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## THE *OLMSTEAD* DECISION: THE ROAD TO DIGNITY AND FREEDOM

Sylvia B. Caley\* and Steven D. Caley<sup>†</sup>

### INTRODUCTION

The history of discrimination in Georgia against persons with mental disabilities is long and tragic. As early as 1845, the Georgia legislature established the first institution for segregation of the mentally disabled. It was described as the “Lunatic Asylum” for “lunatics” and “idiots,” who could be discharged only upon having “recovered [their] senses.”<sup>1</sup> The Georgia legislature passed additional legislation in 1868 in which it found that persons with mental disabilities were “either lunatics, idiots, epileptics, or demented inebriates” who should be segregated as “inmates” in a “lunatic asylum” as if they were common criminals.<sup>2</sup> Society’s pernicious attitudes towards those with mental disabilities continued unabated in Georgia at the turn of the twentieth century when the Georgia legislature established the “Training School for Mental Defectives” for the segregation and confinement of those who “constitute[s] a menace to the happiness of himself or of others in the community” because they were mentally defective at birth or became “mentally defective” due to injury or accident.<sup>3</sup> Not surprisingly, given the attitudes at the time, the state termed such segregated treatment of the mentally disabled as the state’s “noblest charity.”<sup>4</sup>

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1. Lunatics Asylum, 1845 Ga. Laws 200, § 5, 204 (“No lunatic or epileptic, who shall have recovered his senses so as to go abroad without offence or terror to others, shall be discharged from the asylum without suitable clothing . . .”).

2. The Admission, Management and Discharge of Patients, 1868 Ga. Laws 268, § 1374, 268, 270 (“Persons who may become inmates of said Asylum are either lunatics, idiots, epileptics, or demented inebriates.”).

3. Act Establishing Training School for Mental Defectives, 1919 Ga. Laws 377, § 3, at 379.

4. JOURNAL OF THE HOUSE OF REPRESENTATIVES OF THE STATE OF GEORGIA, OCT. 23, 1902, Gen. Assem., Reg. Sess., at 47 (1902).

In 1985, Justice Marshall aptly described such legislation as a “regime of state-mandated segregation and degradation . . . that in its virulence and bigotry rivaled, and indeed paralleled, the worst excesses of Jim Crow.”<sup>5</sup> As noted by Justice Marshall, blatant discrimination and segregation against persons with mental disabilities continued throughout the United States during the 1900s. In 1973, the U. S. Congress passed the Rehabilitation Act<sup>6</sup> in order to address this discrimination. As noted by the Congress during the passage of the Americans with Disabilities Act of 1990 (ADA),<sup>7</sup> however, the Rehabilitation Act and other legislation constituted a “patchwork quilt in need of repair” with “holes in the fabric” and “serious gaps in coverage that leave persons with disabilities without adequate civil rights protections.”<sup>8</sup> The sad result was that persons with disabilities were “still too often shut out of the economic and social mainstream of American life.”<sup>9</sup> As Senator Lowell Weicker, the original sponsor of the ADA, stated during consideration of the ADA’s passage: “Separate is not equal. It was not for blacks; it is not for the disabled.”<sup>10</sup> Senator Edward Kennedy likened segregation of persons with disabilities to an “American apartheid,”<sup>11</sup> and the Congress repeatedly invoked *Brown v. Board of Education*<sup>12</sup> as a basis for prohibiting segregation based upon disability.<sup>13</sup>

#### DEPLORABLE CONDITIONS CONTINUE IN GEORGIA

Shortly after Justice Marshall’s opinion in the *Cleburne* case, in 1986, attorneys at the Atlanta Legal Aid Society established a mental

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5. *City of Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 462 (1985) (Marshall, J., concurring and dissenting in part).

6. 29 U.S.C. § 794 (2000).

7. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 327.

8. S. REP. NO. 101-116, at 19 (1989); H.R. REP. No. 101-485, at 48 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, 330.

