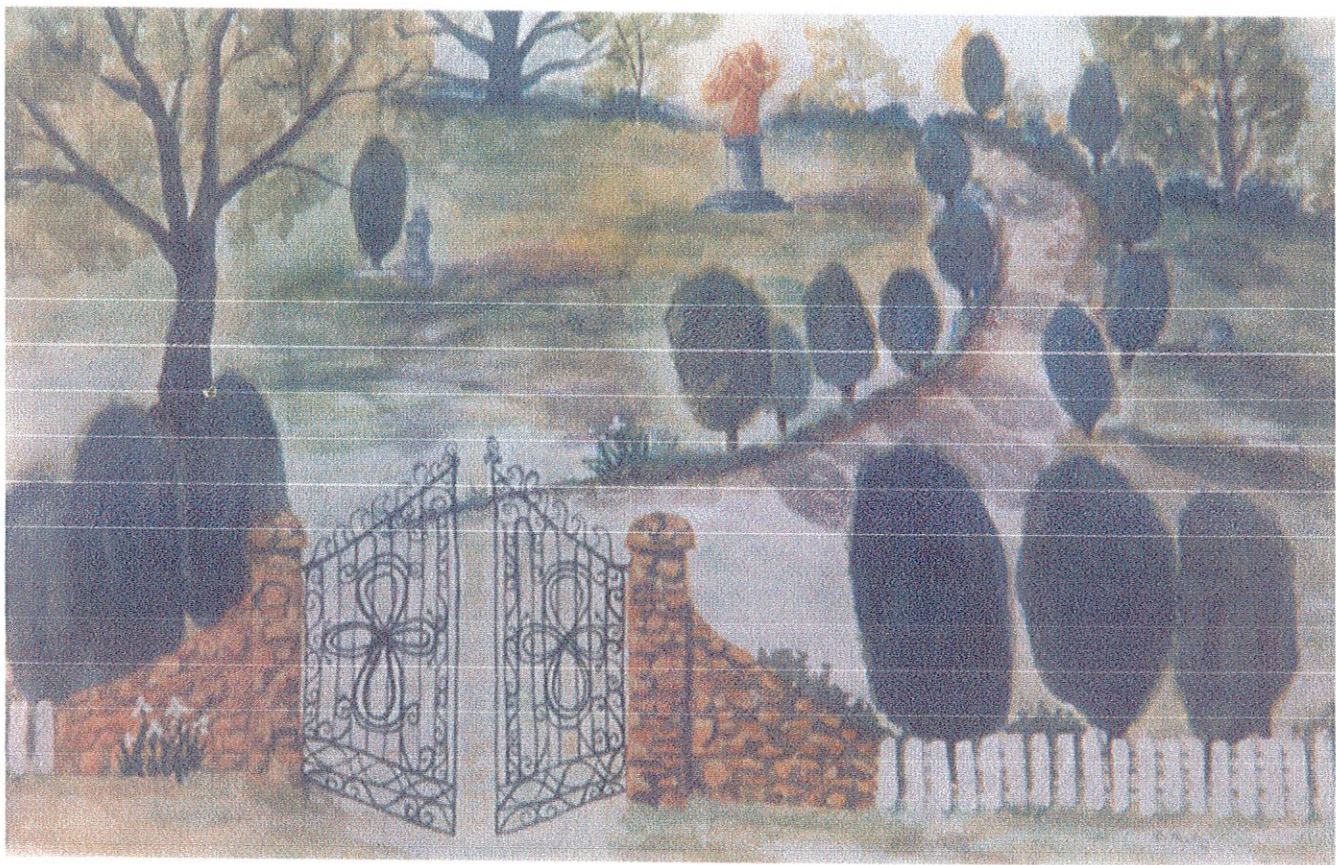


# *The Georgia Story:* How to Successfully Restore a State Hospital Cemetery



A technical assistance manual funded by the federal Center for Mental Health Services as part of a special project of the National Empowerment Center entitled: *It's About Time: Discovering, Recovering and Celebrating Psychiatric Consumer/Survivor History.*

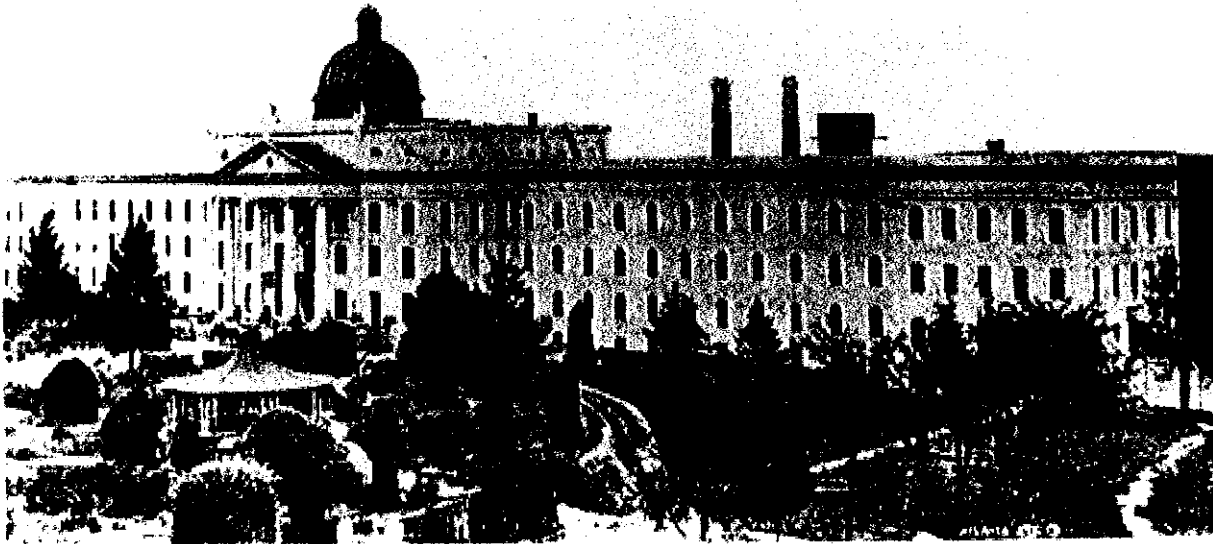
by Larry Fricks for the Georgia Consumer Council



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*Front view of main building (Powell) 1894*



*Present day view of Powell Building*

*Dedication:*

*To the 30,000 people buried at Central State  
Hospital--*

*You are not forgotten*





(1)

The Georgia Consumer Council was formed and staffed by the Office of Consumer Relations. It was the Georgia Consumer Council members who toured the cemetery at Milledgeville in March 1997 and chose to start the cemetery restoration and memorial. Looking back, the members of the Georgia Consumer Council credit much of the success to taking the high moral ground and promoting a positive message that was not about blame or finger pointing. This project was about building something good, about restoring dignity and respect, not about attacking others, state institutions or the past. Georgia's consumers set off on a positive journey that demonstrated deep resolve and hard work. Along the way that quiet "can-do" attitude became a magnet for others to join in and help serve a greater purpose.

Georgia's Office of Consumer Relations is part of the state's senior management team for the Division of Mental Health, Mental Retardation and Substance Abuse (DMHMRSA). Larry Fricks is the Director.

Copies of this technical assistance manual can be obtained by contacting: Larry Fricks, Office of Consumer Relations, 2 Peachtree Street, Suite 23-411, Atlanta, Ga 30303; (404) 657-2100; e-mail [LFricks@dmh.dhr.state.ga.us](mailto:LFricks@dmh.dhr.state.ga.us)

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*“That the effort to bring recognition and dignity to the 30,000 patients buried on the hospital grounds is being undertaken by those who have been mentally ill themselves is an indication of how far society has come since the early days of the hospital. We no longer waste the talents and abilities of these survivors, and this project, when completed, will stand as a monument to their determination.”*

*—Dr. Peter Cranford, Georgia*



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*“These were the unwanted of society, the throwaways. Nobody cared if they had markers. We knew that could have been us. It was devastating.”*

*—Doris Hester, Georgia*

## **Chapter 1. A History of Georgia’s Cemetery Restoration**

*“Rows upon rows of numbered, small, rusted markers as far as you can see. No names, just numbers. It must be the most gruesome sight in Georgia. Unknown humans, shunned when living, deprived of their very names in death - and literally known only to God.”*

The soul-stirring quote above is attributed to Joe Ingram, an employee at the state psychiatric hospital in Milledgeville for 50 years. Mr. Ingram’s poignant words capture much of the stigma and despair associated with mental disabilities. That despair was amplified in March of 1997 when members of the Georgia Consumer Council toured a cemetery at Central State Hospital and were confronted with the bleak reality that many of the “rows of numbered, small, rusted markers” had been removed, or were choked with underbrush. Astonishingly, we learned that during the late 1960’s, or early 1970’s, the markers had been either pulled up or pushed down into the ground, to make it easier for hospital crews to mow the grass. Several members of our group openly wept as the awareness of the degradation and inhumanity sank in. Comments were made that society has more respect for a pet cemetery than was evidenced by the abused and neglected human graves surrounding us that day. Our emotions ranged from hurt to rage, with all of us sensing that the experience would forever touch our lives.

Further research revealed that the six neglected cemeteries on the hospital grounds interred up to 30,000 of our brothers and sisters, making it perhaps the largest graveyard for people with disability in the world.

As Georgia Consumer Council member Doris Hester stated, “These were the unwanted of society, the throwaways. Nobody cared if they had markers. We knew that could have been us. It was devastating.”

Before that dreary March day was over, our devastation was reborn as a unified vision to restore the cemetery, identify as many graves as possible and erect a memorial that would serve as a perpetual reminder of the horror of our past.

The memorial includes an ornate iron gate that is a replica of a gate that once led into the women’s cemetery. It will always be open to visitors and is accompanied by replanted white iris brought to Georgia by early settlers – a symbol of the resilience required to survive our disabilities and history of neglect and abuse. A bronze angel, recognized as a symbol of hope in all major religions, will



*When a group of oppressed people can not only recover, but can recover to the point where they are able to make an impact on the greatest symbol of their oppression, stigma shrinks and hope returns.*

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stand as a guardian overlooking the cemeteries. Between the entrance gate and the bronze angel, along an old road bed lined with cedar trees, a series of rock boxes will be constructed to display some 2,000 displaced iron markers. White iris will also be planted in the rock boxes alongside the markers.

And then began a series of miracles that none of us will ever forget. It was as though a higher power had chosen this time to shine a light on our dark past and illuminate new hope for the future. Media stories swirled around our project including coverage in *The Atlanta Journal-Constitution* and *USA Today*. Donations began to trickle in, missing grave markers were unearthed, and state authorities, advocates, family members and consumers climbed on a bandwagon of support. Dr. Peter Cranford stepped forward to donate as a project fund-raiser the printing rights to his book, *But for the Grace of God, Milledgeville! The Inside Story of the World's Largest Insane Asylum*.

And then closure. The last major piece of the project fell in place in a very dramatic way. On the last day of the annual statewide consumer conference held August 22-24, 2000, Dr. Tom Hester - Georgia's Medical Director, who also oversees the eight state hospitals - brought the audience to their feet and tears to the eyes of many consumers when he formally apologized for the past abuse and neglect in our institutions.

"I am sorry," said Dr. Hester. "I am sorry on behalf of the state of Georgia, I am sorry on behalf of institutions, which, in the past, despite whatever intentions they may have had, have trampled human spirits, have not allowed recovery to flame."

He also asked forgiveness for disrespect of the cemeteries and pledged that Georgia would fund action that would complete the cemetery project, make application for cemeteries to be on the National Historic Register and provide perpetual care. The speech was so climactic and such a balm for healing that the Georgia Consumer Council members voted to have it replicated in full and published in Chapter 5 of this technical assistance manual.

Looking back, the members of the Georgia Consumer Council credit much of the success to taking the high moral ground and promoting a positive message that was not about blame or finger pointing. This project was about building something good, about restoring dignity and respect, not about attacking others, state institutions or the past. Georgia's consumers set off on a positive journey that demonstrated deep resolve and hard work. Along the way that quiet "can-do" attitude became a magnet for others to join in and help serve a greater purpose.





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*“When I grew up people told you if you didn’t behave, you were going to Milledgeville. We’ve come a long way, baby, and we have to restore the cemetery to show how far we have come.”*

*—Tilda Davis, Georgia*

And the spirit of cemetery restoration has also surfaced in other areas of the country. In Chapter 6, we will look at unique cemetery projects underway in Massachusetts, Minnesota, Arizona, Connecticut, Ohio, South Dakota and Washington.

But now let’s look in depth at the Georgia story. It is our hope that this technical assistance manual will help support other consumer/survivor groups in the country that believe *It’s About Time: Discovering, Recovering and Celebrating Psychiatric Consumer/Survivor History*.

