Olmstead v. L.C. & E. W.

The Story of the Olmstead Decision and Three Determined Women from Georgia

Cover photo and individual portrait photographs of Lois, Elaine, and Sue were taken by Shari Beshers at Alpha Studios, Inc., in Marietta, Georgia. We wish to thank Shari and Alpha Studios for their talent and generosity.

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Olmstead
v.
L.C. & E.W.

The Story of the U.S. Supreme Court Decision Known as the "Olmstead Case."

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The Institute on Human Development and Disability
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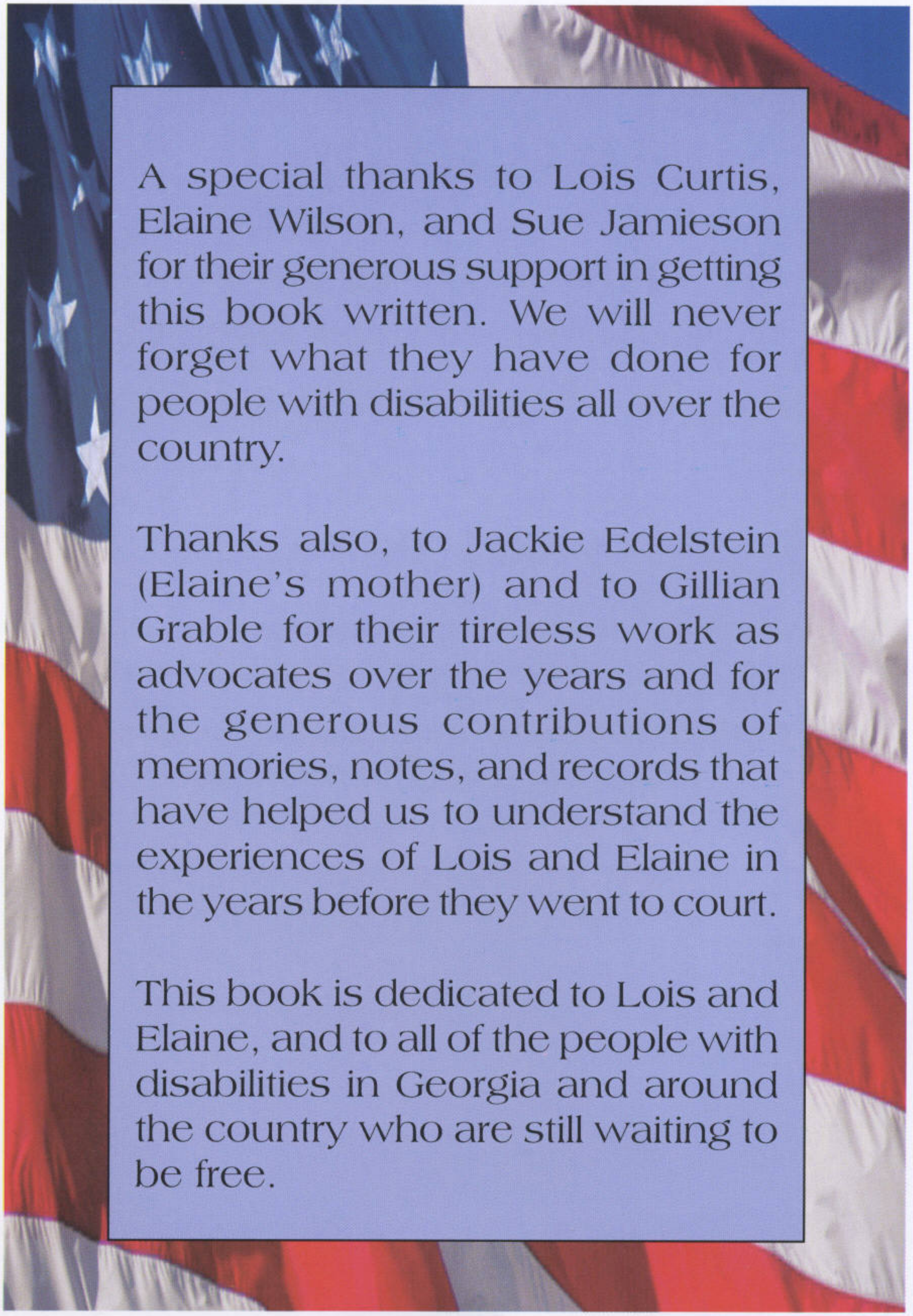
The College of Family and Consumer Sciences
at the University of Georgia

With help from:

three determined women from Georgia:

Lois Curtis,
Elaine Wilson
(free at last!)
&
Sue Jamieson
The Atlanta Legal Aid Society, Inc.



A special thanks to Lois Curtis, Elaine Wilson, and Sue Jamieson for their generous support in getting this book written. We will never forget what they have done for people with disabilities all over the country.

Thanks also, to Jackie Edelstein (Elaine's mother) and to Gillian Grable for their tireless work as advocates over the years and for the generous contributions of memories, notes, and records that have helped us to understand the experiences of Lois and Elaine in the years before they went to court.

This book is dedicated to Lois and Elaine, and to all of the people with disabilities in Georgia and around the country who are still waiting to be free.

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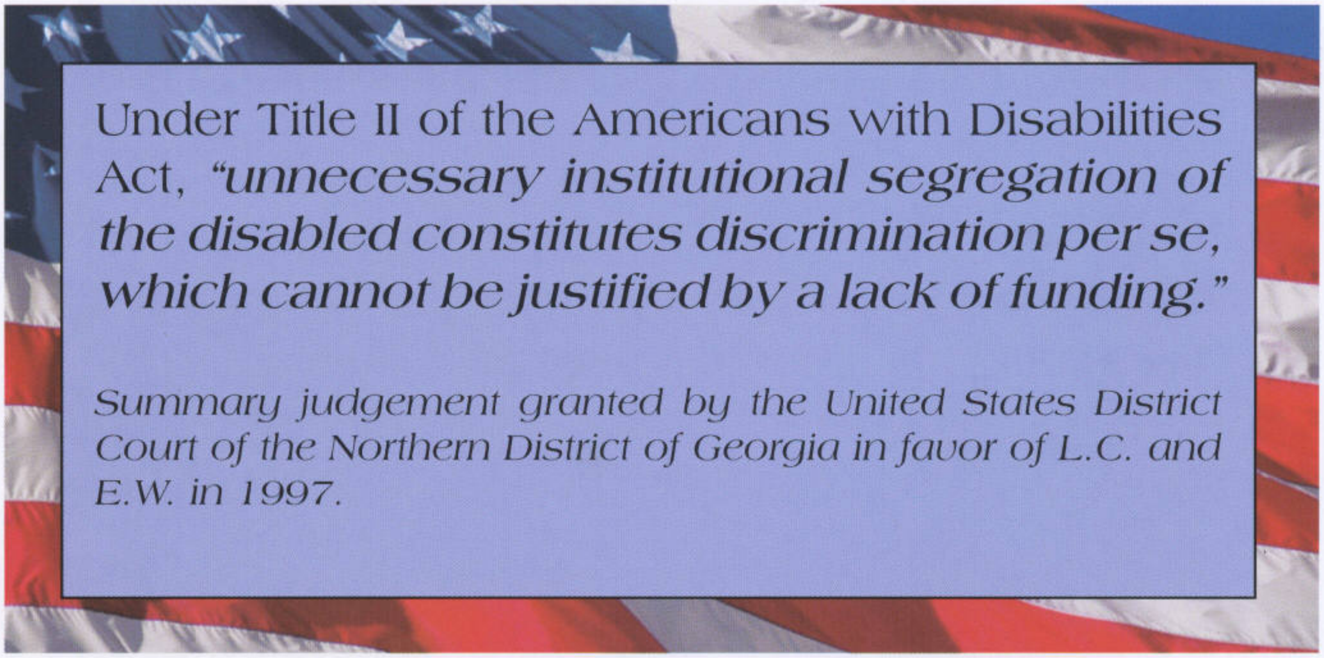


Under Title II of the Americans with Disabilities Act, *"unnecessary institutional segregation of the disabled constitutes discrimination per se, which cannot be justified by a lack of funding."*

Summary judgement granted by the United States District Court of the Northern District of Georgia in favor of L.C. and E.W. in 1997.

