you are working, from devalued social roles and into fuller participation and acceptance in community life.

PASSING

A PASSING practicum is an opportunity to spend five days and evenings with nine other people and an experienced team leader looking intensely at two real operating services for people with disabilities. Using a higher level of consciousness gained in the Valued Social Roles (SRV) workshop, you will be able to systematically observe a myriad of practices which would have been unobservable before. New realizations and insights will help you in your personal life, your work, and your civic life as you relate to people who are typically isolated from community.

“ The world we have made as a result of the level of thinking we have done thus far creates problems we cannot solve at the same level of thinking at which we created them. ”

Albert Einstein

VALUED SOCIAL ROLES 2003

DATE	May 22, 23, 24, 2003
LEADER	Joe Osburn
PLACE	Carrollton, GA
FEE	\$150
# OF PARTICIPANTS	40

DATE	October 9, 10, 11, 2003
LEADER	Darcy Elks
PLACE	Atlanta, GA
FEE	\$150
# OF PARTICIPANTS	40

“ Whether or not you can observe a thing depends upon the theory you use. ”

Albert Einstein

PASSING 2003

DATE	Sept. 23 - 27, 2003
LEADER	Joe Osburn
PLACE	Macon, GA
FEE	\$250
# OF PARTICIPANTS	10

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GAO Vision and Mission State- ments

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.

Mission Statement

To organize our re-sources and follow our 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.

The GAO

Advocate

March 2003

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This newsletter is
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formats upon request.

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- 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 (PAIMD);
- US Dept. of Education/Rehabilitation Services (PAIR);
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