## *Chapter 2. Why Restore?*

**A**cross the country, the term “recovery” is frequently surfacing in regard to people with mental illnesses. Historically, that word rarely appeared when folks discussed serious and persistent mental illnesses such as schizophrenia and manic depression that often conjured up images of lifetime disability and hopelessness. In fact, the hopelessness is often worse than mental illness, and we have discovered that many Georgia consumers who have been residents of state institutions or longtime attendees of day treatment programs have little or no hope that they can recover. Georgia was the first state to recruit a team of consumers as AmeriCorps\*VISTA members trained to conduct hope-in-recovery dialogues. More and more consumers are awakening to their peers sharing the good news that we can and do recover. That good news has been voiced best in recent years by the consumer movement and is beginning to have an impact on the service delivery system nationwide.

For example, based on the old beliefs that we can’t and don’t recover, Georgia invested heavily in an institutional system that removed us from society and resulted in what became known as “the world’s largest insane asylum” located in Milledgeville. Founded in 1842 as the Georgia State Lunatic Asylum (now called Central State Hospital), this institution swelled into a small city of some 3,000 acres with its own zip code and a patient population that soared to more than 12,000 in the late 1950’s and early 1960’s. Most people who were sent to Milledgeville never returned home, and many - up to 30,000 - were simply buried on the hospital grounds. In many ways, state institutions became the primary symbol of stigma and hopelessness. The asylum opened in Milledgeville was the fourteenth in our nation and was no different than other state institutions. The original goal was humane treatment, but along the way dark atrocities scarred its history including abuse and neglect, forced lobotomies, dangerous experimentation without consent, the use of electric shock treatment for punishment, and over medication.

*“It shows that we can not only reclaim our lives, but also can restore the dignity of the lives of our brothers and sisters.”*

*—Linda Buckner, Georgia*



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As Dr. Peter Cranford describes the Milledgeville institution in his book entitled *But for the Grace of God*, “It has witnessed the heights of man’s humanity and the depths of his degradation.”

The once-giant institution used to strike fear in the hearts of Georgians.

“When I grew up people told you if you didn’t behave you were going to Milledgeville,” says Georgia native Tilda Davis, a new leader in the state’s consumer movement.

But today, because the beliefs are changing, Georgia is shifting the majority of its funding into community services, and has begun to invest more in recovery-oriented services such as supported employment.

“We’ve come a long way, baby,” says Tilda, “and we have to restore the cemetery to show how far we have come.”

What Tilda is describing is one of the core reasons that restoring a state cemetery and building a memorial can be so powerful: it attacks the dark underbelly of the stigma of mental illness and has dramatic outcomes of personal empowerment and self help.

“Stigma is greatly reduced,” says Americorps\*VISTA member Donna Neeley.

When a group of oppressed people can not only recover, but can recover to the point where they are able to make an impact on the greatest symbol of their oppression, stigma shrinks and hope returns. And such symbols of hope must be preserved so we never forget how far we have come--from among the most stigmatized members of society ever known, to a group of organized peers who are able not only to document their brutal past, but also to memorialize those who were the greatest victims of the injustice.

“It shows that we can reclaim our lives, and at the same time restore the dignity of the lives of our brothers and sisters,” says Consumer Council member Linda Buckner.

As an added value, a cemetery restoration project serves as a rallying point for a movement like ours with enormous potential to organize around a common goal. Such a project also reminds consumers that they are part of a new way of doing business and helps renew their hope in self-directed recovery. In Chapter 6 we will share insights into how the consumer movement in Minnesota has developed a detailed, self-advocacy training that includes a video and manual about their cemetery project.





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*"The cemetery project has become a powerful moral force and is bringing the dead back to life."*

*—DeLois Scott, Georgia*

"I'm glad that we have a new system," says Myrta (Dee-Dee) Rodriguez who is also an Americorps\*VISTA member. "I feel very, very lucky."

JoAnn Baldwin agrees that the cemetery project helps her appreciate the improved medications and treatment available and the opportunity to be served in the community rather than "stay in an institution."

Dr. Peter Cranford, who started the Psychology Department at Central State Hospital and wrote the book, *But for the Grace of God*, sums it up this way, "That the effort to bring recognition and dignity to the 30,000 patients buried on the hospital grounds is being undertaken by those who have been mentally ill themselves is an indication of how far society has come since the early days of the hospital. We no longer waste the talents and abilities of these survivors, and this project, when completed, will stand as a monument to their determination."

DeLois Scott, Executive Director of the Georgia Mental Health Consumer Network, says the cemetery project has become a powerful moral force and "is bringing the dead back to life."

For some Georgia consumers such as Vonda Copeland and Belva Barndhart, who had family members with mental illness, the project is very personal and helps soothe their pain regarding the injustices done to their ancestors.

Belva's grandfather committed suicide and because of the shame of taking his own life, the family did not record his death date and did not want to acknowledge his passing.

"We have to honor these people," says Belva.

Vonda's great grandfather was a patient in Milledgeville. She says the cemetery project helps her believe that people do care, and helps her feel better about her ill-treated relative and herself.

Goldie Marks, who serves as President of the Georgia Mental Health Consumer Network, was a former patient at the institution in Milledgeville and received shock treatment there. She says for 26 years she was unable to return to that institution because the emotional scars were too deep. But the cemetery project has proved healing for Goldie; she is now comfortable visiting the grounds of the hospital.

"It has given me peace," says Goldie.

*"It has given me peace."  
—Goldie Marks, Georgia*



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That's echoed by Kaytha Barton who says that when she first visited the cemetery in Milledgeville she was overcome with feelings of sadness and thoughts of "it could be me." But now Kaytha says that she is at peace and "feels good about what we've done to give our brothers and sisters the remembrance they deserve."

Casey McClain and Diane McCarty, who have both worked at Central State Hospital, wrote more in-depth insights regarding the cemetery project that are in Exhibit A of the Appendix. Casey's is entitled, *In Search of Papa Williams*, and journals the special meaning of locating her great-grandfather's grave in Milledgeville and the peace it has brought her family. Diane shares insights into the emotional journey the cemetery project led her on in a personal account, *Road to an Angel Via Hope, Recovery and Spirituality*.

Finally, a cemetery project can not only unite local consumers around a powerful moral cause and help bring closure to families searching for ancestors, it can also ripple out into other states. In Exhibit A of the Appendix is a poem written by Mike McNellis, a consumer in California who so impressed consumer leaders in Georgia that he was invited to read his moving tribute during the 1999 annual Georgia Consumer Network conference. And now consumer organizations in a dozen other states have begun similar projects.

### ***Chapter 3. Organizing and Forming an Action Plan: Fund-raising, Collaborating with other Groups and Working with the Media***

Every consumer movement has its similarities and its differences, so organizing for a cemetery restoration project will, no doubt, vary from state to state and community to community. The organization of Georgia's cemetery project was shaped significantly by the organization of Georgia's formal consumer movement, so it makes sense to share some insights about how that movement is aligned in this state.

The key components of Georgia's statewide mental health consumer movement in the order that they came into existence are as follows:

- The Georgia Mental Health Consumer Network, Inc., (GMHCN) which is a 501 (C-3) nonprofit that was incorporated in 1991, has a very active board of directors from across Georgia and a full-time executive director. GMHCN hosts the largest consumer conference of any one state in the country, and at that annual conference the attendees vote on the top 5 priorities they want the





*The memorial includes an ornate iron gate that is a replica of a gate that once led into the women's cemetery. It will always be open to visitors and is accompanied by replanted white iris brought to Georgia by early settlers – a symbol of the resilience required to survive our disabilities and history of neglect and abuse. A bronze angel, recognized as a symbol of hope in all major religions, will stand as a guardian overlooking the cemeteries.*

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state service system to focus on for the upcoming year. Since the first conference was held in 1992, the #1 priority has been employment, and GMHCN has had significant impact in shifting the state toward supported employment.

- The Georgia Office of Consumer Relations, which was founded in 1993 at the request of the leadership of GMHCN, was established to be an internal change agent focusing on the top priorities of GMHCN and shaping state policy to carry out those top priorities. In Georgia, maximum impact on the service system is achieved through the teamwork of a strong external consumer advocacy movement, which sets the top priorities through its voting consumer membership, and then is supported in the implementation of those priorities by the Office of Consumer Relations. Georgia's Office of Consumer Relations is part of the state's senior management team for the Division of Mental Health, Mental Retardation and Substance Abuse (DMHMRSA), and can help shape policy. This tandem effort is supported by the moral force of first identifying what the consumers say they want and then carrying out that vision through planning and policy.
- The Georgia Consumer Council was organized in 1994 after Georgia underwent dramatic restructuring of its service delivery system by creating 13 regions and shifting funding decisions to 13 regional boards. By law those new boards had to be comprised of at least 50 percent family members and consumers representing services for mental health, mental retardation and substance abuse. People First of Georgia was founded as a statewide consumer organization for people with developmental disabilities, and the Georgia Association for the Prevention and Treatment of Substance Abuse was organized for consumers with substance abuse issues. There was need to have a junction for all three statewide consumer organizations – GMHCN, People First and GAPTSA -- and consumer representation from the newly formed 13 regions and the state hospitals. As a result, the Georgia Consumer Council was formed and staffed by the Office of Consumer Relations. It was the Georgia Consumer Council members who toured the cemetery at Milledgeville in March of 1997 and chose to start the cemetery restoration and memorial. Actually, until 1921 when a state hospital was opened in Georgia for people with mental retardation, most persons with any disability who were cared for by the state were sent to Milledgeville. Among the some 30,000 buried there, most are people of cross disability. Thus, the Georgia Consumer Council was well suited to carry out the cemetery project.

Georgia, therefore, had an infrastructure in place that could impact the policy makers and build support for the vision of cemetery restoration and erecting a memorial.

The action plan came together as follows:

*The Smithsonian Institution in Washington, D.C. is now displaying one of the numbered iron markers from the cemetery in Milledgeville as part of a special exhibition commemorating the 10-year history of the Americans with Disabilities Act.*

- First the vision came from the Georgia Consumer Council that we would restore the cemetery and build a memorial.
- The Office of Consumer Relations next met with the DMHMRSA Director and secured full backing for the project.
- The Georgia Consumer Council began using its monthly meetings to plan phases of the restoration and memorial. Once they decided on what they wanted, bids were taken on special items such as a bronze angel to be erected in the cemetery.
- Central State Hospital hired Georgia Consumer Council member Diane McCarty as its first consumer specialist. The hospital supported the project and Diane became the local spearhead, communicating the vision of the council members to the hospital administration and personally investing her gifted talents in raising community awareness.
- The media was contacted regarding the cemetery project and the first of many stories appeared in newspapers and on radio and TV. (See media stories in Appendix, Exhibit B).
- The Superintendent of Central State Hospital contacted the Department of Corrections and arrangements were made for inmates to help clean up first of the overgrown cemeteries.
- The hospital also provided labor to help build the first phase of the memorial, which included erecting a rock wall at the entrance to the cemeteries.
- As a result of the media coverage, the first donations for the project came in to begin the Georgia Consumer Council's fund-raising efforts.
- The Board of Directors of the Georgia Mental Health Consumer Network, Inc., agreed that their nonprofit corporation would act as the fiscal agent for the cemetery project with funds held in the GMHCN checking account. Checks made out for the project were now tax deductible with every penny going toward the restoration and memorial.
- At the August 1997 annual GMHCN conference, consumers made donations to the cemetery project. At that time, the first rendering of the memorial was unveiled.
- Other advocacy organizations in Georgia – such as the National Mental Health Association of

Georgia and the National Alliance for the Mentally Ill of Georgia--stepped forward to support the cemetery project with funds and promotions.

*Dr. Peter Cranford, who wrote **But by the Grace of God**, presented the Georgia Consumer Council with the right to publish the only history of Milledgeville and sell that book as a fund-raiser for the project.*

- Dr. Peter Cranford, who wrote, *But by the Grace of God*, presented the Georgia Consumer Council with the right to publish the only history of Milledgeville and sell that book as a fund-raiser for the project.
- The Georgia Consumer Council retained the University of Georgia to publish Dr. Cranford's book, secured personal, corporate and advocacy funding for the printing of the book, and began selling the book statewide.
- Dr. Pat Deegan, of the National Empowerment Center, Inc. (NEC) located in Lawrence, Massachusetts, contacted the Georgia Consumer Council about the cemetery project. Dr. Deegan had begun researching cemeteries located on the grounds of state hospitals around the country. She had the vision for *It's About Time: Discovering, Recovering and Celebrating Psychiatric Consumer/Survivor History*. Dr. Deegan traveled to the state and met with the Georgia Consumer Council. Her article about the Georgia cemetery project in the NEC newsletter and her presentations across the country helped promote the efforts nationwide.
- Diane McCarty constructed a portable display board, that included many of the news articles on the cemetery project and one of the numbered iron markers, to use with presentations made across the state and at national mental health conferences.
- Georgia consumer leader Stuart Perry walked from Americus, Georgia, to Chicago, Illinois, to raise awareness about treating depression. With support from the National Mental Health Association, he sold a special edition of Dr. Cranford's book along the 1,000-mile journey.
- Various fund-raisers by Georgia providers during the Spring/Summer of 2000 helped pay the cost of the bronze angel. The checks were presented at Georgia's annual consumer conference held in August.
- The Smithsonian Institution in Washington, D.C., is displaying one of the numbered iron markers from the cemetery in Milledgeville as part of a special exhibition commemorating the 10-year history of the Americans with Disabilities Act.
- Consumers from Georgia are trying to place the cemeteries at Central State Hospital on the National Register of Historic Places. The National Register, which is maintained by the U.S. Department of the Interior, helps preserve historic properties by providing formal recognition of a property's historical, architectural, or archaeological significance. National Register designation helps in future community preservation planning and ensures that the property will be considered for state or federally assisted projects. More specifically, properties listed on the National Register may qualify for state and federal preservation grants, federal investment tax credits, preservation easements to nonprofit organizations and local property tax abatements. The plan was supported by the Commissioner of Georgia's Department of Human Resources, who sent letter requesting the cemeteries be placed on the National Register of Historic Places to begin that



*Georgia consumer leader Stuart Perry walked from Americus, Georgia, to Chicago, Illinois, to raise awareness about treating depression. With support from the National Mental Health Association, he sold a special edition of Dr. Cranford's book along the 1,000-mile journey.*



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process. The application is currently underway.