Introduction

Olmstead v. L.C. & E.W.

In 1995, two women, Lois Curtis and Elaine Wilson, were both residents of Georgia Regional Hospital in Atlanta. Both of these women had been diagnosed with mental illness and had been in and out of state institutions most of their lives. Both women were lonely, depressed, and they wanted very much to leave the hospital and go home. Lois and Elaine also had one other thing in common: neither one of them needed or benefitted from hospitalization. On the contrary, both Lois and Elaine were becoming more dysfunctional because of their daily isolation and boredom.

There was no argument about what was better for Lois and Elaine. Their doctors believed that they would fare better if they lived in the community and could participate in the routine of normal life. AND they believed that Lois and Elaine were both quite capable of doing just that. State of Georgia policy is to "provide community-based alternatives to total institutional care so that mentally retarded individuals can continue to live in their home communities" (Ga. Code Ann. § 37-5-2 (1982). The Americans with Disabilities Act requires that public services be administered in the "most integrated setting" that is appropriate to the individual. (28 CFR § 35-130 (d) (1998). So why were Lois and Elaine living in a hospital – year after year?

> *"[State hospitals were designed to provide] a service that aspired to cure by means of environment and moral treatment [but] actually became unconsciously brutalizing by taking people out of their communities and eliminating their everyday choices, by responding poorly to their need to learn and grow, and by cutting them off from their family, friends, and other community members."*
>
> *David Truran*
> *The Georgia Advocacy Office*

The Georgia Department of Human Resources maintained that they had no resources for supporting Lois and Elaine to live in the community. This was not because the citizens of Georgia do not want to provide support for people with disabilities. Georgia spends millions of dollars a year to do just that. But virtually all of that money goes to state institutions, even though experts in the field of disabilities, the Congress of the United States, the Administration on Developmental Disabilities, and people with disabilities themselves understand that community-based services are more beneficial, and more humane. The State of Georgia however, was unwilling to allocate the funds that were necessary to support Lois and Elaine in the community.

Enter Sue Jamieson, a lawyer with the Atlanta Legal Aid Society, Inc. In 1995, Sue filed a case against the Georgia Department of Human Services on behalf of Lois Curtis. Soon after, Elaine's mother contacted Sue, and Elaine was added to the suit. Thus began the adventures of Lois, Elaine, and Sue that led them all the way to the U.S. Supreme Court. This is their story. It is our hope that the real story of the three Georgia women of "the Olmstead Decision" will help others to understand why this court case was so important for Lois and Elaine and for people with disabilities everywhere.

As you read this story, keep in mind that Lois and Elaine are not unique. There are many thousands of people in Georgia who are now living in institutions and should not be there. Institutional, congregate settings are harmful to the human condition because isolation and segregation are contrary to the natural development and well-being of all social beings. Isolation and segregation cause depression, loneliness, and despair. To deprive any person of home, family, friends, and community simply because they have a disability is inhuman.

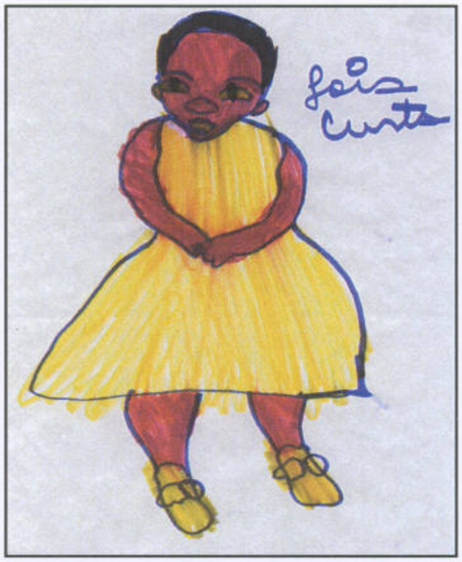
Lois Curtis

Lois Curtis is an active and charming young woman. Her large, winning smile and her engaging personality have helped her to make many good friends. Lois also has a cognitive disability and mental illness. She sometimes has trouble communicating with others and understanding what others want her to do. Lois' childhood was difficult. She grew up in a public housing project in an area of Atlanta that is overshadowed by the gray walls of a large penitentiary. The shadows of institutional walls have haunted Lois' life ever since.

Lois' family, including her mother, her sister, grandmother, uncle, nieces and nephews, have always loved and cared for Lois. Unfortunately, Lois also experienced violence and hardship in her neighborhood and in her own home. The origin of Lois' disability is unclear, but by the time she was about twelve years old, she was diagnosed with severe mental disabilities.

At that time, she had to leave public school and was bused to a psycho-educational center (a facility that serves students with severe emotional and behavioral problems). Lois learned to ride the bus to get to the center, but the separation from her friends and her community was traumatic and her behavior did not improve. Not long after she began attending the psycho-educational center, Lois was sent away to a psychiatric hospital that was many miles away from her home and her family. Lois lived in this institution with 400 other people with disabilities. This was only the first of many institutional placements for Lois. By the time Lois was in her mid-twenties, she had spent over half of her life in places segregated and congregated by disability.

Lois spent those years in and out of many institutions, hospitals, and private care/boarding homes. But, wherever she went, Lois always remembered that her family loved her. She remembered the sewing skills her mother had taught her and she remembered that her grandmother had shown her how to clean and care for a home. Lois' dream was to live in her own apartment, somewhere near her family, and where people understood her and respected her as a person.



When Lois was fourteen, she was introduced to Gillian Grable* from Project Rescue, (now the Atlanta Alliance on Developmental Disability). Gillian was immediately impressed with Lois' talents. "Lois enjoyed sewing, writing, makeup, jewelry, and artwork," says Gillian. "She had so many gifts and they were all wasted in institutional settings. We worked with Lois until she was 22 years old. But State support for community services was difficult to come by, and there were no providers who understood Lois' need to be in her own home and in her own neighborhood with the support to become part of a community. If these supports had come together, Lois' life would have been very different. The current system perpetuates the cycle of admission in and out of institutions and keeps people living on the edge." Gillian referred Lois' case to Sue Jamieson at Atlanta Legal Aid, Inc., while Lois was still a teenager.

Atlanta Legal Aid worked with staff from Project Rescue to find a permanent home for Lois near her family where she could find a loving and supportive place in her community. Unfortunately, the community placements for Lois were not adequate. Her reputation for troubled behavior would follow her, and she would be confined and neglected by providers who did not understand Lois and were not able to help her to use her many talents constructively. Lois would eventually lash out in ways that were sometimes violent to others, and she would be sent back to an institution where she would stay, segregated and locked away for years at a time.

Large segregated facilities were not sensitive to Lois's need for contact with her family or her need to form active friendships with peers who shared her interests. Lois sometimes has difficulty sitting still for long periods of time; she prefers to move around and to stay active. Lois began chain-smoking cigarettes when she lived in institutions as a way to comfort herself and to keep herself occupied. But despite her attempts to conform and adapt to the rigid structure of the institution, Lois would eventually find the lack of stimulation and the overwhelming sense of confinement and loneliness too frustrating and would pick up the phone and call Sue Jamieson at Atlanta Legal Aid. Lois never forgot the people who were trying to help her, she remembered the number for Atlanta Legal Aid and she called them often.