9. *Americans with Disabilities Act: Hearing Before the Subcomm. on the Handicapped of the S. Comm. on Labor and Human Resources*, 101st Cong. 195 (1989) (statement of Richard L. Thornburgh, Att’y Gen. of the United States).

10. *Id.* at 215.

11. 135 CONG. REC. S4993, at 8514 (daily ed. May 9, 1989) (statement of Sen. Edward Kennedy).

12. *Brown v. Bd. of Educ.*, 347 U.S. 483 (1954).

13. H.R. REP. NO. 101-485, at 26 (1990), *reprinted in* 1990 U.S.C.C.A.N. 445, 448–49.

health law unit to address the systematic state-sponsored segregation and discrimination against persons with mental disabilities in Georgia. Susan C. Jamieson, the founder of that unit has described eloquently the deplorable conditions in Georgia's state-run institutions:

State psychiatric facilities are shocking places. After twenty years of visiting Georgia facilities, I am still shocked. I have gotten used to the bleak environment. Over time, one adjusts to the cold, the noise, and the smell, and many people who have been admitted twenty or thirty times have gotten used to it, too. But it is the chilling sameness of each individual's story that is so troubling. Fear and a sense of dislocation are palpable. Every conversation is heavy with exhaustion from the effort to preserve a sense of dignity in a locked ward with strangers and from the lack of energy that accompanies the drugs administered. There is a deep sense of injustice that the law permits forced segregation in an impersonal, violent place. Perhaps the worst part of every story is the tedium and frustration that comes with the repetitive daily routine. Even when the institution is a refuge or a safe haven for a person, the fact remains that every day is a desperate struggle to hold onto one's identity against all odds.<sup>14</sup>

Attorneys working with the mental health unit soon observed that many persons requiring their representation either never received a community placement or were caught in a revolving door of institutionalization, which involved initial institutionalization, discharge to a community setting with inadequate or nonexistent support services, and re-institutionalization. In short, persons

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14. Interview with Susan C. Jamieson, J.D. (Oct. 15, 2010). Ms. Jamieson is the former director of the Mental Health Unit, Atlanta Legal Aid Society, and co-counsel in *Olmstead v. L.C.*, 527 U.S. 581 (1999). Ms. Jamieson's observations have been confirmed by recent federal investigations of Georgia's institutions which have documented numerous instances of barbaric treatment and suspicious deaths. As a result, Georgia recently announced that it was shutting down all adult mental health services at Central State Hospital in Milledgeville, an ancient institution established in the 1800s by the legislation described above. See Craig Schneider, *An Era Ends at Mental Facility*, ATLANTA J.-CONST., Jan. 21, 2010, at A1.

fortunate enough to obtain a community placement were set up for failure from the outset.

Moreover, typical legal approaches did not work well. Most lawsuits were brought under the Fourteenth Amendment or the Rehabilitation Act. However, the courts found that the Fourteenth Amendment merely required minimally adequate treatment and habilitation as determined by the state's treating professionals whose opinions were entitled to deference so long as they exercised qualified professional judgment.<sup>15</sup> This state-friendly standard was impossible to overcome in most cases. Cases under the Rehabilitation Act typically floundered on the shoals of the Act's requirement that there be discrimination based solely on disability<sup>16</sup> and on the courts' otherwise narrow construction of the Act's applicability. As a result, the mental health law unit decided it needed to find a new approach to end unnecessary segregation of persons with disabilities in institutions.

Their task was aided by their regular presence in the state's institutions—they knew the staff and many of the patients. Frequently, they had the opportunity to review and evaluate clients' medical records, and over time they gleaned insight into what treatment staff would recommend regarding the needs of various patients. Based upon the judicial system's history of hostility and fear of releasing mentally disabled persons from institutions and the system's deference to the state's doctors, the attorneys decided that a new legal approach would need to be made on behalf of an individual who the state's treating doctors agreed was qualified to be placed in the community.