- By the Spring of 2000, the Georgia Consumer Council reached the conclusion that its members would focus on raising the funds for the bronze angel, and would ask the Division of Mental Health, Mental Retardation and Substance Abuse (DMHMRSA) to help support the application for the National Register, finish cleaning up the remaining cemeteries, complete the memorial using the 2,000 displaced markers and provide perpetual care. If DMHMRSA was not able to meet the request, the council members would seek legislative support to fund such action during the next General Assembly. The request was formally submitted to DMHMRSA and the response was truly remarkable. The state used the annual consumer conference held in August 2000 to respond to the request. It not only offered full support to complete the project as envisioned by the Consumer Council and to provide perpetual care, but also offered a formal apology, delivered by Dr. Tom Hester, Georgia's Medical Director who also oversees the eight state hospitals. Dr. Hester's speech is printed in Chapter 5.

This is the action plan that has unfolded to date in Georgia. We hope at least some of our steps may help other consumer organizations. As mentioned before, having a local consumer infrastructure in place is important, but a cemetery project of this magnitude can help organize consumers statewide into a unified consumer movement that survives to address other issues.

With regard to fund-raising, collaboration with other groups and working with the media please consider the following insights:

- Fund-raising - The members of the Georgia Consumer Council decided early on that both the outcome, and the process of the project could be a major stigma buster that sent a powerful message of self help, empowerment, hope and recovery. Therefore, the members decided that consumers should use the grassroots approach to raise as much of the funding as possible. Obviously, a state legislature could be approached to fund such a project, and one day, Georgia consumers may choose to go that route. But to date, there has been an uncanny "moral force" propelling us to do it on our own, and along the way many powerful messages have unfolded. For example, Dr. Peter Cranford stepping forward and offering his book as a fund-raiser no doubt resulted from his admiration for consumers' leading the way on this project. And though there have been state hospital staff, such as Bud Merritt and Linda Morrison at CSH, who doggedly attempted to raise awareness about the neglected cemeteries, the project never "grew wings" and lifted off until it was owned by the Georgia consumers. Ultimately, the council members came to





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*Obviously, a state legislature could be approached to fund such a project, and one day, Georgia consumers may choose to go that route. But to date, there has been an uncanny “moral force” propelling us to do it on our own, and along the way many powerful messages have unfolded.*

the conclusion that the state should be asked formally to pitch in and support some aspects of the project. That request was responded to in a very dramatic way that included financial support and a healing apology. But never underestimate the influence and respect earned by consumers demonstrating the determination to “go it alone” if need be. Consumers can use a cemetery project to gain respect, and to educate policy makers and the public by seeking funding through the state legislative process.

- **Collaboration With Other Groups** – This is essential. We discovered that the moral force around such a project ripples into people, organizations and places you would never imagine. Again and again we have seen where inclusion has strengthened the message, the process and the outcomes. A perfect example has been the fund-raising support provided by the community service boards, the public providers of services for the system, as well as by advocates and family members.
- **Working With The Media** – Once again, if your cemetery project comes from the consumer movement, the news media are attracted because they find a story within a story. They are drawn to the project and its outcomes and also to the fact that the people who were once so stigmatized and ostracized by society are the very ones leading the way. We did not have significant success sending out press notices, but have discovered that a few journalists became so personally involved that we simply phoned them when we had a media-worthy event and usually received extensive coverage. Personal contact with journalists has greater impact than mailing press releases. On several occasions we learned that the journalists most interested either had been treated for mental illness themselves, or had a family member with mental illness.

We also experienced considerable success with holding annual commemorative events that attracted the media. For example, we stage a special ceremony at the cemetery each October during national Mental Illness Awareness Week which provides the opportunity to share with the media the accomplishments during the last year, plus our plans for the future. Every December, the Georgia Governor’s wife visits Central State Hospital as part of a traditional Christmas celebration and we use that opportunity to invite her to hang wreaths on the gates of the cemetery. That event draws media coverage and serves as an excellent photo opportunity.

We also shine a spotlight on the reporters who have “gone the extra mile” in their coverage of the cemetery project by presenting them with an award at the annual consumer conference. The year 2000 award was presented to Don Schanche Jr. of the *Macon Telegraph* who has written numerous stories about the cemetery project. We asked Don to share his insights on why our project has received such excellent media coverage.



*The records kept by the state hospital in Milledgeville since it opened in 1842 are poor and some are lost. Also, ground crews either removed or pushed down into the ground thousands of iron markers in the late 1960's or early 1970's, and we saw that it might not be possible to replace all the markers. That is a major reason the Georgia Consumer Council has developed a memorial that would incorporate all the misplaced markers.*



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Here's Don's input:

"There is something compelling whenever people without a voice are given the chance to speak.

And if the voiceless people happen to be speaking from the grave — and if they are given voice by living people who have suffered and been voiceless themselves — there is no way to ignore the story.

I was fortunate to be an editor of The Union-Recorder in Milledgeville during the late 1990s when the Georgia Consumer Council began its cemetery project at Central State Hospital. Through my contacts at the hospital I learned about Diane McCarty, a mental health consumer who was spearheading an effort to restore the names, the perpetual care and the dignity of 30,000 deceased hospital patients who lay in anonymous graves in the 150-year-old hospital's cemetery. I had heard about the cemetery for years — the people buried under numbered stakes, with no name to mark their graves — and felt there must be a story. But not until Diane and other Council members opened the door, and opened their own lives, was there a way to make that story personal and meaningful.

I think there were several keys to why the story connected in such a powerful way with people in the media and the public.

First there was the revelation of a hidden human tragedy. It had been hidden as much by public apathy — a sense that "that's just the way it is" — as by any official policy. News reporters are drawn inexorably to this kind of theme. One of their jobs is to reveal human tragedy so that the rest of society can know about it. To reveal a tragedy on such a huge scale as existed in the cemetery project was irresistible to reporters.

There was deep symbolism here too. To give a voice to the voiceless and an identity to the anonymous dead is to create powerful reverberations in the soul. That power existed here.

But it was untapped power until someone like Diane was willing to step forward and breach the wall of silence.

That wall existed for several reasons. One is the stigma attached to mental illness. It takes a brave person to step forward and speak, knowing that he or she is liable to be called "crazy." Another is the shield of confidentiality that surrounds an institution like Central State. While a person is entitled to keep his or her medical records confidential, and away from the prying eyes of the public and the

media, I believe that shield often is invoked to protect the institution as much as or more than the client. That shield has hindered public scrutiny of many of the conditions that have needed to be exposed over the years. And I believe that in an unintended and ironic way, it has also helped perpetuate the stigma of mental illness. What is hidden cannot be talked about. What cannot be talked about remains a “shameful” secret. Again, I do not wish to suggest that a person should not have the right to his or her own confidentiality. But that person also must have the right to speak and step out of the shadows.

*“There is something compelling whenever people without a voice are given the chance to speak. And if the voiceless people happen to be speaking from the grave — and if they are given voice by living people who have suffered and been voiceless themselves — there is no way to ignore the story.”*

*—Don Schanche Jr.*

That is what Diane did when she told her own story — unashamed and forthrightly — of illness and recovery. That is what Larry Fricks did when he told his story to the powerful people in Atlanta. I believe that when people have the courage to tell their stories and breach the silence, not only do they get attention, but they make change possible. And in this case, when those stepping forward spoke not just for themselves but for the thousands who died before them, it was like a pent up dam was bursting and unleashing untold power. And the news media were an outlet for that power.

Dealing with the media is not without risk.

What if you tell your story and no one listens? And worse, what if you tell it, only to have it mangled by the reporter you tell it to?

I think it comes down to relationships and trust. You can begin by looking at the newspapers and TV news broadcasts. Look at the work of the reporter or reporters that you’re going to be dealing with. Get to know them. Size them up. Is this someone you feel comfortable with? Someone you trust? Someone who gets the facts right? Someone who seems genuinely interested in what you have to say? You may have the option to do some shopping here. (At first, anyway, as you choose the time and place to “break” your story. As momentum builds, you may draw a pack of reporters. But by this time, your story probably has already taken shape.)

Information is important here. If, in addition to telling your own story, you can provide factual information about mental illness itself, you can help educate the reporters with whom you speak. The PR office at the Division of Mental Health/Mental Retardation/Substance Abuse has reams of information that it can share. The Surgeon General’s report on mental illness is a good source. There are lots of good books available. Recommend them to the reporters. Or if you have the information in hand, provide it yourself.

As a reporter, one thing I like to do during an interview is repeat some of what I’m hearing, so that my interviewee can know how well I grasp what he or she is telling me. If I’m not getting it all, then he or she can correct my understanding. I don’t take offense if my interviewees ask me to repeat what I have just heard. I think they have a right to know how much I understand of what they’re telling me. So don’t be afraid to ask.

*“...when those stepping forward spoke not just for themselves but for the thousands who died before them, it was like a pent up dam was bursting and unleashing untold power. And the news media were an outlet for that power.”*

—Don Schanche, Jr.

Finally, if you're going to be a frequent media contact, it's important to be available. News reporters work all hours of the day and night, and need information at odd times. If they have your home phone or pager number, they can connect with you. It's up to you whether you want to put up with the inconvenience of being that available — but it's one way to make sure your story gets told.”

## **Chapter 4. Obstacles:**

**T**he major obstacles to the Georgia cemetery project are as follows:

- The records kept by the state hospital in Milledgeville since it opened in 1842 are poor and some are lost. Also, ground crews either removed or pushed down into the ground thousands of iron markers in the late 1960's or early 1970's, and we saw that it might not be possible to replace all the markers. That is a major reason the Georgia Consumer Council has developed a memorial that would incorporate all the misplaced markers.
- Administration and staff are constantly changing and barriers can arise if incoming new leadership does not support a cemetery project. So far, that has not been a problem in Georgia, but levels of support vary with different commissioners, division directors and hospital administrators. Constant change in leadership brings focus on the need to establish perpetual care and protection. Thus, the Georgia Consumer Council is supporting the placement of the cemeteries at Central State Hospital on a state and federal historic register and will begin that endeavor during the year 2000. There are also preliminary plans for a way to ensure perpetual care.
- Confidentiality has been somewhat of a barrier in that Central State Hospital has a policy that administration will not identify persons buried on the grounds unless they have been dead for at least 75 years. This does not appear to be state law, but simply hospital policy, which could no doubt be addressed if it were creating a major barrier.
- Funding is still a potential barrier and that process is ongoing.

## **Chapter 5. Closure: The Power of Apology, Forgiveness and Healing**

When Dr. Tom Hester took the brave step of asking forgiveness for past abuse and neglect and pledged the state's financial support for the cemetery restoration and perpetual care, something magical happened. It's similar to seeking the higher power associated with recovery from addiction and it was extremely effective that Dr. Hester aligned his apology and amends with the 12-step process. His sincerity and vulnerability also brought a form of spiritual healing to help wipe out the rage and mistrust of the past and open both sides--the state system and the consumers--to a new relationship. The past can never be forgotten, but perhaps it can be forgiven, and the fabric of a new



partnership woven that helps us walk as equals into tomorrow, building a journey of recovery together.

"It's so powerful," says Sherry Olvey, Program Director of the Georgia Consumer Leadership Institute. "Not only did he apologize, but he also acknowledged the power of recovery and wanting the state to become a recovering body."

"An apology is the beginning of showing that they really want to change," adds Tim McClention, Consumer Specialist at Atlanta Regional Hospital.

Linda Buckner says the apology moved her to tears because, "there have been times that all I needed from the system was for someone to say that they were sorry, but no one ever did. Now they have met us half way and we can begin the healing."

"It's an expression of true partnership," explains Dave Allen who supervises the team of consumer specialists at the Atlanta Regional Hospital. "True partnership can't begin until you admit you were wrong."

DeLois Scott credits the apology to the positive way the members of the Georgia Consumer Council went about the cemetery project. "We got the apology because we worked hard in a respectful way, and we never blamed or pointed our finger at anyone," reflects DeLois. "We were persevering and they came."