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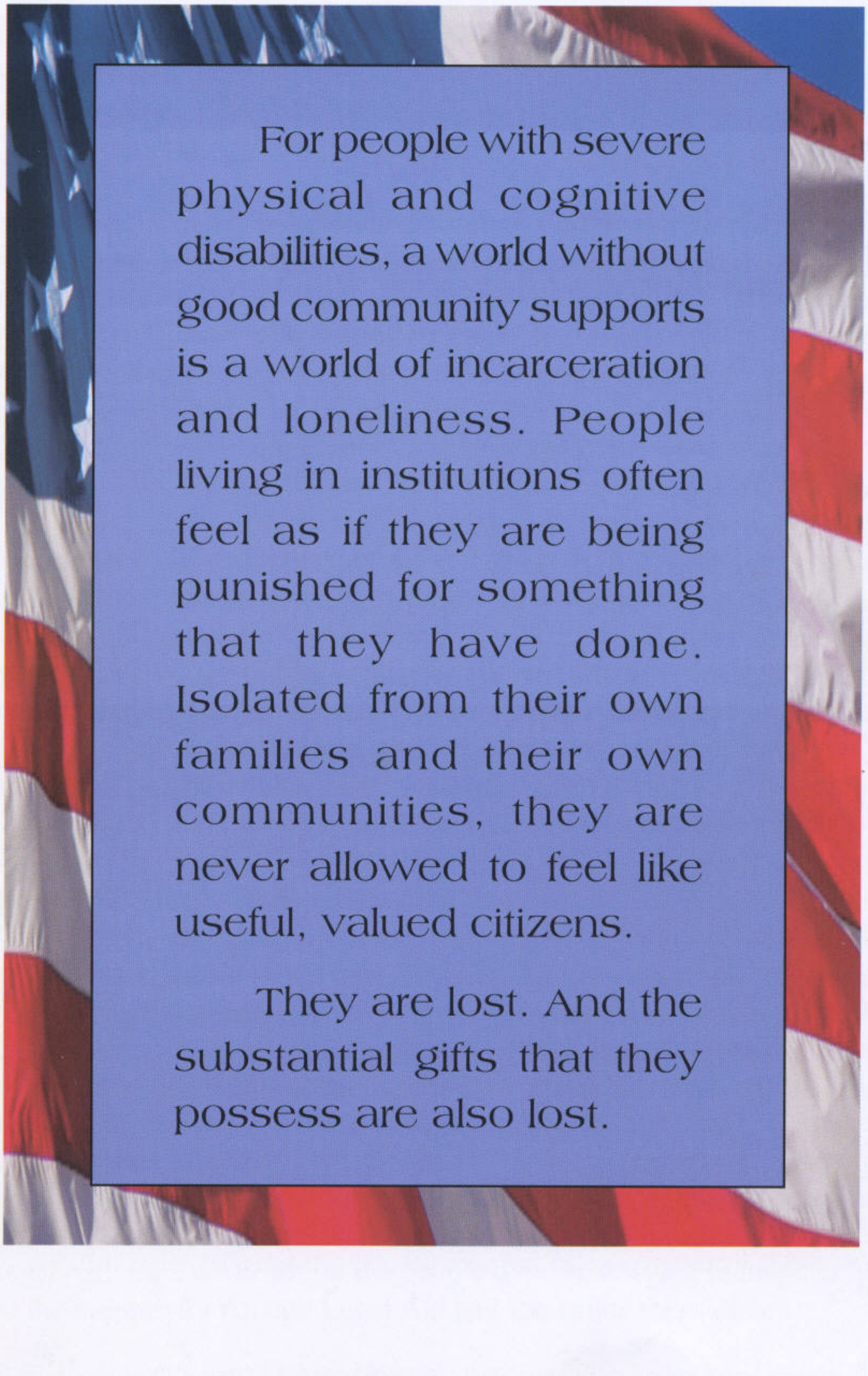
* Gillian Grable currently works for the Georgia Advocacy Office in Tucker, Georgia. See resources listed on page 29.

It is important to this story, that the reader understands that this characteristic of Lois – to make contact with other people, to hone in on the very people that could truly help her – is a rare gift for someone in Lois' circumstances. Most people with disabilities, who are institutionalized for many years at a time, languish in state hospitals, nursing homes, and treatment centers. They are seldom able to make meaningful, consistent contact with anyone in the outside world who can help them to get out of the institution and support them to lead fulfilling lives in the community.

Lois' uncommon self-advocacy began a chain of events that has affected the lives of people with disabilities across the nation. Whether she intended to or not, Lois became a civil rights activist and her actions became a catalyst within the disability rights movement. Lois' actions will have a profound affect upon the system of supports for people with disabilities, indeed there are already individuals who have been released from institutions because of Lois and the "Olmstead Decision." For people like Lois, who have lived their lives from inside the walls of state institutions, this is nothing short of a miracle.

Changing the system from inside a mental hospital is a tall order indeed. Acts of defiance and resistance by people with cognitive disabilities and mental illness are most often seen as "behavioral problems" that must be managed. No act of civil disobedience from inside the institution would have brought Lois' plight to the attention of the Nation. If Lois had done what Rosa Parks did during the civil rights movement, if she had sat down and refused to comply with the rules that she considered to be unjust, she would have risked being restrained, medicated, or both. This is simply normal everyday life in a mental hospital.

History may very well come to see Lois as the "Rosa Parks" of the Disability Rights Movement. Just like Ms. Parks, Lois would not resign herself to the way things were. And, while Lois may not have risked life and limb to change the system, her heroism lies in the simple fact that, against all odds, she persisted. Lois persisted until her cries were heard. She persisted until the people that heard her cries were prompted to act. She persisted until the system was, at last, ready to hear her.



For people with severe physical and cognitive disabilities, a world without good community supports is a world of incarceration and loneliness. People living in institutions often feel as if they are being punished for something that they have done. Isolated from their own families and their own communities, they are never allowed to feel like useful, valued citizens.

They are lost. And the substantial gifts that they possess are also lost.

Elaine Wilson

At the age of one Elaine Wilson contracted a serious illness. It may have been meningitis or polio (there had been a near epidemic of polio that summer). Whatever it was, it caused Elaine to be hospitalized with a raging fever and it was feared that she might not recover. When the fever finally broke and Elaine was well enough to be sent home to recuperate, her mother found that Elaine could no longer do the normal baby things that she could do before her illness, like crawl, pull-up, or even sit up by herself.

The doctors told them that it was just weakness from the illness and that Elaine would recover over time. Elaine did regain her strength and abilities, but very slowly. And as the years went by, she developed much slower than the other children her age. According to Elaine's mother, "She [Elaine] never walked or ran with the ease of most young children. She always appeared to be awkward or clumsy, and was ordered to wear corrective shoes for many years."

When Elaine started school, it became clear that her developmental problems went beyond her physical abilities. Elaine had a short attention span and, even with a tutor to help her, could not keep up with the other children in her class. At this time, Elaine's mother decided to have her tested by a professional psychologist. The doctor's diagnosis was brain damage due to the prolonged high fever during her illness. He told them that Elaine would never be like other children and that she should be institutionalized.

Elaine's mother chose to keep her daughter at home and for the remainder of Elaine's childhood she did her very best to find the right schools (both public and private) for Elaine. It was not easy. In the mid '60s, there were not very many programs for children with disabilities and not many people understood the best way to teach children who had severe cognitive impairments. Elaine learned to read and write, but she had great difficulty understanding numbers and was unable to learn to count money or to tell time. The process of learning was difficult for Elaine and she became frustrated and would sometimes have terrible temper tantrums.