Lois Curtis was just one such person.<sup>17</sup> She also was a good example of the revolving door of institutionalization. Beginning in the early 1990s, the mental health law unit represented her in many

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15. See, e.g., *Youngberg v. Romeo*, 457 U.S. 307 (1982).

16. The Rehabilitation Act actually used the now discredited term "handicap." The 1992 amendments substituted "a disability" for "handicaps" and "disability" for "handicap." Rehabilitation Act Amendments, subsec. (a), § 102, 106 Stat. 4344, 4348 (1992) (codified as amended at 29 U.S.C. § 794 (2000)).

17. Lois Curtis eventually became the named plaintiff in the *Olmstead v. L.C.* decision.

cases, including a case filed in Probate Court alleging a violation of her right to appropriate treatment. Because she had a lawyer, Lois was released from the institution, but she was placed in a personal care home without adequate supports and where the provider was not trained to assist persons with developmental and psychiatric disabilities. Predictably, the placement failed, the provider could not handle Lois' behavior, and Lois returned to the hospital. This particular placement failure cemented the state's resolve that Lois' proper place was in a state institution. Thus, the revolving door of institutionalization that had been Lois' life for over ten years, since she was fourteen years old, continued.

#### THE ROAD TO DIGNITY AND LIFE

In working through the process of identifying clients, developing issues, and determining legal strategies, there is no substitute for developing personal relationships, putting in the time to investigate and understand the circumstances, and appreciating the physical and political landscapes. The *Olmstead* experience provided poignant learning lessons for the plaintiffs' litigation team—lessons that the team members continue to carry with them.

As Lois' legal team evaluated new strategies to achieve an appropriate, sustainable community placement for her, many of her caregivers at the hospital acknowledged that institutionalization was deleterious to Lois resulting in regressive behaviors.<sup>18</sup> The medical facts were integral to the case. Lois Curtis was diagnosed as being mildly mentally retarded and as having schizophrenia or a mood disorder. Her first hospitalization was at age eight because her mother could not control her and feared that Lois might hurt her younger sister. Between 1980 and 1995, Lois accumulated 18 admissions to Georgia Regional Hospital at Atlanta (GRH-A). During these admissions, Lois' life was monotonous, she rarely had

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18. Affidavit of M. Cecelia Kimble, Ph.D., in support of Motion for a Temporary Restraining Order and Preliminary Injunction, *L.C. v. Olmstead*, No. 1:95-cv-1210-MHS, 1997 WL 148674 (N.D. Ga. Mar. 26, 1997).

visitors, she never left the hospital grounds, and her greatest interest was smoking cigarettes. While Lois spent extensive periods of her life in institutions, her maladaptive behavior never was addressed from a developmental disability perspective. Her frequent, long-term periods of institutionalization further exacerbated her bad behavior. She never learned to manage her behavior.

As the State came to understand that legal action would be pursued on Lois' behalf, the State initiated plans first to send Lois to a day program and later to discharge her into her mother's care. Placement in the mother's home had failed numerous times in the past due to lack of adequate community services and supports, so the legal team held no expectation that revisiting this placement would meet with any success. The hospital's continuing control over Lois' day-to-day activities presented ongoing significant challenges for the legal team. Eventually, because the State acknowledged that Lois was qualified to be in the community, the team made the decision to file suit on her behalf.

At the very outset, the team had to consider two primary, yet potentially competing goals: obtaining the best possible outcome for Lois while also obtaining an outcome that would force systemic change so that neither Lois nor the hundreds of other similarly affected individuals would ever be segregated and confined unnecessarily again in the harsh and destructive environment of a state facility. Filing the case as a class action was evaluated and rejected because the facts of each case were unique and the service needs of each person were individually specific. Furthermore, the attorneys were mindful that the courts, even the federal courts, had been especially hostile to class actions filed on behalf of persons with mental disabilities. Finally, an important goal of the litigation was to obtain a favorable precedent under a relatively new statute at the time, the ADA, which would open the door and lay a strong foundation for future, more expansive, advocacy.