"We created a moral force," adds Georgia Consumer Council member Glenda Brown.

"If you have the right intent the universe has a way of putting things the way they are supposed to be," concludes Cobb County consumer leader Judy Masching.

*Speech by Thomas Hester, M.D., Medical Director for Georgia MHMRSA*

*Date: August 24, 2000*

*Place: Georgia Mental Health Consumer Network Statewide Conference*

*St. Simon's Island, Georgia*

*Note: This speech was transcribed from videotape*

The numbers are staggering. Since 1842 when Central State Hospital was established, more than 44,000 consumers have died. Some 30,000 are buried on the grounds with graves marked with a number, in an effort by staff to protect confidentiality. The scene was shocking and was described by Joe Ingram (a 50-year Central State employee). He described the cemetery at Central State, "Rows upon rows of numbered, small, rusted markers as far as you can see. No names, just numbers. It

*Dealing with the media is not without risk. What if you tell your story and no one listens? And worse, what if you tell it, only to have it mangled by the reporter you tell it to?*

*—Don Schanche, Jr.*

*The sincerity and vulnerability of Dr. Hester's apology also brought a form of spiritual healing to help wipe out the rage and mistrust of the past and open both sides - the state system and the consumers - to a new relationship.*

must be the most gruesome site in Georgia. Unknown humans, shunned when living, deprived of their very names in death, and literally known only to God." The numbers are staggering. The scene was shocking.

In March of 1997 there was an awakening. There was an awakening when the Consumer Council visited the cemetery site at Central State and saw that not only had these anonymous markers been overgrown by brush and debris, but in fact, many had been removed--removed to make maintenance of this area easier. And that there was no way to reconnect even the unnamed numbers to the human bodies that were buried there.

This awakening that occurred went forth from the Consumer Council to the state. Together staff at Central State, supported by the Division, in partnership with the Consumer Council, worked on the construction of a gate and worked to try to locate as many of the graves as could be located.

The consumer movement has taught me that recovery can occur on more than an individual level. That in fact, recovery as I understand it, based on my experience with 12-step recovery, is dependent on a peer support process. It is dependent on working with others. I learned from the consumer movement that this recovery, if you will, of consumers as a corporate body, a movement for change, strengthens their recovery by honoring the consumers that came before - bestowing on them the dignity of human recognition that was taken away by the action of those not in recovery.

I also believe that this recovery as a group has infiltrated the state and the facility (hospital) system. As I look back at the 12 steps, it seems to me that for the state and facility system to continue its recovery process, it needs to focus on at least four of the 12 steps:

Step Number Four - "Made a searching and fearless moral inventory of ourselves."

Some of those problems in our moral inventory have been the overcontrol through the use of seclusion and restraints, over-medication, and over-direction. One of our moral shortcomings has been a focus on segregation, isolation, and keeping consumers apart from their community. Probably the moral shortcoming that is the hardest to understand has been the trampling of human dignity leading to the desecration of graves.

Step Number Five - "Admitted to God, to ourselves and to another human being the exact nature of our wrongs."



The state and facility system have publicly acknowledged in a number of settings including the first national conference, late last year, of facility (state hospital) superintendents from around the country. I was able to address that group, show the pictures and tell the story of what happened in Georgia and the cemetery. Today I reiterate and admit the exact nature of our wrongs as a facility system in overcontrolling, segregation and desecrating consumers alive and dead.

*"I learned from the consumer movement that this recovery, if you will, of consumers as a corporate body, a movement for change, strengthens their recovery by honoring the consumers that came before - bestowing on them the dignity of human recognition that was taken away by the action of those not in recovery."*

—Dr. Tom Hester

Step Number Eight - "Made a list of all persons we had harmed and became willing to make amends to them all."

I think we've begun a process of making amends. But I am here today to signal the beginning of making amends through two approaches. One is to humbly say to you that I am sorry. I am sorry on behalf of the State of Georgia. I am sorry on behalf of institutions who in the past, despite whatever intentions they may have had, have trampled human spirits, have not allowed recovery to flame. I'm sorry that we've overused medications. I am sorry that we have overused intrusive measures like restraint and seclusion.

But in addition to a public apology, another part of recovery is going into action. Making amends is not enough. It is not enough just to admit the exact nature of your wrongs - and apologize. And so today I am committing, on behalf of the state of Georgia and the facility system, to take four actions:

The state will pay for the survey to be completed to support the application of the cemetery at Central State to be on the National Historic Register. (applause)

The state will pay and support the cleaning up of all the graves that are covered under debris and overgrown. (applause)

The state will help the consumers' vision of finding a home for the unplaceable markers...(applause)...by constructing planters that lead from the gate to the angel. The planters will allow a place for the iris' to grow that have been collected by consumers. The iris' are symbolic of the strength of those individuals who lie in the graves that shall forever be unmarked, and to honor each of those markers that can't be placed in these planters.

A commitment for perpetual care and maintenance so that we never go back again. (applause - standing ovation)

It is essential for the system, the state and the facility system, to recover and to recognize that by going through these steps of making a searching and fearless moral inventory, that admitting the exact nature of our wrongs, and making amends to those that we have harmed, that we as a system and as providers will realize promises. But in order to keep those promises and experience those promises as the key factor - and the key factor is identified in Alcoholics Anonymous - "We will not regret the past, nor wish to shut the door on it." We can never forget! We cannot afford to forget

*“One of our moral shortcomings has been a focus on segregation, isolation, and keeping consumers apart from their community. Probably the moral shortcoming that is the hardest to understand has been the trampling of human dignity leading to the desecration of graves.”*

*—Dr. Tom Hester*

what happened at the cemetery - what happened to consumers! We must never forget and continue our recovery by abandoning control-efforts and promoting recovery and self-determination; leaving the bonds of segregation and isolation and promoting integration into the community for consumers! And above all...Never go back to desecration and recognizing the inherent dignity in humanness. As I've often learned that groups can recover, that “we can do what I can't.” I believe that the partnership between the state and the facilities, with the consumer movement as two recovering bodies, if you will, can accomplish far

more than any group can together.

I humbly ask your forgiveness and commit myself to making these commitments a reality. (loud applause - tears - standing ovation!)

## *Chapter 6. Cemetery Projects in Massachusetts, Minnesota, Arizona, Connecticut, Ohio and South Dakota*

- *The Massachusetts' story:*

**I**n November 1998, while wandering around the grounds of Danvers State Hospital in Massachusetts, Dr. Pat Deegan stumbled on an abandoned cemetery in a dense jungle.

“At first I couldn't believe my eyes,” says Dr. Deegan. “I found three-inch circular markers with numbers.”

A meeting attended by a group of consumer leaders, most of whom were former patients at Danvers State Hospital, sprouted into the Danvers State Memorial Committee with the goal of having the state restore and properly memorialize the cemeteries on the hospital grounds. The cemetery restoration in Massachusetts has taken a unique twist, however, because the hospital in Danvers has been closed, and the land is being put up for sale. Thus the Danvers State Memorial Committee has opted to pursue legislation that would carve out a percentage of the sale proceeds not only to restore and memorialize the cemetery, but also to create a trust to fund perpetual care.

Dr. Deegan says consumer-run cemetery projects are clear examples of a profound and very historical shift in how people with mental illness are beginning to think about themselves.

“This (consumer) movement is growing stronger, and we no longer will allow ourselves to be ignored,” adds Dr. Deegan. “Now we have more respect for ourselves and are demanding respect from others. There's a collective pride.”

Research by the Danvers State Memorial Committee revealed that there were 768 people buried on the hospital grounds. The Committee secured a \$10,000 grant from the state Office of Consumer



Affairs and used the funding to help organize the campaign. Committee members gained ideas for their memorial plans by touring a cemetery in Boston called Mt. Auburn, where mental-health reformer Dorothea Dix is buried.

“Our vision was a quiet sanctuary with benches and lots of nature,” says Dr. Deegan.

The Committee members also envisioned posting the names of all the people interred in the cemetery but discovered that the hospital burial records had been lost. That barrier was overcome by conducting research of the death records at the town hall in Danvers. To date those efforts have turned up the names of some 400 people buried on the grounds of Danvers State Hospital. Unfortunately, there is no way to match names to graves, so future plans may include erecting a wall of names like the Vietnam War Memorial in Washington, D.C., says Dr. Deegan.

The early plans focused on the committee taking responsibility for cleaning up and landscaping the graves, but concerns grew regarding who would be responsible for the perpetual care. Then emerged a strategy that the state of Massachusetts should be held accountable for the project and the long-term care.

“We saw this as a chance to make a loud statement to the Governor, legislators, the mental health system, the 11 state hospitals and the public,” says Dr. Deegan.

The committee began to raise public awareness by holding special media-focused events on the grounds of the hospital, such as a cemetery blessing followed by the people in attendance placing a coronation on each grave.

But Dr. Deegan warns that a cemetery project undertaken by consumers is a marathon constantly hampered by bureaucratic barriers. One of the first obstacles was that the state Department of Mental Health (DMH) claimed that because the cemetery was on the grounds of a closed hospital, the responsibility belonged to the Department of Capital Asset Management (DCAM) charged with selling state property.

“DMH would flip it to DCAM, and DCAM would flip it back,” says Dr. Deegan. “After a few rounds of being batted back and forth, our group decided it was time to go to a television investigative reporter.”

Committee members sent press releases, newspaper articles and photographs to local TV stations. A call came from an investigative reporter who eventually toured the cemetery and agreed to do a story that included an interview of the Commissioners of both DMH and DCAM. After that story aired, calls of support came in from across the state and the two commissioners each agreed to put up \$5,000 for cemetery clean up. But the clean-up effort turned out to be a huge disappointment. It consisted of hiring a Bobcat operator who simply ran over the graves pushing up the underbrush and

*“This (consumer) movement is growing stronger and we no longer will allow ourselves to be ignored. Now we have more respect for ourselves and are demanding respect from others. There’s a collective pride.”*

*—Dr. Pat Deegan, Massachusetts*

*Future plans may include erecting a wall of names like the Vietnam War Memorial in Washington, D.C.*

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in the process ripped some of the grave markers out of the ground.

“It was a wreck,” recalls Dr. Deegan.

The Committee was outraged and called the media in to see the outcome of the cemetery clean up. Photographs of the damage done at the Danvers State Cemetery were produced into slides for presentations. Photo slides were also made of graves located in 18 other cemeteries across Massachusetts that interred some 24,000 people. And finally, slides were produced from photos of a local pet cemetery that was neatly maintained and landscaped with grass, flowers and statues of Jesus. The slide show was presented to community groups, advocacy organizations and legislators.

“It helped to get people outraged and realize that this is really wrong,” says Dr. Deegan. “Our solidarity was growing.”

Then the Committee convinced the Commissioners of DMH and DCAM to each put up an additional \$22,000 (\$44,000 total) to properly clean up the cemeteries and plant grass where the Bobcat operator had made such a mess.

Senator Fred Berry of Danvers became interested in the project and he teamed up with other area legislators to introduce a bill authorizing that five percent of the sale proceeds of all state properties would go to fund the establishment of a State Cemeteries Commission. The new Commission would perpetuate the care for all the state cemeteries including those located at prisons and facilities for people with mental retardation and chronic physical illnesses. This broadened the effort into a cross-disability coalition. Though the bill failed to pass in the 1999 legislative session, it will be reintroduced during the next year.

“We won’t be satisfied until every cemetery in the state is cleaned up, landscaped and memorialized,” says Dr. Deegan.

Following are some quotes from ex-patients of Danvers State Hospital regarding their project:

“It has been said that no families have come forward to claim their relatives buried in these cemeteries. We are their family,” says Mark Giles. “This is about respect. We have been neglected too long. The rebirth of the cemetery is just a small step towards respect and dignity for us all.”





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***“We are speaking for those who can no longer speak for themselves. We are the voices of those who are buried here. We are the echoes they left behind.”-***

***—Bill Capone, Massachusetts***

“To me, seeing these cemeteries is the worst thing I have seen happen at Danvers State Hospital,” says Jim Squeglia.

“We are speaking for those who can no longer speak for themselves,” says Bill Capone. “We are the voices of those who are buried here. We are the echoes they left behind.”

Sally Fallman says, “We need to acknowledge these people in death, but also how they suffered in life.”

“We have a vision,” concludes Judy Robbins. “We see the cemeteries both as sacred ground and sanctuaries for both the living and the dead. We see places of peace and beauty. We see proper memorials, a quiet fountain and the sound of birds.”

Ultimately, the Massachusetts story has a happy ending. Says Dr. Pat Deegan, “The state came through with the funds to do some nice landscaping. And they decided to have a celebration in October. Sometimes the hardest-fought battles bring great rewards.”