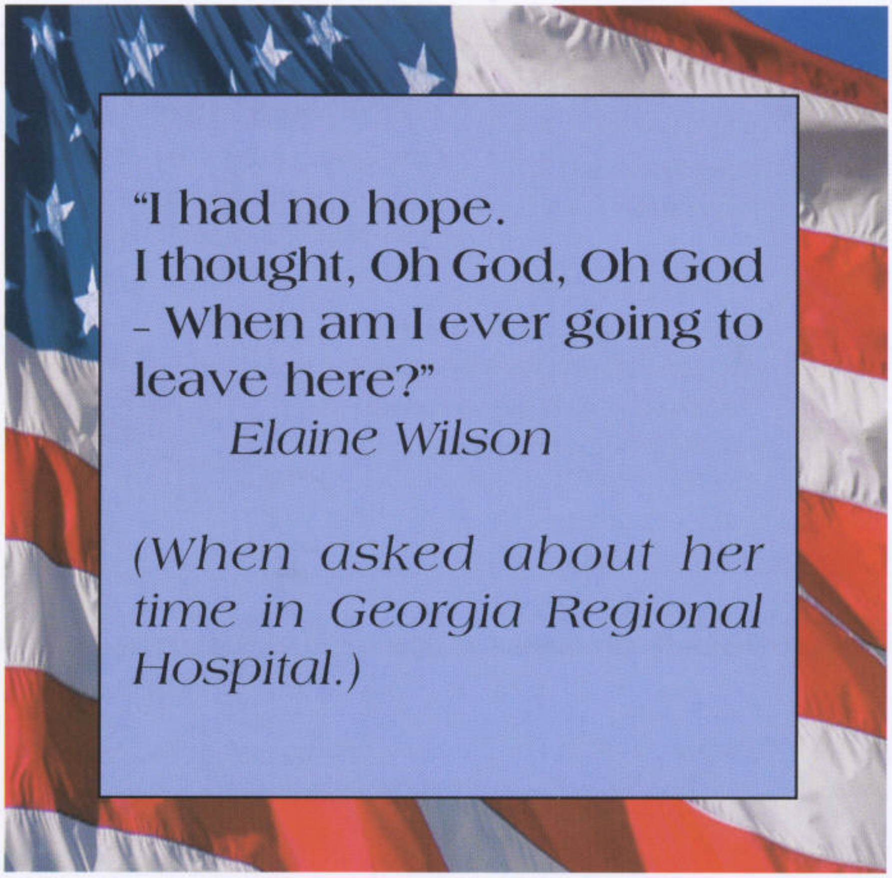
When Elaine was fifteen years old, her mother enrolled her in Gracewood State School and Hospital in Augusta, Georgia. There, they re-evaluated Elaine and produced the same diagnosis, mental retardation with a recommendation of institutionalization. Elaine's family did not want to leave her at Gracewood and were heartbroken without her. But all of the experts told them that institutionalization was the only resource that would meet Elaine's needs.

Elaine did not like Gracewood. She did not enjoy the repetitive skills that they tried to teach her there and she hated being away from her family. Over time, Elaine became more and more frustrated; she tried to tell them that she didn't want to be there, but all they saw was a rebellious and hostile girl who refused to behave. No one seemed to see the real Elaine – the charming and outgoing Elaine that loved meeting new people and making friends. While she was at Gracewood, Elaine went to her first real dance. Her date (a young man who was also a resident at Gracewood) gave her a beautiful corsage. She still remembers those flowers and the "prom" photo they took that night. That evening was a glimpse at a real life that Elaine would not see again for a very long time.

Elaine left Gracewood in the early '70s when she was committed to Central State Hospital in Milledgeville. Now a young adult, Elaine stayed in Central State until the early '80s, when changes in Georgia law prompted her release into what were called boarding or personal care homes. Elaine remained in one of these homes for only a few months to a year and then she would be institutionalized again in one hospital or another (including Georgia Regional). Elaine continued this odyssey in and out of institutions for the next 15 years. During those years, Elaine received shock treatments, was restrained, medicated, and isolated in locked rooms that contained only a mattress.

"When I was in an institution," says Elaine, "I didn't like myself." Institutionalization made Elaine feel like a bad person who was being punished – or like a broken person who needed to be fixed. She had no friends, no community, no life. "I was trapped there," she says, "like I was in an itty bitty box and I couldn't go left and I couldn't go right and there was no way out."

In 1995, after being placed in more than 37 different facilities, Elaine was, once again, a resident of Georgia Regional Hospital. On this occasion, she had been there for more than a year and was very lonely and depressed. She tried to cooperate with therapy but she knew that, no matter what she did, she would eventually be placed in another nursing home or discharged to a homeless shelter, where she would stay for a short while before she was readmitted to a state hospital. For Elaine, there seemed to be no end to this cycle, and no place where she belonged.



"I had no hope.
I thought, Oh God, Oh God
- When am I ever going to
leave here?"
Elaine Wilson

(When asked about her time in Georgia Regional Hospital.)

Timeline
Lois & Elaine

1966
ElaineWilson (15 years old) is institutionalized.

1967 - 1979
Lois Curtis is born and lives in public housing in Atlanta.

Early 1970s
Elaine (now in her early twenties), is transferred to another state institution.

1980
Lois (13 years old) is bused to a psycho-educational center and then transfered to a state institution far from home.

1981 - 1985
Lois is referred to Project Rescue and Atlanta Legal Aid – Lois meets Sue Jamieson. Lois goes in and out of psychiatric hospitals.

Early 1980s - 1988
Changes in Georgia Law allow Elaine to be discharged to private group homes and care facilities. She is bounced from one to the other – never staying in one facility for more than a few months.

1986
Lois (now 19 years old) is sent to a state psychiatric institution and then discharged to a group home.

Timeline
L.C. & E.W. v Olmstead

May, 1995
The Case is filed in United States District Court for the Northern District of Georgia on Lois' behalf.

January, 1996
Elaine Wilson joins the case.

February, 1996
Lois is placed in the community.

March, 1997
United States District Court for the Northern District of Georgia finds in favor of Lois and Elaine – finds that "*unnecessary segregation of people with disabilities is discrimination per se . . .*" Georgia files an appeal.

1989 -1991
Elaine is admitted to Georgia Regional Hospital and later discharged to a mental health facility in Florida. She returns to a private care facility in Atlanta in April, 1991.

1991 - 1995
Elaine bounces from various private care facilities to Georgia Regional Hospital and Georgia Mental Health Institute. Records show more than 30 admissions to these hospitals during this time period.

1988
Lois is sent to a state institution for people with mental retardation where she remains for 711 days.

1990
Lois is sent to a psychiatric hospital where she stays for 417 days.

1991 - 1996
Lois remains in Georgia Regional Hospital.

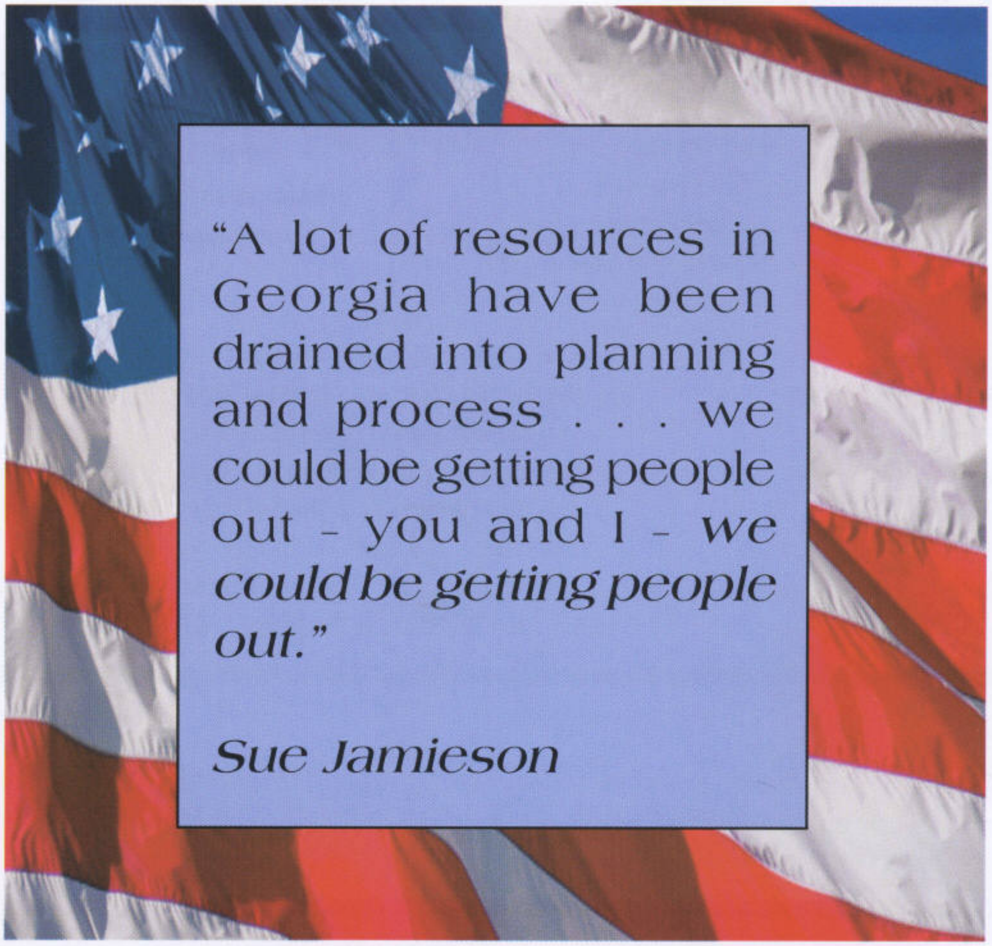
1991
Lois (now 24 years old) gets a Medicaid waiver, a job and her own apartment! But she lacks proper supports – she loses her job and has no day supports at all. She is readmitted to Georgia Region Hospital and loses her Medicaid funding.