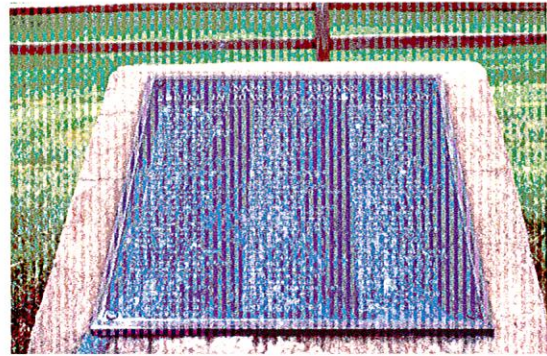
- ***The Minnesota story:***

**I**n Minnesota, the consumer organization known as ACT (Advocating Change Together) has documented a cemetery project and used the documentary to produce a self-advocacy training that includes a high-quality facilitator’s manual and a video.

ACT was founded in 1979 by consumers with developmental and other disabilities and began in 1992 producing educational video programs known as *Tools for Change* that focused on self advocacy and disability issues. In 1999, ACT copyrighted the video documentary, *A Few Simple Words*, based on a cemetery project located on the grounds of a state hospital in Minnesota. The video and training manual teach the spiral model of organizing which includes the following six steps:

- Beginning with personal experience – The training starts by introducing Gloria, a Minnesota consumer who visited a cemetery located at the Faribault Institution and found graves with only numbers. Gloria realized that her husband, who had lived at four different institutions, would have been buried with only a number if he had died as a ward of the state. This personal experience led Gloria to reflect on the many people with disabilities who are forgotten in institutions.

*Gloria realized that her husband, who had lived at four different institutions, would have been buried with only a number if he had died as a ward of the state. This personal experience led Gloria to reflect on the many people with disabilities who are forgotten in institutions.*



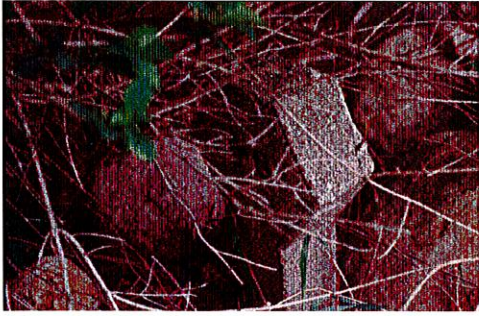
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- It's not just me – Gloria discovered that other people in her self-advocacy group were also upset about the numbered grave makers and neglect of people living in institutions. Gloria's issue evolved into a group issue.
- Knowledge is power--Working together, the self advocates (plus their allies) visited other institution cemeteries in the Minnesota cities of Owatonna and Rochester and learned that the issues of neglect existed there, also. Through the process of gathering information, new advocates joined the project.
- Don't mourn, organize!--The expanding group of self advocates and allies chose the name *Remembering with Dignity* and began to make plans. They got the names of people buried at the Faribault cemeteries so that they could place new grave markers with names and birth/death dates, increase public awareness of conditions in state institutions and preserve history by collecting oral histories from people who had lived in the institutions.
- Time to take action--Armed with a plan, the group educated legislators about their issue and requested assistance to obtain the names of people buried at the Faribault Institution. Members of *Remembering with Dignity* began promoting the project on radio, television and in the newspapers. Stories collected from oral histories were used in the play entitled *Let Heaven and Nature Sing*, which portrayed residents of the Faribault Institution in the 1940's. This public awareness campaign resulted in the release of names of persons buried at the Faribault cemeteries and \$200,000 in funding from the Minnesota Legislature to purchase new grave markers.
- Reflection – The outcomes of the project included getting the names released, increasing public awareness, funding from the legislature and most importantly, the uniting and strengthening of the disability community. After reflecting on their accomplishments, the group decided to stay united and focus on a new goal: pursuing a formal apology from the state of Minnesota for locking people with disabilities in institutions. The new project, named *A Few Simple Words*, is underway.
- *The Arizona Story:*

In Mesa, the cemetery at Arizona State Hospital has recently been restored after 33 years of neglect.

This project differs from the others in that it has not had significant input from the state's consumer





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*In Arizona, budget cuts in the 1960's forced the staff to shut off the irrigation system. The grass and many of the towering evergreens died; walkways disappeared, and grave markers sank inches into the ground.*

movement. Local consumer leaders in Arizona such as Jo Ann Hayden say that oversight has resulted in the project lacking credibility, and there has been no opportunity for empowerment, unity, education, stigma busting or healing.

According to a story in the newspaper, the *Arizona Republic*, written by Stephanie Paterik, just a year ago, the hospital graveyard had become an unsightly trash site strewn with drug needles and condoms.

Budget cuts in the 1960's forced the staff to shut off the irrigation system. The grass and many of the towering evergreens died; walkways disappeared, and grave markers sank inches into the ground.

After three decades of neglect, the once abandoned cemetery now boasts well manicured lawns and neat grave markers, thanks to the volunteer effort of some 50 community members who helped employees and patients restore the grounds. Donations of labor and supplies reduced the \$40,000 restoration cost by half.

According to the *Arizona Republic* news story, the Mesa Rotary Club and Boeing employees are credited with helping to uproot dead trees and plant new ones. They raised the grave markers, planted flowers and built new pathways.

"This project exposed our members to something that should have never happened," Mesa Rotary President John Choate said. "In our small way, we tried to right some of the wrongs."

Although the nearly seven-acre cemetery was designed to hold 3,700 graves, only 2,420 bodies rest there. All but five were patients at the hospital, many of whom died in the late 1800's and early 1900's.

A fire in 1935 destroyed all burial records recorded before 1929. Many other records have been lost over the years.

The cemetery is rich with history and notable people. The most prominent person buried on the hospital grounds is former soldier Isiah Mays, who received a Congressional Medal of Honor for gallantry in 1890.

Mays was born a slave in Carters Bridge, Virginia, in 1858 and died at the hospital in 1925. He served in the U.S. Army Cavalry during the Indian wars as part of the all black unit known as the Buffalo Soldiers.



*After three decades of neglect, the once abandoned Arizona cemetery now boasts well-manicured lawns and neat grave markers, thanks to the volunteer effort of some 50 community members who helped employees and patients restore the grounds.*



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No others will be buried in the cemetery, and the restored grave sites will remain a memorial to the people with mental illness of past decades.

- *The Connecticut Story:*

The Connecticut cemetery project began when consumer leader Jim Fox and an associate came up with the idea that there should be a memorial service for the 1,500 people buried at the Connecticut Valley Hospital (CVH) cemetery located in Middletown.

“We had no intention of launching such a giant project,” says Jim. “We contacted the chaplain at CVH and learned that a local pastor was planning a memorial for the first one hundred people buried there.”

Jim says that the first major hurdle was securing the names of the people buried at the CVH cemetery.

“The names were confidential to protect the families from the stigma of mental illness,” says Jim, “I contacted my legislator to see if the law could be changed.”

Jim’s request was turned down, but another door opened. It was discovered that a list of all of the names of the people interred at the CVH cemetery existed on file in the Middletown public library.

A date was set for the memorial service.

“I notified the *Hartford Courant* and through some contacts arranged coverage with the Middletown segment of the paper,” says Jim, “and the pre-event coverage was excellent.”

A reporter from the *Hartford Courant* also covered the memorial service, which included representation from most of the religious congregations in the city.

“After some preliminary speeches and a bagpipe concert, a procession was formed and went from grave to grave,” says Jim. “The ministers and a priest took turns reading the number of the grave, the name of the person along with their dates of birth and dates of death. We did this for 100 graves. It will take us 15 years to do the whole cemetery.”

The memorial service brought some sense of closure for families searching for relatives buried on the CVH grounds.



*“After some preliminary speeches and a bagpipe concert a procession was formed and went from grave to grave. The ministers and a priest took turns reading the number of the grave, the name of the person along with their dates of birth and dates of death. We did this for 100 graves. It will take us 15 years to do the whole cemetery.”*

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*—Jim Fox, Connecticut*

“A brother and sister showed up with a picture of their grandfather,” says Jim. “He had disappeared in there (CVH) during the 1920’s or 30’s. He was a circus wagon painter by trade, and developed lead-paint dementia. They had been searching for him for years and finally found him in the Middletown Library (records). They felt that our service was the funeral he never had.”

The memorial service included personal stories from other family members who had been searching for their relatives lost in the mental health system and buried in unmarked graves.

The Connecticut Attorney General ruled that the confidentiality law did not apply to the people buried in the CVH cemetery. The Connecticut Department of Mental Health has agreed to provide funding to put the names of the interred on all 1,500 graves at a rate of 100 names per year, for fifteen years.

Jim says that a key component to the success of the CVH cemetery project was the coalition formed with the clergy of Middletown. Then planning a memorial service that resulted in giving back the dignity of names associated with 100 graves brought those former patients to life as people who once walked the earth. The personal stories from relatives provided real social identity.

“They were father, grandfather, aunts and uncles, sons and daughters,” says Jim. “Media coverage changed the event from a private service to a public event which raised the awareness of the community. This led to the social change that gave the people back their names.”

- *The Ohio Story:*

**I**nspired by the stories of the cemetery restorations in Georgia and Massachusetts, Mike Fontana led the charge in Ohio. A patient during the 1980’s at the former Central Ohio Psychiatric Hospital located in Columbus, Mike now serves as president of the Mental Health Association of the Cincinnati Area.

“In another era, I and the many consumers I work with may have wound up in such a grave,” said Mike in a 1998 story published in *The Cincinnati Post*.

Mike’s efforts have focused on the cemetery located on the grounds where Longview State Hospital once stood since the 1930’s. It is estimated that as many as 1,160 people may be buried at this site that is overgrown from two decades of negligence. Many of markers are covered by sod, and no one



*"In another era, I and the  
many consumers I work with  
may have wound up in such a  
grave,"*

*—Mike Fontana, Ohio  
The Cincinnati Post, 1998*



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can find the list of names for the patients interred there. According to documents in the Hamilton County Recorder's Office, the cemetery has 1,160 plots. In 1936, a crew from the Depression-era Records mapped the cemetery and showed that there were six veterans of war included among the buried.

In the 1980's, Longview became the Pauline Warfield Lewis Center. According to Mike, many of the Longview Hospital buildings were demolished and much of the land was sold to the Institute for Applied Manufacturing Science (IAMS). IAMS owns all the land around the cemetery, but the cemetery itself is still controlled by the Ohio Department of Mental Health.

The good news, says Mike, is that officials of the Lewis Center have pledged to restore the cemetery and have a memorial service to rededicate the grounds. There are also plans to provide perpetual care.

- *The South Dakota Story:*

**A**mong the most unique cemeteries in the country is the square half-acre of lawn surrounded by a split-rail fence between the fourth and fifth fairways of the Hiawatha Golf Course in Canton, South Dakota.

Here lie 121 inmates of the Hiawatha Insane Asylum, the only federally-run mental institution for American Indians that operated from 1902-34. The federal government eventually donated the land to the city of Canton, which built a golf course on it. In May, an annual memorial service was conducted at the Canton site as golf carts whizzed by.

According to a story published by Peter Harriman in the *Argus Leader*, this year's memorial service drew supporters from North and South Dakota, Minnesota, Nebraska, Iowa and Massachusetts.

Ivan Looking Horse of Minneapolis, keeper of the White Buffalo Calf Pipe, spoke to a circle of 13 American Indian and non-Indian people from six states gathered around him at the ceremony, according to the story reported by Peter Harriman.

"A lot of people from different tribes are buried here," said Looking Horse. "A lot of them died horrible deaths."



The annual memorial service was begun more than a decade ago by Harold Iron Shield.

Dr. Pat Deegan was among the attendees at the year 2000 memorial service. According to Dr. Deegan, as reported in Peter Harriman's story, Hiawatha was built by the federal government on the rolling hills east of Canton as the result of lobbying by former South Dakota Senator E.R. Pettigrew.

In 1929, Dr. Deegan says, a Bureau of Indian Affairs (BIA) doctor from Washington, D.C., visited the site. He found people chained to pipes and patients as young as five years old. The asylum was supplied with water so hard it turned linen black. Refrigeration for food was primitive and disease was rife.

"Even by the standards of 1929 asylums," she says, "he found a subhuman environment."

Tribal people from around the country were sent to Hiawatha, and Indian children who misbehaved at boarding schools were threatened with being shipped to the place. The asylum was run by a superintendent who kept hardly any records, spoke no Indian languages and diagnosed people as mentally ill on the basis of crude communication with sign language.

Dr. Deegan says she heard a taped interview recorded in 1979 of a former asylum employee who recalled the night-long wailing that occurred whenever a new inmate was brought to the institution.

After the 1929 BIA visit, approximately 60 of the 90 patients were released. The BIA doctor could find no indication of mental illness among them. In 1934, the hospital was closed, and the remaining 30 or so patients were sent to another federal asylum, St. Elizabeth's in Washington, D.C. Throughout its history, 300 patients were placed in Hiawatha.

Sixty-six years after it closed, the asylum remains a source of anger. Pemina Yellow Bird of the North Dakota Intertribal Reinterment Committee objects to the cemetery's location, surrounded by the golf course. Better it was overgrown and forgotten, she says.

"Overgrown is great. Overgrown is wonderful. Let the people rest in peace. Let them go back to the earth," she says.

Golf course members respect the site, says Marsha Eliason, secretary of the Hiawatha Golf Course board. Signs on the fence surrounding the cemetery and a notice on scorecards state that play through the cemetery is prohibited. Groundskeepers keep the lawn mowed. A couple of years ago, she says, the tee box on No. 5 was moved to reduce the likelihood drives would end up in the cemetery.

"Unless you have a bad slice, you should not be in there at all now," Eliason says.

*Here lie 121 inmates of the Hiawatha Insane Asylum, the only federally-run mental institution for American Indians that operated from 1902-34. The federal government eventually donated the land to the city of Canton, which built a golf course on it.*

*Pemina Yellow Bird of the North Dakota Intertribal Reinterment Committee objects to the cemetery's location, surrounded by the golf course. Better it was overgrown and forgotten, she says.*

The cemetery rarely is visited, except for the annual memorial service, and the course is closed the morning that takes place.

"Whatever they put up there, we leave. We don't interfere with anything they do. Our members are really respectful of the place," she says.

Despite a steady wind whipping across the course, Looking Horse, the pipekeeper, removed his shoes and a black leather jacket as he began the memorial ceremony.

Assisted by Orvilla Long Fox of Eagle Butte, he arrayed food offerings to the dead spirits of the place—watermelon chunks, apple and orange slices, strips of jerky and tobacco. He placed these before four freshly cut twigs jabbed in the ground and affixed with banners of red and white felt.

A bowl of burning sage sent its smoke across the site, and the pipe, broken down to its brick-red stone bowl and straw-colored lavishly carved stem, was placed next to the offerings. All but the pipe will remain for four days, Looking Horse says.

Accompanied by a skin drum beaten by Chris Denny of Sioux, Looking Horse knelt and led the other Indians in wailing chants.

"I am asking the old people here today to come back through dreams and visions with their medicine bundles," Looking Horse explains. "We have to keep going with what little we know." He asked Joe Bad Moccasin, an elder, to speak.

"I am thankful the people here today have come to learn our ways," he says. "They are as sacred today as they were in the old days.

"My heart feels good for those who have gotten here today. Maybe this is a lesson for those who should be here and are not. I see some pipe keepers, some sun dancers. For our white brothers and sisters who are here, we are thankful."

The pipe made its way around the circle, each person drawing in tobacco smoke, then raising the pipe to the sky and lowering it towards the earth. The ceremony concluded with a ritual round of hand shaking among the participants.

- *The Washington Story*

In Tacoma, Washington, led by hospital ombudsman Laurel Lemke, a handful of Western State Hospital staff are working to renovate the hospital cemetery, in the center of Fort Steilacoom Park, as a way to bring the hospital's many programs and the community together. Between the years 1876 and 1953, the hospital buried dead mental patients in 2,777 graves which run in rows, although the graves were placed in different areas of the cemetery at different times through the years. The layout reveals gaps between burial plots and sequential mapping.



(20)

*“In 1929, a Bureau of Indian Affairs doctor from Washington, D.C., visited Hiawatha Insane Asylum in South Dakota. He found people chained to pipes, and inmates as young as five years old. The asylum was supplied with water so hard it turned linen black. Refrigeration for food was primitive and disease was rife.”*

*—Dr. Pat Deegan*

“I’m sure that when they started this they didn’t know what it was going to be,” says Charlie Jones, hospital horticultural coordinator according to Steve Dunkleberger’s 2000 article in the *Lakewood Times*.

Most of the graves are marked only with a burial number as a way to hide the identity of the mental patient and shelter the person’s relatives from perceived shame of having a mental patient on the family tree. A handful of families have replaced the numbered concrete bricks with properly identifying grave makers. County parks workers mow the cemetery once every two weeks during the summer. The cemetery has otherwise been allowed to fall into disrepair. The crude fence needs work. Weeds and bushes grow unkempt. Hospital workers can only find some of the headstones by probing a few inches into the soil in search of the stone markers.

“Many of the stones have been covered up with grass and moss, but those are the ones we can still read,” says Jones.

Graves one through 16 remain unfound. Hospital records reveal gaps. Lines of headstones are simply gone. The remaining brick stones replaced larger headstones in the mid-1960s to make mowing the grass easier for county workers. Only 12 of the original stones remain, stored in a nearby building.

Hospital volunteers want their efforts to restore respect to the cemetery. Some work in dusty back rooms as they try to research the history of the graves. Others work on their hands and knees to uncover the graves and mark them for later restoration and identification. Workers want to repaint and etch the numbers onto the stones that have worn down during the decades of eroding rain and bleaching sun.

“I want it to be a pretty place,” Laurel Lemke says. “I want this to be a place people can remember and look forward.”

The repairs and renovations to the cemetery could cost about \$177,000. The project includes building a fence around the property, cleaning and repainting the headstones and relandscaping the grounds with native plants. A bronze statute of an angel comforting a child will mark the land as a cemetery. An information booth could tell the cemetery’s story. But cemetery volunteers do not want the restoration to be just another local historical site to educate people about the past. They hope it will be a tool in the treatment of current patients. The plan includes patients from



*Most of the graves are marked only with a burial number as a way to hide the identity of the mental patient and shelter the person's relatives from perceived shame of having a mental patient on the family tree. A handful of families have replaced the numbered concrete bricks with properly identifying grave makers.*

the hospital's gardening program adopting the site and being paid to maintain the cemetery grounds. A dedication ceremony is set for October 2000.

# APPENDIX

## ***Exhibit A: Poems, Letters and Personal Stories***

### PREFACE TO THE 1998 EDITION OF “BUT FOR THE GRACE OF GOD”

More than four decades ago, my purpose in attempting to compile a history of the Milledgeville hospital was two-fold: to understand the needs of the hospital well enough so that a psychology department could be established, and to provide meaningful occupation for those patients who were deteriorating from lack of challenge. As I learned more of the sacrificial service of Drs. Green and Powell, a third purpose emerged—to honor the memory of those two humanitarian superintendents.

After resting on a shelf for 28 years, the book was published in 1981 because I realized that if the history were not preserved, the good and bad of past years would be lost, and political plundering could be repeated. I felt Georgians needed to be enlightened as to the hospital's early greatness and its decline when it later became politically controlled. Little did I know that the book would also serve as salve for a painful past and benefit a cemetery project promoting hope for the future.

I first learned of the cemetery project in the summer of 1997, when I was asked for any additional information I would recall concerning the location of the cemeteries. Then in 1998, when I attended a meeting of the Georgia Consumer Council in Augusta, I was greatly impressed by the dedication of the members and the quality of their leadership. I offered my services to assist in any way I could, and as I spoke, it occurred to me that they could raise money through the sale of my book, *But for the Grace of God*, and I offered to them free use of my copyright.

That the effort to bring recognition and dignity to the 30,000 patients buried on the hospital grounds is being undertaken by those who have been mentally ill themselves is an indication of how far society has come since the early days of the hospital. We no longer waste the talents and abilities of these survivors, and this project, when completed, will stand as a monument to their determination.

Sincerely,  
Peter Cranford



BUT FOR THE  
GRACE OF GOD



# MILLEDGEVILLE!

*The Inside Story of the World's Largest Insane Asylum*

DR. PETER G. CRANFORD

# *The Ghosts of Central State*

*The cry of Central States ghosts can be heard on windy,  
moon lit nights.*

*We lie here black and white in six cemeteries side by side,  
twenty thousand and more.*

*Neglected and forgotten in death, just as when we were alive.*

*Afflicted by illnesses so cruel, that our loved ones suffered too.  
While we endured the terror, being imprisoned in body and mind.*

*Our families quietly bore the taint of insanity –  
in a world that is so unkind.*

*In the care of strangers, we grew old and died,  
In death our families dared not claim us  
As from society, their shame they sought to hide.*

*The state had taken care of us until our dying day  
And so the state buried us in the cold, cold Georgia clay.  
Numbered mental stakes mark our place of rest  
Names were not necessary when burying lunatics.*

*When the Georgia Consumer council heard of the graveyards decay,  
They decided they must preserve the sites as a tribute  
To those who can say –*

*They are us and we are them in so many ways,  
They suffered and died all alone in a less enlightend age.*

*Now the ghosts of Central State rest in peace  
Under lovely Georgia pines,  
Cared for and respected in death,  
Unlike older times.*

*Poem by: Mike McNellis*

# In Search of Papa Williams

By Casey McClain

It was the summer of 1963. Beth was 10 years old. Her sister was almost eight. They had the wonderful experience each year of spending the summer with their mother's parents. "Papa" and Gaga," also known as Count and Mollie Brantley. Mr. & Mrs. Brantley lived in the country. It was a small community called Mt. Green. Mt. Green was in between Millwood and Manor. If you're still lost, the closest town was Waycross.

That particular summer was very exciting. Their grandmother was getting a new washer, one that would spin out, not like the ringer one she had. More important, however, she was getting an electric dryer. Now these two wonderful home improvements wouldn't fit on the back porch where the old washer stood, so their Daddy, the sons, the sons in law, and the cousins were cleaning out the old smokehouse so a new wash-house could be built in its place.

Beth and her sister sat on the back porch steps to watch. They weren't allowed to get closer. The adults said it was because of snakes. More likely it was to keep them from getting into everything. Out of the rafters of the old smokehouse came several oblong packages wrapped in old cloths, ragged from both the years and the mice. Those were quickly claimed by Beth. Under all the trappings were four old photographs. With all of a child's natural curiosity she shouted for "Gaga" and demanded to know who the people were.

On that day began the quest for "Papa" Williams. The story Grandmother told as she sat in her bedroom rocker was a sad one, even a child could feel the loneliness and the loss.

Grandmother's father, Herbert Martin Williams, was born in 1859 in North Carolina. He left his family and journeyed to Georgia with his brother to seek his fortune. Settling in Ware county, he met and married Dicy Lucinda Whitley, started a turpentine business, farmed, and began a family. Herbert and Dicy had three daughters, Queenie, Mollie and Bessie. Then came a son, Marshall, who died about two years later, and in 1900 a new baby boy named Toby. Dicy died within a week of his birth, Toby died within the year. Unable to care for his young children and make a living, Herbert boarded them with neighbors. Soon after, his business partner swindled him out of all he had.

As grandmother told the story, tears came to her eyes. She remembered at age fifteen, as a young bride of one year, finding out that her Papa had been taken to a hospital in Milledgeville, later died and was buried there. She received the news some two weeks after the event and never knew where to find his final resting place.

Over the years the grandmother, granddaughters, an aunt, and one of the girls parents traipsed about old country cemeteries locating the graves of Grandmother Dicy, the little boys, and many other ancestors, placing

markers on the ones where it was needed. Their research files held countless letters written in attempts to locate "Papa."

Finally, after a ten-year search, they hit the mark. A letter from Central State Hospital arrived and with it, the confirmation that Herbert Martin Williams, "Papa," had indeed been a patient, had died, and was buried there. He was only forty-nine years old.

In 1997, the younger sister came to work at Central State Hospital as a Behavior Specialist, a Unit Coordinator for Psychology. For the small family life had come full circle. Three days before the first candlelight memorial service on behalf of the thousands who died and were buried in the cemetery, during her lunch hour, she and the consumer advocate, Diane McCarty, walked to the spot where on an earlier visit the sister had seemed to sense Papa Williams' presence the strongest. Using the two existing markers as guides, they went to check the cemetery records. Sure enough, the location was correct. Their journey had come to an end.

The German poet Goethe wrote "A little ring encompasses our lives and many generations link the rings of theirs, thus forming a chain that is without end." Locating Papa Williams' grave and the Central State Hospital restoration project completed the ring in this family's chain. They are complete as are the countless other families of those who rest there.

But the cemetery and its dedication is more than just one family's story. It is a battleground, deserving of preservation, home to those people who fought the relentless war with mental retardation, mental illness and addictive disease. It is our Arlington and our Andersonville. Today, we must not only dedicate the cemetery, we must dedicate ourselves as consumers, families, advocates, and professionals to the cause of research which will find ways to prevent, treat, and cure the conditions that create disabilities. We must fight for insurance parity and for access to new more effective medications. We must speak out loudly, seek out and destroy the insidious enemy called "stigma" and we must work tirelessly and passionately to ensure tragedies as this never recur. Consumers and their families must continue to have a real and substantive voice in decisions around care and choices about how, when and what kind of support services is delivered and by whom. Then and only then can we, with these souls buried here, rest in peace.

Harriet Beecher Stowe wrote "*The bitterest tears shed over graves are for words left unsaid and deeds left undone.*" *Let us pledge to leave no word unsaid and no deed undone. Let us speak in a unified voice, working together, hand in hand, until our task is accomplished.*



# Road to an angel via hope, recovery, and spirituality

There was no way we could have known on that day in March, 1997 how many hearts we were going to touch with something we just needed to do for ourselves. In one chilling moment our lives changed. We gazed in disbelief at the forgotten. I'll always say, "If a group of people can get the same idea at the same time, it happened that day." We didn't have to say it, but we knew, had we all lived in an earlier generation we could have been buried shoulder to shoulder right there together in graves covered by a half a century of growth, downed trees, and neglect—nameless after a life of no life. This was the beginning.