July, 1997
Elaine is placed in the community.

November, 1997
The 11th Circuit Court of Appeals reaffirms the District Court's Decision, stating, *"By Definition, where, as here, the State confines an individual with a disability to an institutionalized setting when a community placement is appropriate, the State has violated the core principle underlying the ADA's integration mandate."* Georgia appeals to the U.S. Supreme Court.

April 21, 1999
The U.S. Supreme Court hears Arguments in the Case. The Court issues its decison on June 22, 1999. Justice Ginsberg wrote: *"We affirm the Court of Appeals' decision in substantial part. Unjustified isolation, we hold, is properly regarded as discrimination based on disability."*

July, 2000
Lois and Elaine appear in the Court of Judge Marvin H. Shoob, U.S. District Court where the "Olmstead Case" came to a final close with the signing of a settlement agreement.



> “A lot of resources in Georgia have been drained into planning and process . . . we could be getting people out - you and I - *we could be getting people out.”*
>
> ***Sue Jamieson***

Sue Jamieson

Sue Jamieson is an Atlanta resident and an attorney with the Atlanta Legal Aid Society, Inc. She grew up in New Jersey where she was part of a large family. Her father was an attorney and both of her parents were very politically active. They cultivated in their children an interest in social issues and a desire to take an active role in making the world a better place.

After graduating from Brown University, Sue joined the Peace Corps and lived and worked in Brazil. It was during this time in her life, that Sue decided that "doing good is fine – but I needed to have some skills," so she enrolled in Law School at Rutgers University, in New Jersey. After getting her law degree, Sue decided on a career in legal services because "it was a wonderful opportunity to enable persons who could not afford legal assistance to use the law to enforce and protect their rights."

Then, in 1979, while working on a project to increase legal services to a rural part of North Florida, Sue walked into a state institution near Jacksonville. She was stunned. "I was shocked that such a place could exist in the United States in the (then) 20th Century. But I was equally shocked at the fact that this population – the most isolated imaginable – was not typically provided with access to advocacy and to legal services. In my view, their legal situation was more drastic and urgent than most of the cases I had worked in my years doing legal services work."

Since that day, Sue has focused her efforts on providing advocacy to people with disabilities who are living in institutions and in nursing homes. "I continue to be very disturbed by the same two things that struck me in 1979," says Sue. "Society puts and keeps people in institutions and nursing homes even though, for most of the people that I have met, this is the absolute worst thing to do for them. And, once there, these people are isolated and have almost no access to meaningful, consistent and qualified legal advocacy."

When Sue came to Atlanta, she was committed to working in legal advocacy for people with disabilities. Steve Gottlieb, the Executive Director for Atlanta Legal Aid, allowed her to develop an Institutional Advocacy Project. "This is really unusual for legal services," attests Sue, "and very fortunate for me. Otherwise I would need to be doing a great deal of other kinds of outreach and I would not be available to meet the other needs that many low income people have." Sue liked Atlanta. But not for the reasons one might imagine. "Atlanta," says Sue, "is unique – it had two major institutions (mental hospitals) within the city of Atlanta." One of these institutions has since closed. The other is Georgia Regional Hospital, where Sue does most of her work.

Sue first met Lois Curtis when Lois was a teenager. According to Sue, "Lois was shuttled in and out of state institutions, even as a child and a teenager. She wanted so much to go to school and to have friends and to look her best. Instead, she was routinely institutionalized." Sue worked with others to help find alternatives to institutional placement for Lois. "I succeeded a few times," said Sue. "This went on for the first eight years that I knew her." Sue watched as Lois spent more and more time in institutions. "Lois became disconnected and discouraged and less and less able to cope with the 'outside world.'"

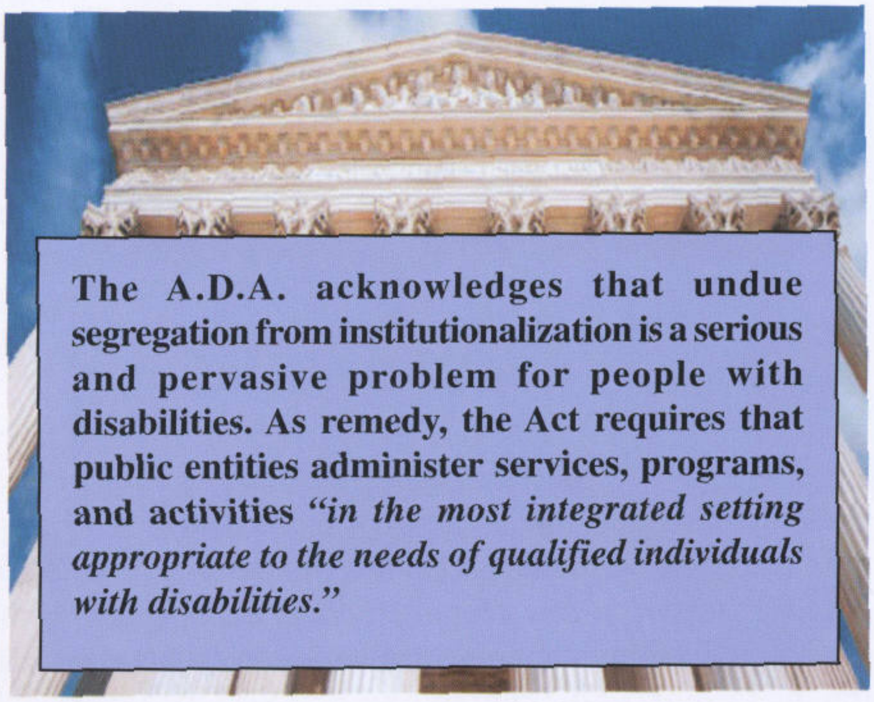
In 1992, after she was re-institutionalized to Georgia Regional Hospital, Lois called her friend Sue at Atlanta Legal Aid and Sue tried once again to find her a better placement. She asked the Dept. of Human Resources to consider any community-based alternatives for Lois. The answer was "no" – the State's position was that "there were no openings." Sue tried to negotiate for a plan that would help Lois to move gradually into the community, but the State still refused to provide any community-based services for Lois.

Lois continued to live at Georgia Regional for three more years and her situation became more and more desperate. According to Sue, "Lois was lonely and unhappy. She was desperate for friends and was preoccupied with smoking cigarettes. Lois didn't benefit from any of their 'cognitive therapy' because she does not learn from talking about things in the abstract, especially the same things over and over again, year after year." Sue knew that something had to be done for Lois and for others like her that were trapped in hospitals and other institutional settings.

Sue and three other wonderful lawyers: Sylvia Caley, Steve Caley, and Charles Bliss, filed and argued the resulting legal actions on behalf of Lois and Elaine in Georgia. Michael Gottesman argued the case before the U.S. Supreme Court.

Lois & Elaine Take Their Case to Court

In May, 1995, Sue decided to file a case in federal court on Lois' behalf because Lois' situation was desperate and no other options were available. Also, by that time, one federal appeals court had already ruled that the ***Americans with Disabilities Act*** (passed by Congress in 1990) prohibits institutional placement if community-based services can provide the supports needed. (This is called the *"integration regulation"* in what is referred to as the Helen L Case.) Sue knew that it was time for Lois and others to get their day in court.