Where did we go from there with our determination? We put our motto to work for these tens of thousands of our brothers and sisters. "FROM SILENCE-TO A WHISPER- AND NOW A VOICE"—May the world hear us, "We will not be treated that way again"! We live in a world today of good medications, treatment, peer support, and a better understanding. No longer asylums to house, but hospitals to treat and release to communities where supports can provide a person with a brain disorder a better life. We wanted a way to honor those gone before us. Their lives and treatments are our history to understand and help us grow spiritually in appreciating what is happening within ourselves. We will erect a memorial to all buried here and elsewhere.

I have never had anything in life bring out my true emotions as this work has done for me. I can stand before hundreds including family and friends and say, "That can be me if I don't do something." If we let society forget dignity and compassion, respect for humanity, and the differences of peoples, we may return to what we forget doesn't work and treatment could return to the way it was, and we may end up nameless and forgotten.

I have put blood, sweat, and tears into this project for two years. I've worked first hand in almost every part of it. From the beginning when I didn't have a clue what to do until now helping other states try to find their answers. The most gratifying part of the whole thing is telling a family member I found their relative. Most of the time we tell families not to give up—because we won't. Just recently we found a lady's grave we had searched for since the beginning because of the work we have done in these two years. Of course there are families we have to tell, at this time, the probability of ever finding the relative is infinitesimal, at least in my lifetime. We hope to bring enough awareness to the plight of people with mental illness, mental retardation, and addictive disorders whether living or dead so there is a better understanding to the diseases and help remove the stigma attached to an illness no one ever chose to have.

May this angel stand for all—those gone and forgotten, those in recovery with their hope and spirituality—and for those yet to be born in a time when they can't believe we had to do such a thing to bring honor, respect, dignity, and compassion to a hidden-away people no longer shackled.

This is just my heart speaking. Ask anyone who have been to this cemetery and they can give you a story just as I. You uncover a rusty old stake after digging down about eight inches into the Georgia red clay and you don't just read a number, you can feel the soul. I know we only will scratch the surface of this our history, but recovery, hope, and spirituality will be ours "BUT FOR THE GRACE OF GOD."

by Diane McCarty  
October 14, 1999

## Exhibit B: Media Stories

# Angel will guard those 'locked up, forgotten' in life

**Central State cemetery** restored to memorialize the mental patients who lived and died there.

**By Christy Oglesby**  
STAFF WRITER

No longer are they shunned as lunatics or know as patients. People receiving treatment for mental illness now are consumers.

That name "gives us a sense of empowerment over our lives," said Larry Fricks, director of consumer relations for the state's Division of Mental Health, Mental Retardation and Substance Abuse. "With today's medications, we are taking over our lives, living in the community and working jobs."

But they haven't forgotten the less enlightened times, and that's why Georgia's Consumer Council held a "gate opening" ceremony Sunday at a patient cemetery it is restoring at Central State Hospital in Milledgeville.

The intricate iron gate, placed in front of one of the hospital's six cemeteries, is a replica of one that stood outside the women's cemetery at Central State, which opened as the Georgia Lunatic Asylum in 1842.

Beth English's grandfather was among those buried there.

"It's just a miracle that the whole thing has been saved," she said. "At this time, when there are so many wonderful medications for mental illness and people with mental retardation are living in the community, you just think about had they lived during this time how different their lives would be. It's important that this commemoration take place so

that we never go back to warehousing people and forgetting."

Between 20,000 and 30,000 people who received treatment at the hospital were buried in the cemeteries, with only numbered stakes as grave markers to maintain confidentiality. No one can say accurately how many acres the cemeteries cover.

Over time, the cemeteries were overgrown by meadows and woods, and in the 1960s, groundskeepers pulled up about 1,000 stakes and tossed them aside to mow the lawn.

People were buried there because their family members never came to

get their remains.

"It's a statement about how we treated people with mental illness in the past," Fricks said. "We were locked up and forgotten."

Today the Americorps Vista Volunteers from Middle Georgia will remark identified graves. The process is difficult because cemeteries were separated by gender and race, and numbers were recycled in each of the six cemeteries. Furthermore, no one is certain which cemetery is for which race or gender.

The restoration project, which includes a stone wall, iris to represent

resiliency and a looming bronze angel where many of the discarded grave markers were found, will cost about \$50,000 to complete, Fricks said. Donations and process from the reprinting of "*But for the Grace of God*," by Dr. Peter Cranford, a psychologist who worked at the hospital from 1951-52, has paid for the work thus far.

"We hope that even when this generation is gone," Fricks said, "people will look up at the gate and the magnificent bronze angel guarding the graves and never, ever will something like this happen again."

*Reprinted with permission from The Atlanta Journal-Constitution.*



# Cemetery project to be part of Smithsonian

Organizers to loan exhibit a grave marker, pictures and written histories

**By Jennifer Fowler**  
THE UNION-RECORDER

A project to reclaim Central State Hospital's client cemetery has earned itself a place in the Smithsonian Institution, officials announced Wednesday.

The project, which is intended to document the names of thousands of clients buried at Central State, will be part of a Smithsonian exhibit to commemorate the 10th anniversary of the Americans With Disabilities Act, said Larry Fricks, director of the state Office of Consumer Relations.

"They're looking at it as sort of a window on the hopelessness of folks with any disability," Fricks said.

Smithsonian officials have asked project organizers to loan the museum one of the cemetery's grave markers, Fricks said.

They've also asked for pictures of the cemetery, a history of Milledgeville and a personal history of someone buried at the hospital, he said.

The cemetery materials would be one of 10 examples in the exhibit, which slated to begin July 1 and be open for six months, Fricks said.

The goals of the cemetery project, which began two years ago, are to reduce stigma and to preserve history, said Dianne McCarty, personal advocate at Central State.

McCarty, who has shepherded the project at Central State, said the Smithsonian's interest seems proof the second goal has been achieved.

"When you try to preserve history, and you end up at the Smithsonian, you've done something," she said.

Project organizers also recently

*'When you try to  
preserve  
history, and you  
end up at the  
Smithsonian,  
you've done  
something.'*

*— Diane McCarty  
personal advocate at  
Central State Hospital*

wrote a manual to teach other state hospitals how to do similar projects, McCarty said.

The manual was part of a \$6,000 federal grant the cemetery group received, she said.

For more than a century, people who died at Central State Hospital were buried in graves marked only with numbers, not names. In time, even the numbered markers disappeared from many graves. The cemetery project, rediscovering their identities, has served as a focal point for a movement to end the stigma of mental disabilities.

In addition to documenting who is buried at the cemetery, which has many unmarked graves, organizers have worked to raise funds for

cemetery improvements and a memorial.

The council's effort has inspired similar projects in 12 states, said Tom Hester, medical director of the state Department of Human Resources' Division of Mental Health/Mental Retardation/Substance Abuse.

"The thing that is so revolutionary about this is that it was all initiated by consumers and has been symbolic of the consumer movement in Georgia," Hester said.

Officials made Wednesday's announcement in a graveside ceremony after the "M-Day program at Central State.

For the second year, First Lady Marie Barnes placed a wreath on the gates of the cemetery in memory of those buried there.

"I think it's a wonderful thing to do to honor the people buried in the cemetery," she said.

Glenda Brown, member of the council, made the two wreaths for the gates and helped hang them. "This is one of the highlights that we have," Brown said. "It's a ceremony for the public to come in and see what we've done.

*Reprinted with permission from  
The Union-Recorder.*



*Staff writer Bette Harrison reports that Georgia mental patients were often hidden away in life and forgotten in death. Now there's a movement to erect a memorial to those buried in the ...*

# Lost graves of Milledgeville

On the grounds of Central State Hospital, there is a dirt road that death knows well.

Protected by century-old cedars and bordered by untamed meadows, it leads to a grassy field edged by woods from which wildflowers beckon.

It was down this canopied byway between 1843 and the early 1900s that thousands of former patients from Georgia's State Lunatic Asylum— young mothers, children, old men and youths; rich, poor, black, white were carried for anonymous burial.

They died from malnutrition, pneumonia, syphilis and tuberculosis—all readily treatable today. Cancer and old age took others. Many weren't mentally ill, just, frankly, unwanted by their families.

They were buried here, the oldest of six Central State Hospital cemeteries because it was convenient: Phones had yet to be invented, the nearest train station was a two-hour carriage ride away, and there was no quick way to notify their families that they had died. Once buried, few were moved home.

No one knows how many of the nearly 30,000 people buried at Central State reside in this cemetery. Every grave once had a numbered iron marker, but in the 1960s, maintenance workers, while mowing the grass, removed them. This act, coupled with the hospital's idiosyncratic record-keeping, ensured that those buried would become as forgotten in death as they had been in life.

The visitors touring Central State on the dreary March day shared a profound interest in the institution's old cemetery; each had survived mental illness and knew that another time, it could have held them.

The group was from the Consumer

Council of Georgia, an organization for people who use mental health, mental retardation and substance abuse services. They do not consider themselves patients so much as "consumers" of these services. And though they viewed the cemetery as the highlight of this tour, their mood on the way over from the hospital's museum was grim.

"It was pretty depressing," recalls Larry Fricks, 47 a Lumpkin County real estate broker and the state's director of consumer relations—a mental health advocate for Georgians. "We saw the original tools they used for lobotomies and one of the first electric shock machines."

Still, no one was prepared for the emotional wallop of seeing the full extent of the graveyard's deterioration.

There were no markers at all near the road or in the field," Fricks says. "Parts of it were a jungle. We had tears in our eyes."

His colleagues were equally shaken. "It was the hair standing up on the back of my neck, a feeling of almost nausea," remembers Macon artist Doris Hester, 56. "These were the unwanted of society, the throw-aways. Nobody cared if they had markers. We knew that could have been us. It was devastating."

They walked through the field to a knoll and looked into the woods. Someone gasped. Partially hidden by underbrush, row after row of markers were interspersed through the trees. "We just stood there, staring at the markers," says Diane McCarty of Eatonton, who works at Central State as a liaison for patients. "No one knew what to say."

Before the day was out, however, they vowed to restore the cemetery, identify as many graves as possible

and erect a memorial, in the words of Fricks, "to honor our fallen brothers and sisters."

They also decided to unveil their vision of the memorial on Aug 28, at the annual meeting of the Georgia Mental Health consumer Network—and to break ground for it today, which is Mental Health Awareness Day.

First, however, they'd need to secure Central State's approval and as many of the missing grave markers as they could find.

## *Bad days and good*

Since its founding as Georgia's first psychiatric hospital in 1842, Central State has been known by many names, but only one strikes fear in the hearts of longtime Georgians: Milledgeville State Hospital.

The institution carried this moniker—usually shortened to "Milledgeville"—from 1929 to 1967, a period many call the most infamous years in the institution's rocky 155 year history.

In 1952, a young Augusta psychologist named Peter G. Cranford spent a year at Milledgeville. Disturbed by what he witnessed, he chronicled its practices and abuses in a book (written in 1953, published in 1981) called "But for the Grace of God: Milledgeville! The inside Story of the World's Largest Insane Asylum."

"It has been visited by fire, disease, flood, earthquake and war," he wrote, "and by its own special horrors. It has witnessed the heights of man's humanity and the depths of his degradation. It has done much more good than evil, and yet, there is still more evil than good men and women will wish to continue to tolerate."

Cranford heard his superintendent

Say shock treatments "ensure good citizenship," and he found perfectly healthy "patients" in a forgotten back ward for the incurable insane.

The hospital's first building was completed in 1843, and by 1845, the asylum had seen 33 patients. According to Cranford's history, they included a 30 year old "violent and destructive white male; a 90 year-old widow "with the general infirmities of old age"; a 50 year old Irish seaman "hostile and destructive; over-religious; saw and heard God"; a 23 year-old female "lunatic and epileptic" whose epileptic convulsions "seemed to follow disappointment in love"; and a 34 year old "idiotic, epileptic and maimed (by falling in a fire in a fit)."

As horrible as the incidents he wrote about were, Dr. Cranford also though much good had occurred at Central State. Tens of thousands of the mentally ill and tubercular left the sprawling 1,000-acre campus better and healthier than when they arrived.

Former Atlanta Constitution reporter Jack Nelson won a 1960 Pulitzer Prize for an expose on the hospital, which prove the catalyst for its greatest change. Today, the institution enjoys a solid reputation as one of the state's 13 regional psychiatrist hospitals.

Bud Merritt, Central State's historian and director of information, is no apologist for the hospital's dark ages. "The staff here was absolutely overwhelmed," he says of that time. "things got too large and too big, too fast.

The revolution of recent decades was due to the creation of regional mental hospitals, research into the physiological roots of mental illness and the ability to alleviate many of the symptoms of mental illness with drug therapies, this avoiding the need to hospitalize many chronically ill patients.

### ***A gift of surprising rains.***

And as Central state garnered renewed respect, so the patient consumer movement gathered growing clout. Thus, the Cemetery

project was quickly approved by everyone with the power to say no.

Locating the missing grave markers and identifying those buried, however, is daunting task. Then again, Diane McCarty's long suit is tenacity.