The A.D.A. acknowledges that undue segregation from institutionalization is a serious and pervasive problem for people with disabilities. As remedy, the Act requires that public entities administer services, programs, and activities *"in the most integrated setting appropriate to the needs of qualified individuals with disabilities."*

Lois' case had already been filed in federal court when Elaine Wilson's mother first contacted Sue. Between 1991 and 1995, Elaine had been in and out of Georgia Regional Hospital and Georgia Mental Health Institute (now closed) *more than 30 times.* Without adequate community support, Elaine could not function outside of the hospital. Inside the hospital, where she was often drugged or physically restrained, it was unbearable for her. Elaine was trapped in a never ending cycle that kept her in state of physical and emotional turmoil.

Late in 1995, Georgia Regional Hospital was getting ready to release Elaine yet again - to a homeless shelter. (This had happened once before, when Elaine's mother received a telephone call telling her that Elaine was in an Atlanta homeless shelter. She rushed there to find Elaine sitting, unattended, on the curb.) Elaine's mother called Sue Jamieson to ask for her help. Sue decided that Elaine's claim was very similar to Lois' (that she needed good community-based supports that would allow her to leave the hospital and live successfully in the community) and so, in January, 1996, Elaine was joined as an "intervenor," to Lois' case.

Lois and Elaine meet the press in Washington (with attorneys Steve Caley and Michael Gottesman).

The case was filed in the United States District Court for the Northern District of Georgia. In their petition, Sue claimed that *Lois and Elaine's civil rights were being violated under Title II of the Americans with Disabilities Act.* That is, since Lois and Elaine's doctors had said that they could be treated in the community, their continued segregation in an institution or hospital was discriminatory and therefore unlawful under the ADA.

The case was filed against the commissioner of the Georgia Department of Human Resources (Tommy Olmstead), the Superintendent of Georgia Regional Hospital, and the Executive Director of the Fulton County Regional Board (collectively the State). The State claimed that it was not discriminating against Lois and Elaine because they were only keeping them in the hospital because the State couldn't immediately find additional money for community-based services. The State held that forcing Georgia to fund more community services would "fundamentally alter" the State's activities. (The ADA requires only "reasonable modifications" in order to comply with the law whereas anything that required more extensive changes constitutes "a fundamental alteration" and is therefore not required under the ADA.)

The Court, however, disagreed with Georgia's claim and stated that since Georgia already had programs in place that provided the kind of community services that Lois and Elaine needed, the State was indeed guilty of discrimination. The Court also stated that such discrimination could not be justified by a lack of funds. Lois and Elaine had won their case.

Sue talks to the press (Nina Totenberg of NPR) on the steps of the Supreme Court Building.

Georgia appealed the case to the Eleventh District, and that court also agreed that Lois and Elaine were being discriminated against under the ADA. To press their case further, Georgia had but one alternative – they appealed the case to the Supreme Court of the United States. In their petition, Georgia asked the Supreme Court to decide whether the Americans with Disabilities Act "compels the state to provide treatment and habilitation for mentally disabled persons in a community placement, when appropriate treatment and habilitation can also be provided to them in a State mental institution."


Attorneys Steve Caley and Michael Gottesman talk to the press on the steps of the Supreme Court Building.

The Supreme Court heard the case on April 21, 1999. Georgia tried to make the case that the ADA only prohibits discrimination between people with disabilities and people without disabilities. In other words, in order to claim discrimination, people with disabilities must show that they are being treated differently than people without disabilities who are in similar circumstances. In its decision, the U.S. Court of Appeals wrote, *"Reduced to its essence, the State's argument is that Title II of the ADA affords no protection to individuals with disabilities who receive public services designed only for individuals with disabilities." (L.C. by Zimring v. Olmstead,* 1997 U.S. Dist. LEXIS 3540). For people with disabilities, this is an argument that threatens nothing less than the quality of their lives.



Lois and Elaine talk to the press in Washington D.C. on the day of their Supreme Court hearing.

The 11th Court of Appeals found Georgia's argument to be illogical and contrary to the explicit language in the ADA. The Supreme Court agreed. Justice Ginsberg stated in the majority opinion that, *"Unjustified isolation is properly regarded as discrimination based on disability"* (527 U.S. at 598).

Justice Ginsberg, according to the majority opinion (joined by Justices O'Conner, Souter and Breyer), was convinced that Lois and Elaine's case was valid under the ADA's definition of discrimination. "We are satisfied that Congress had a more comprehensive view of the concept of discrimination advanced in the ADA" (527 U.S. at 598). Justice Ginsberg wrote: "recognition that unjustified institutional isolation of persons with disabilities is a form of discrimination reflects two evident judgements ... First, institutional placement of person who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life ... Second, confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment" (527 U.S. at 600-601).

The Court handed down its decision on June 22, 1999. And "there it was," says Sue, "the Olmstead Case factually set out what has been true for so many people for so long *and finally* in 1999, the Supreme Court is saying such an obvious thing - ***that people who are segregated in institutions are victims of disability discrimination."*** Lawyers had been arguing about the conditions *in* institutions and the *quality of care* since the 1970's. Lois and Elaine's case, according to Sue, had now, "wiped the slate clean" in that it had finally put an end to extraneous arguments about the *condition* of institutions and allowed lawyers and advocates to make the elegant and simple statement that segregation of people with disabilities is wrong and unconstitutional - *is it okay for a state to make people with disabilities live in institutions in order to get the services they need?* Answer: *No*.

All of the three courts that heard the case were adamant in their decisions as far as the question of discrimination was concerned. They each reaffirmed that the ADA prohibits "unnecessary" institutionalization. They also made it clear, however, that institutionalization may be appropriate when: a) the individual's medical professionals do not recommend community-based care; or b) when the individual does not want community-based care. It was determined, therefore, that the ADA cannot require states to phase out or close state institutions.

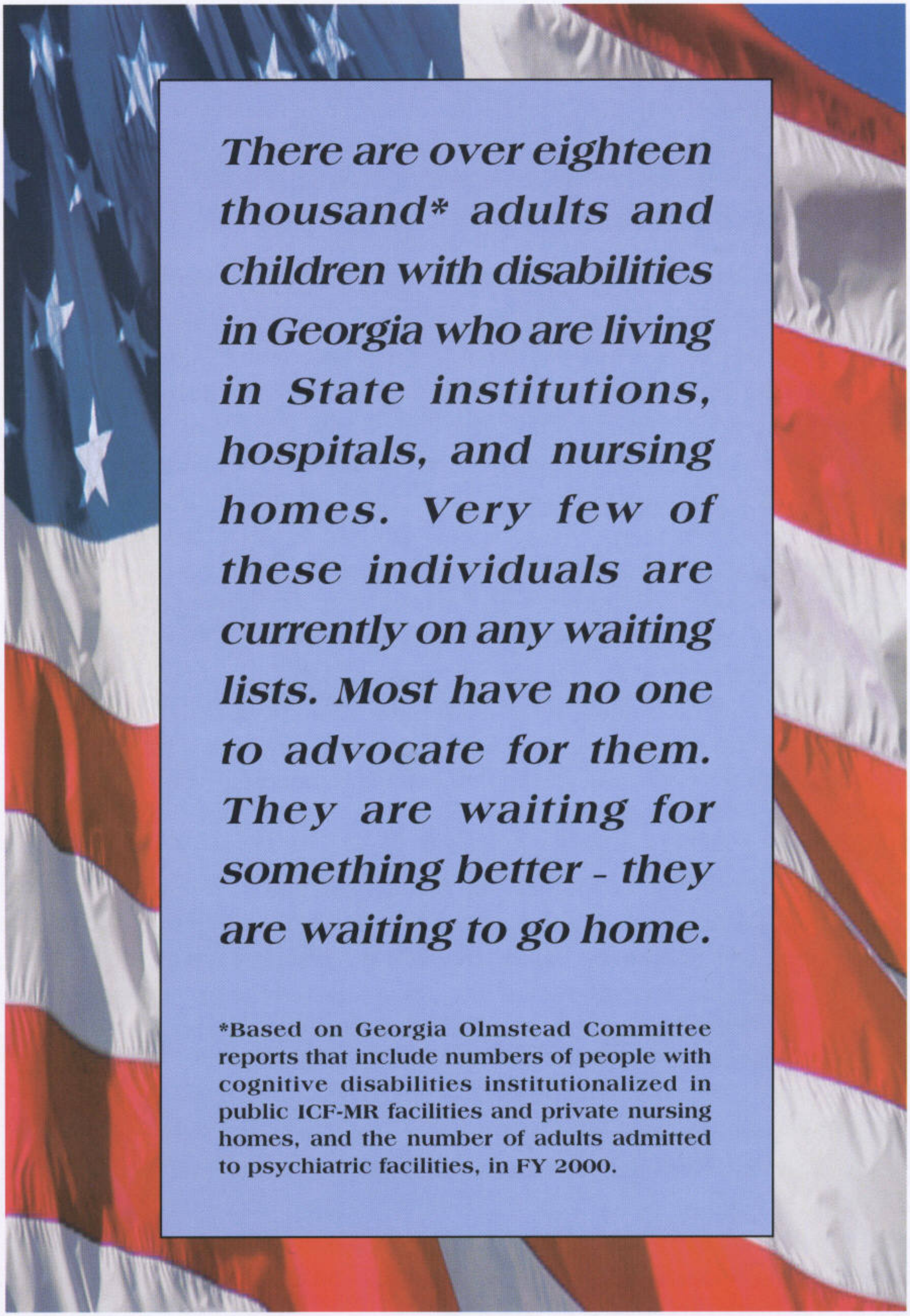
The Supreme Court also made it clear that states are required to make "reasonable modifications" but are not required to make changes that will "fundamentally alter" their existing programs. Justice Ginsberg's ruling acknowledged that states must work within their budgets and need to maintain a full range of services. To help states to comply with the ADA without radically altering their programs, Justice Ginsberg suggested that, "if, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met" (527 U.S. at 605-606).

This one sentence in Justice Ginsberg's decision turned out to be very powerful indeed. Since the Supreme Court issued its decision, many federal agencies have revised their policies for services and funding for people with disabilities, and state agencies across the nation have been very busy devising "Olmstead Plans." This court case (that began to help Lois and Elaine leave the hospital and find homes in the community) became a national mandate to free tens of thousands of people with mental and physical disabilities from unnecessary and unjust institutionalization.

The only thing left undecided by the higher courts was the issue of funding for community supports for Lois and Elaine. This decision was remanded back to Judge Shoob's Court in Georgia's Eleventh District. When a settlement was finally reached (in which Lois and Elaine were guaranteed community-based supports for the rest of their lives), Sue asked the Judge if Lois and Elaine could personally address the court. (All of the other court proceedings had been handled by lawyers, standing in as Guardian ad Litem for both Lois and Elaine.) Judge Shoob gladly agreed.

So, on July 11, 2000, five years after the case began, Lois and Elaine were able to tell the court how they felt about leaving the hospital and having a home of their own. Lois said that she hoped that the court's decision would help other people, and Elaine said that it was good to be "in the free world." But they mostly talked of simple things that most people take for granted like being allowed the privacy of your own room, listening to the radio, making Kool-Aid, and just going outside.

On June 18, 2001, the President of the United States issued an Executive Order calling for the "swift implementation of the Olmstead Decision," asking all federal agencies to work with the states to ensure community-based alternatives for people with disabilities. Because of the Supreme Court's ruling on Lois and Elaine's case, the President proclaimed that, "The United States is committed to community-based alternatives for individuals with disabilities and recognizes that such services advance the best interests of Americans."



There are over eighteen thousand* adults and children with disabilities in Georgia who are living in State institutions, hospitals, and nursing homes. Very few of these individuals are currently on any waiting lists. Most have no one to advocate for them. They are waiting for something better - they are waiting to go home.

***Based on Georgia Olmstead Committee reports that include numbers of people with cognitive disabilities institutionalized in public ICF-MR facilities and private nursing homes, and the number of adults admitted to psychiatric facilities, in FY 2000.**

Afterword

More Are Waiting to Be Free

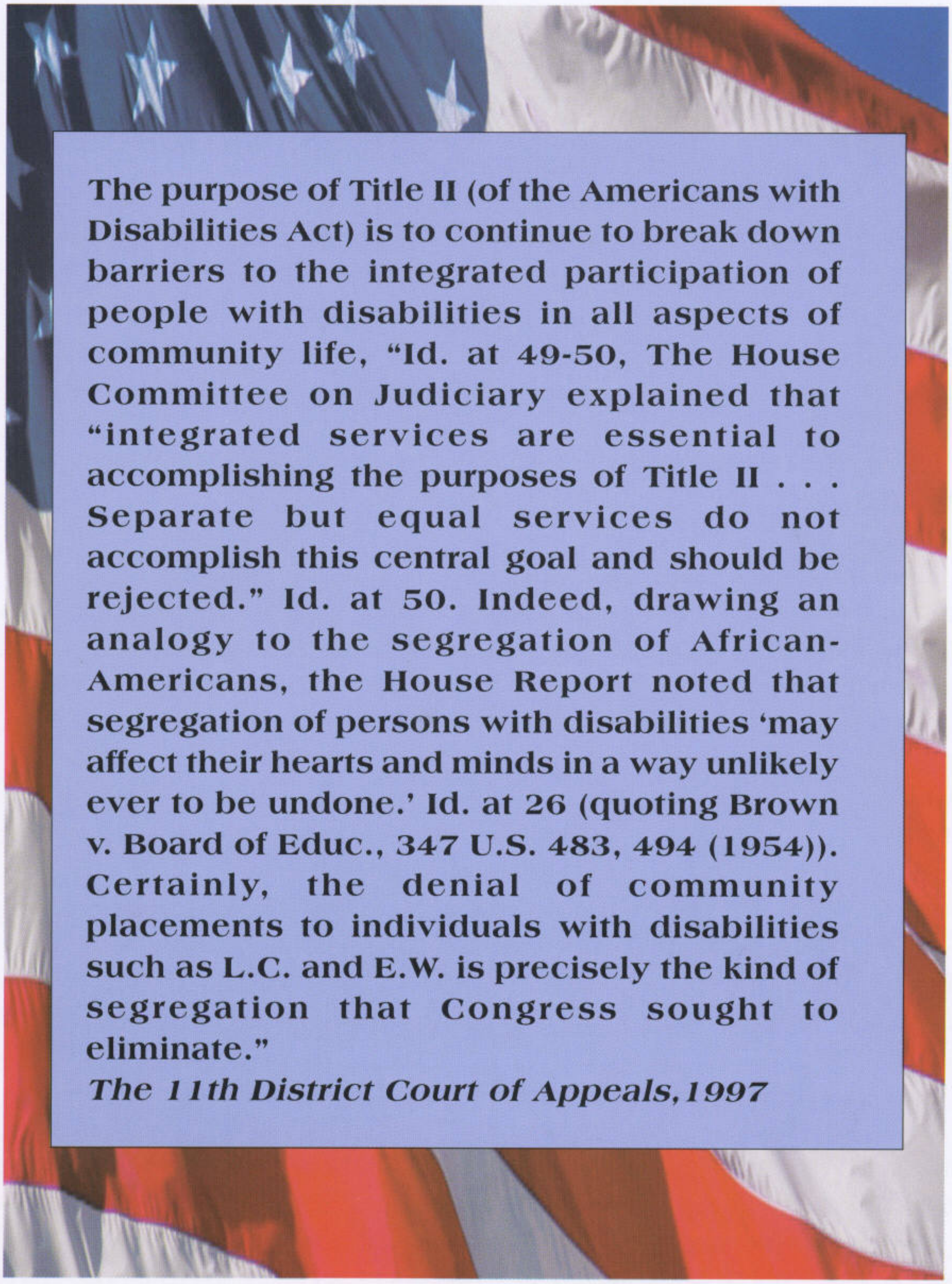
"The situation for both Lois and Elaine in the institution was outrageous," says Sue. "But not, perhaps, any more outrageous than the situations faced by many others. Ultimately, the case was successful in the Supreme Court because the treatment staff never seriously contended that Lois and Elaine should be living in an institution." It is rare that any individual chooses to live in an institution, and most, if not all, people with mental and physical disabilities are capable of living in the community with the proper supports.