As an employee with daily access to the cemetery, McCarty routinely combed the site for grave markers. It was discouraging work.

### ***Then she got lucky.***

In April, after two weeks of rain, she and Doris Hester were roaming the cemetery when a beam of sunlight broke through the clouds, illuminating the knoll.

They walked over and basked in the light. Then McCarty says she was drawn to an area she had been over



many times before. There lying flat on the ground, was a single rusty stake. She summoned Hester, then spied something "sort of shiny" sticking out of a foot-high pile of mud on the other side of a metal fence. "My heart was thumping so hard," McCarty says. "I was thinking, 'Maybe this is where the maintenance men threw all the stakes.'"

At least, it's where they threw about a dozen of them. The women were so excited, they dug them out with their bare hands. McCarty thinks the week of rain had eroded much of the dirt that covered the stakes. "We knew at that moment that we were meant to do this work," she says. "It was like the universe was saying, 'It's time. It's time.'"

Since that day, McCarty has found hundreds of markers, but she knows that finding them is only half the puzzle. The other half is a bit more complicated.

### ***Uncovering old secrets***

"The problem with the old cemetery," Central State's Merritt says, "is that they often used the same [ID] number four times for a white male, black male, white female, black female."

Moreover, because the hospital was founded before the Civil War and during slavery, the old cemetery was segregated by race and sex. But since no one knows which quadrant was which, finding marker, say No. 114 tells only part of the story.

Fortunately, McCarty knows how to extrapolate cemetery information from the hospital's old annual reports, Merritt says. Recently she figured out how many died there in 1919 by the number of funeral pillows made in the sewing shop that year.

But the biggest mystery where the four quadrants of the cemetery begin and end—is still elusive. "I'm getting closer, notes McCarty. "Recently, I found No. 24 by a big oak tree and No. 89 nearby—so I figured this is where one of the four cemeteries begins. But which one?"

In fact, large oak trees and other

natural markers are part of the problem. While the hospital kept records of who was buried where and with which number, it didn't specify sex or race, and it used notes such as "10 feet from the big oak tree" as locators. Alas, 100 years later, that oak tree is long gone.

What frustrates Merritt and McCarty more is how detailed the hospital's other records are, from how many clean sheets were on hand to the number of beans harvested in the gardens.

Realistically, says Merritt, they may never be able to pinpoint where every person is buried. Their goal is to be able to tell a relative how to find the 10 square-foot block where "great-granddaddy was laid to rest."

Ironically, genealogy may have helped the Cemetery Project win approval. "When people looking for their long-lost relatives couldn't find their graves, the hospital was pretty embarrassed," Fricks says.

One such person—more forgiving in this matter than most because, she says, she has worked in the field of mental health—is Beth English, 44 of Vienna.

Someone who has always been interested in her family's history, English tracked her maternal great-grandfather, Herbert Martin Williams, to Central State, only to learn that Williams, who died of dementia at 49 in 1907, was buried in plot No. 1951, but the hospital didn't know where that was.

We wanted to locate him to move him to the cemetery where his wife is buried," English says. "So it was surprising to learn that, under the circumstances, we couldn't. But when she and her family learned about the Cemetery Project, they decided he would remain at Central State.

"We're so excited they're restoring the cemetery," English says. "As a family member, it's so important because it provides some dignity for folks who were never were allowed that. By not moving him, it's a statement our family can make about fighting the stigma of mental illness."

### ***Perpetual guardians***

Making a statement was also important to the Consumer Council of Georgia, which wondered what kind of memorial would best honor those buried in the cemetery.

When they polled members of the Georgia Mental Health Consumer Network, they received dozens of responses. They chose the best three and commissioned artist and council member Hester to synthesize them into a single concept.

Hester, who paints only in water color, worked with a significant handicap-tears. "I'd paint and cry, paint and cry," she notes, then jokes, "They really ought to have chosen someone who worked in another medium."

Maybe not. The painting, in blues and greens, depicts a serene landscape, gated by a wrought iron and stone entrance. A gold angel rises from the knoll where she and McCarty spotted the first grave marker. Clumps of white irises spring up against the stone wall.

When she unveiled it Aug. 28 before her peers on St. Simons Island, Hester explained in a soft voice that the gates and stone wall were featured in a 1928 photo of the women's dormitory; the angel, "considered an acceptable symbol in Christianity, Judaism and Muslim religious traditions," was there "to guard all the graves."

And the white irises, found in old cemeteries throughout the South were planted and she smiled when she said this—"because they were indestructible."

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The Atlanta-Journal Constitution.*



# Consumers driving change in state's mental health system

**By Don Schanche Jr.**

The Macon Telegraph

On Aug 24, the medical director of Georgia's mental health system stood before 400 people with mental illnesses, uttered an apology and received a tearful standing ovation. "I am sorry," Dr. Tom Hester told members of the Georgia Mental Health consumer Network during their annual meeting at St. Simons Island.

"I am sorry on behalf of the state of Georgia. I am sorry on behalf of institutions which, in the past, despite whatever intentions they may have had, have trampled human spirits, have not allowed recovery to flame. I'm sorry we have over used medications. I am sorry we have overused intrusive measures like restraint and seclusion."

His remarkable statement—and a pledge that followed it—state support for maintenance and upgrading of the old patient's cemetery at Central State Hospital—were a powerful acknowledgment that things have changed in Georgia's mental health system.

"When he came out with that apology, it was just overwhelming and unbelievable," said Diane McCarty of Americus, a longtime member of the mental health consumers' movement.

That movement, driven by people who use the state's mental health services, is a big reason why the system changed.

The movement, which has been growing in the U.S. since the 1980s, draws from several sources to empower people who once would have been locked away as "crazy."

Medical researchers have come to see mental illnesses as just that—illnesses. U.S. Surgeon General David Satcher, in a landmark 1999 report, noted that a range of effective treatments is now available for most

mental disorders—even chronic, severe problems such as schizophrenia and manic depression. And yet the report stated, half of all Americans with mental illnesses fail to get treatment. The stigma—The fear of being labeled and marginalized—leads many to suffer in silence rather than seek help.

Satcher also noted that mental illness strikes one in five Americans. Most prevalent are anxiety and depression.

Where people with severe mental illness once were given little chance to live meaningful lives, now they speak openly of "recovery."

"I'd say that medications have had a huge impact, but right up there is a belief that we can recover," said Larry Fricks, director of the Office of Consumer Relations in the state Division of Mental Health/Mental Retardation/Substance Abuse.

Fricks, himself diagnosed with manic depression in 1985, said the stigma of mental illness—and the loss of hope that it once entailed—were a heavier burden than the madness.

"When you had a diagnosis of mental illness, the world came to see you as that diagnosis," he said. "I lost 'me.' I wasn't Larry Fricks. I was Larry Fricks, manic depressive. The hopelessness was worse than the illness."

He added, "The consumers in this country are rising up and saying, 'You were wrong. We can and do recover.' We're making it our lives' work to go ahead and share that good news with each other."

In Georgia, the mental health consumers movement had a tenuous beginning in 1990, when 30 consumers met in the conference room of a hotel in Tucker. By 1993, the movement was strong enough to host a statewide conference attended by 700

consumers. By 1997, membership had grown to more than 3,000.

They called for more jobs for people with mental illnesses. And they made the old patients' cemetery at Central State—where thousands of deceased patients lie in anonymous graves—a kind of rallying symbol. Restoring the cemetery was a symbolic gesture of empowerment for all people with mental illness.

The choice of the word "consumers" is deliberate. People once spoke of mental "inmates," then "patients" and later "clients." Each successive word was intended to remove the stigma that had become attached to mental illness.

The word "consumers" suggested Lee Carty of the Bazelon Center for Mental Health in Washington, implies that, like shoppers in a marketplace, people can become savvy and influence the services that they use.

As the consumer movement grew in Georgia, it helped bring about changes in the law.

Georgia which once operated one of the largest mental "asylums" in the nation, has decentralized its mental health/mental retardation/substance abuse services. Instead of relying mainly on institutions to treat and house people with mental disorders, it has shifted toward community based services under the control of regional and community boards. Since 1996, about \$82 million has been shifted from state hospitals to community services.

Sixty-four percent of the state's \$963 million in MH/MR/SA spending to 1999 went to community services.

A 1993 law, commonly known as House Bill 100 had a lot to do with the changes. House Bill 100 included in it regional boards and community service boards and mandated that at least 50 percent of the members of

those boards would have to be consumers or their family members," Hester said in an interview. "To my knowledge, that had never been done in the United States."

Fricks said House Bill 100 "was the Magna Carta for us. It changed history."

It also created new jobs for people with mental illnesses, which has been the network's top priority each year. They liaison between consumers and the state. Community mental health centers all over Georgia now have consumer specialists as well.

In Americus, McCarty operates something called a "peer center." It's an independent, grant-funded service, run by mental health consumers reaching out to other consumers.

They can get training for literacy or to take the GED test, advocacy training, employment counseling and recreation.

"In no way do we provide treatment here," said McCarty, who opened the center last spring. "We are a support service for recovery." While there are numerous peer support services throughout the state, McCarty's is the only consumer-run peer center in Georgia.

But Hester said consumer-run services may become more common.

"I think you will see in Georgia the development of consumer-owned services, he said. "Consumers will establish businesses and compete with other providers."

The road to community-based, consumer driven services has not been altogether smooth. In 1999, state auditors issued a scathing report on the administration of Georgia's community-based MH/MR/SA programs.

It said accounting and recording keeping were sloppy, services providers were manipulating the system to maximize Medicaid payments, improper claims were being under written by Medicaid, and treatment services were deficient.

State Rep. Bobby Parham of Milledgeville, a longtime critic of House Bill 100, said the Legislature inevitably will respond to the prob-

lems with tighter controls.

"The concept we're looking at is control of the money," he said. "Let consumers have input, and let the boards have input, but make sure one region doesn't get more than the others."

Parham said he expects legislators will look at the problems in the 2001 General Assembly, but they may wait until 2002 to make major amendments to House Bill 100.

Parham added, "There is a certain percentage of mental health patients who can't be serviced in a group home or mental health center in every town. There are just problem cases that don't respond to conventional therapies and will not function in anything but an institutional setting."

He acknowledged the old system had abuses, but said the state will continue to need mental hospitals.

None of which will sit well with members of the consumers' movement. During the meeting at St. Simons, activist Stuart Perry was busy registering mental health consumers to vote. He said state leaders will have to listen when the movement makes itself felt at the ballot box.

"We're having a good time," he said. "We're gonna have a better time marching up to the Capitol and telling the governor that 50,000 people with mental illness in Georgia are registered to vote."

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The Macon Telegraph and News*

## **Exhibit C**

### Photo Identifications (21 Photos)

- Photo 1: Members of the Georgia Consumer Council – courtesy of Consumer Council
- Photo 2: Former First Lady of Georgia, Shirley Miller – courtesy of Central State Hospital archives
- Photo 3: Iron markers at Central State Hospital – courtesy of CSH archives
- Photo 4: (l-r) First Lady of Georgia, Mrs. Marie Barnes, Council members, Glenda Brown and Goldie Marks - CSH archives
- Photo 5: Iron gate at CSH cemetery – courtesy of Dr. Pat Deegan
- Photo 6: Iron marker at CSH – courtesy of CSH archives
- Photo 7: (l-r) First lady, Marie Barnes, council member, Glenda Brown and former First lady of Georgia, Mrs. Shirley Miller – courtesy of CSH archives
- Photo 8: Iron markers at CSH – courtesy of Dr. Pat Deegan
- Photo 9: (l-r) First lady, Marie Barnes and Georgia Consumer Council Members – – courtesy of CSH archives
- Photo 10: (l-r) Former Governor and Mrs. Ernest Vandiver and Mrs. Haddock – courtesy of CSH archives
- Photo 11: Grave marker at patient cemetery, Independence State Hospital (Iowa) – courtesy of Dr. Pat Deegan
- Photo 12: Iron marker at CSH – courtesy of CSH archives
- Photo 13: Cemetery markers at Danvers State Hospital (Massachusetts) – courtesy of Dr. Pat Deegan
- Photo 14: Rally at Danvers State Hospital – courtesy of Dr. Pat Deegan
- Photo 15: Memorial of names (Canton, South Dakota) – courtesy of Dr. Pat Deegan
- Photo 16: Stone marker at Danvers State Hospital – courtesy of Dr. Pat Deegan



Photo 17: Grave marker at Arizona State Hospital – courtesy of Dr. Pat Deegan

Photo 18: “C 63” is for Catholic in cemetery segregated by religion like this one (Metropolitan State hospital in Massachusetts) – courtesy of Dr. Pat Deegan

Photo 19: Rows of markers for ex-patients from Tauton State Hospital in MA. Burial is not on hospital ground but in town’s pauper’s field – courtesy of Dr. Pat Deegan

Photo 20: Absolutely “No play from Cemetery” warns golfers who hit their balls on to the golf course that was built over the cemetery (Canton, South Dakota) – courtesy of Dr. Pat Deegan