Both Lois and Elaine are now living successfully in neighborhoods near Atlanta. They enjoy the comfort of living at home, with the aid of community-based services and the support and camaraderie of neighbors and friends. While their lives have not been trouble free, neither Lois nor Elaine has been reinstitutionalized since they were released from Georgia Regional Hospital.

Lois and Elaine's Supreme Court decision (now commonly referred to as "Olmstead") is having an effect all over the Country. State governments are now required to comply with the Americans with Disabilities Act by demonstrating that they have a plan to move eligible people from institutions to community-based services and any waiting lists for these services must move at a "reasonable pace."

Unfortunately, as Sue points out, "most people in institutions are not on any waiting lists." They are alone, without advocacy - without anyone to tell them that they are entitled to community services. "I sometimes feel," says Sue, "as if there is a civil rights movement but those whose civil rights are involved are not aware of it. It's sad when you think of all the people in institutions specifically for individuals with developmental disabilities and mental retardation because those are the people who are least likely to know about their rights and to have access to information so that they can call us for help."

Lois and Elaine hope that their case helps other people. "When they say that," asserts Sue, "I don't think that they are talking about big policy. They are talking about how they wish that the people in Central State could get out. That's what we have the power to do and it frustrates me frankly, that we are not doing it. We could be getting people out. I've spent most of my life here trying to get that going." If you ask Elaine what advice she would give to others who are trying to get out of institutions, she smiles confidently and replies - "Call Sue."



The purpose of Title II (of the Americans with Disabilities Act) is to continue to break down barriers to the integrated participation of people with disabilities in all aspects of community life, "Id. at 49-50, The House Committee on Judiciary explained that "integrated services are essential to accomplishing the purposes of Title II . . . Separate but equal services do not accomplish this central goal and should be rejected." Id. at 50. Indeed, drawing an analogy to the segregation of African-Americans, the House Report noted that segregation of persons with disabilities 'may affect their hearts and minds in a way unlikely ever to be undone.' Id. at 26 (quoting Brown v. Board of Educ., 347 U.S. 483, 494 (1954)). Certainly, the denial of community placements to individuals with disabilities such as L.C. and E.W. is precisely the kind of segregation that Congress sought to eliminate."

The 11th District Court of Appeals, 1997

Resources for Advocacy and Support

Atlanta Legal Aid Society, Inc.
246 Sycamore St., Suite 120
Decatur, GA 30030-5434
(404) 377-0701

Atlanta Alliance on Developmental Disabilities
1440 Dutch Valley Place, NE, Suite 200
Atlanta, GA 30324-5371
(404) 881-9777 • www.aadd.org

Georgia ADA Exchange
4164 Admiral Drive
Chamblee, GA 30341
(770) 451-2340 • www.georgiaadaexchange.org

The Georgia Advocacy Office
100 Crescent Centre Parkway, Suite 520
Tucker, GA 30084
1-800-537-2329 or (404) 885-1234 V/TTY • http://thegao.org

Georgia ARC Network
1000 Main Street
Forest Park, GA 30297
(404) 361-9311

The Governor's Council on Developmental Disabilities
2 Peachtree Street NW, Suite 210
Atlanta, GA 30303
(404) 657-2126 • www.ga-ddcouncil.org

The Institute on Human Development and Disability
850 College Station Road
Athens, GA 30602-4806
(706) 542-3457 • www.uap.uga.edu

People First of Georgia
850 College Station Rd
Athens, GA 30602-4806
(706) 542-6086 • www.uap.uga.edu/georgiapeoplefirst

Statewide Independent Living Council
3125 Presidential Parkway, Suite 200
Atlanta, GA 30340
(770) 452-9601 • TTY (770) 452-7087

To Elaine and Lois

There were two women, Elaine and Lois,
In an institution that wasn't their choice.
They wanted out so they used their voice.
To make a difference was their plan,
To help themselves and their fellow man.
They hired the lawyers who said, "We can."
And went to fight, their future to plan.
Elaine and Lois went through a big fight,
To set folks straight and put things right.
To tell institutions to go fly a kite.
To live in their community is a God-given right.
They convinced the judges they should live on their own,
Make their own choices, have their own homes.
Thanks Lois, thanks Elaine.
Your action has made it even more plain.
Stand up for yourself, and self-advocate be.
There is nothing to lose and everything to gain.
So tonight we honor you both for what you have done.
You fought the system, and thank God,
YOU WON!

Gail Bottoms, People First of Georgia

Presented to Lois Curtis and Elaine Wilson at the
People First Community Freedom Celebration
Decatur, Georgia
August 6, 1999

How Lois Led Us All the Way to the U.S. Supreme Court

It is 2:00 A.M.
I wake with a voice that demands to be heard.

It is strange to call her L.C.
Over the eighteen years since we first met, we have always called each other by our first names.

In my mind are snapshots of the past.

It is 1981. We are sitting and talking at a school table in a psycho-education center. I am watching Lois draw glamorous pictures of herself – always with makeup and earrings. I remember myself at her age, fourteen, staring into a mirror and putting on makeup and earrings.

We are sitting in the beauty salon owned by a friend of mine. Lois is a young woman now. As I pass him the curlers, my friend spends hours giving her a beautiful jerri curl.

Lois has a pass to visit me at my house. Seeing my mother's heavy Necchi sewing machine on the dining room table she says, "I want to sew." A pillow forms under our hands.
We leave the table and go to make quiche for lunch in my kitchen.

After our day together, we are driving back to the hospital where she lives. Lois is holding the pillow close to her chest.

My chest is tight as I walk with her into the big day room. The noise is overwhelming. Lois' voice cannot be heard here. I do not want to leave her.

It is 1994. We are sitting in a Chinese restaurant with a group of people we have gathered for Lois' futures planning. After we read the menu, Lois orders shrimp chow mien. A member of the group says, "I didn't know she liked shrimp." I respond, "Lois never had the chance to order shrimp before today."

I hold a picture of Lois' vision for the future that we drew that day after lunch. There is her house, as she imagined it, in a neighborhood near where her family lives. Lois is living with a house mate, listening to music and cooking in her home. In this vision, Lois is taking art classes, studying for her GED and typing. Lois imagines herself working at an art store or sewing clothes. She is going out to eat with friends, swimming at the Y, playing on a volleyball team and reuniting with her family at a reunion.

A year after the futures planning gathering Lois says, "I would like to talk to God and for Jesus to get me out of the hospital for Christmas." We are sitting in my living room with her circle of allies and family, talking about next steps. For a year the circle has been wrestling with the question, "How can we help Lois get the support she needs to live in her own home?" In the middle of our discussion Lois exclaims, "I want to type!" I pull out my electric typewriter and sitting at my dining room table, she types all the names of those she remembers who have played a part in her life.

We are celebrating Lois' birthday in a park. The cake and friends singing hold us for a moment, in the taken-for-granted pleasure of celebrations.

Lois' birthday is the same as Bastille Day. A national holiday in France, this date commemorates the fall of the Bastille, a prison in Paris, 210 years ago.

Since Lois was thirteen years old, she has lived over half of her life in places segregated by disability.

We were led all the way to the U.S. Supreme Court by Lois' insistent voice that she be heard.

It is now 4:00 A.M. Who is listening to all the other voices?

Gillian Grable

Institute on
Human Development
and Disability
The University of Georgia

A University Center for Excellence in Developmental Disabilities Education, Research, and Service
A Unit of the College of Family and Consumer Sciences
at the University of Georgia