The team made the difficult decision to file the first case on behalf of an individual claimant rather than as a class action. The wisdom of this decision later was confirmed at oral argument before the Eleventh Circuit Court of Appeals. A turning point in the argument

occurred when Judge Barkett turned to her colleagues on the Court and emphasized that this was not a class action, such that several of the state's arguments, including its fundamental alteration argument based on funding concerns, were irrelevant. The point was noted in the Eleventh Circuit's written opinion.<sup>19</sup> One other primary consideration for the legal team was to file a case where availability of community services would not be an issue. Thus, the legal team decided to represent plaintiffs for whom community programs already existed.

The litigation began with Lois Curtis, well known to the attorneys of the mental health unit. Elaine Wilson later was joined as another individual party to the lawsuit. Both of these women had dual diagnoses of mental retardation and mental illness, and were therefore eligible for the Mental Retardation Waiver Program (MRWP), a funding mechanism available through the Georgia Medicaid program that could be used to provide the community supports required by both women. Georgia did not have a comparable residential support program for persons diagnosed only with mental illness. The availability of the MRWP extinguished any argument that the litigants were seeking mandated services without a funding source.

#### LANDMINES ALONG THE WAY

The new legal approach that the legal team decided to use was a claim under the Americans with Disabilities Act. After Lois had sought representation and while the team was in the process of preparing the foundation for their claim, the team had a lucky break—the Third Circuit Court of Appeals handed down the first favorable precedent under the ADA for persons with mental disabilities in *Helen L. v. Didario*.<sup>20</sup> Suit was filed on behalf of Lois shortly thereafter.

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19. See *L.C. v. Olmstead*, 138 F.3d 893, 905 n.10 (11th Cir. 1998).

20. *Helen L. v. DiDario*, 46 F.3d 325 (3d Cir. 1995).

Everyone knew that a fight was in store. Perhaps the realization that the litigants were involved in a war became more apparent in retrospect. Eight days after the lawsuit was filed in May 1995, and in a blatant effort to torpedo the case, the state discharged Lois once again from GRH-A to the care of her mother—only this time, the discharge was for a two-week trial period with the intent of making it final. This placement was inappropriate because since age 8, Lois had not lived successfully with her mother. Like the other placements in the past to her mother's home, this placement lacked training for the mother and supportive services and community resources for Lois. Not surprisingly, Lois' mother complained of Lois' smoking, poor hygiene, and bad behavior. The placement was doomed, and predictably it failed.

When the state proceeded to re-institutionalize Lois, her legal team filed a motion for a temporary restraining order to require a proper community placement. This motion was resolved with Lois' admission to Brook Run, a less restrictive institutional setting than GRH-A, and an agreement to prepare Lois for a full community placement. Even though Lois did not need to be institutionalized, she again found herself in an institutional setting because an appropriate community placement plan did not exist. While at Brook Run, her treatment staff developed a community placement plan. Even so, she was not discharged to her community living situation until February 1996.

Elaine Wilson, diagnosed as mildly mentally retarded along with a psychiatric diagnosis of personality disorder, lived in the same locked ward at GRH-A with Lois. She had over 30 admissions to this institution over a 20-year period. Her history of placements following discharge from the institution included inappropriate personal care homes and homeless shelters. For example, one community provider believed that the appropriate habilitation for Elaine was "to pray the demons out of her." During her many admissions to GRH-A she was not evaluated, did not receive ongoing assessments, and no one trained in developmental disabilities provided her care. People with developmental disabilities often exhibit maladaptive behaviors which may be misunderstood by

providers not trained appropriately. Elaine developed learned dependence on the routines at GRH-A and exhibited frustration, depression and hopelessness. The environment at GRH-A was chaotic and complex, and the longer she remained, the more her behavior deteriorated.

In addition to her developmental and mental health challenges, Elaine battled many physical maladies. Perhaps worst among her problems was advancing kidney disease. She was prescribed many medications and experienced side-effects from these medications. In early 1997, Elaine's kidney problems nearly scuttled her placement in the community. Staying on top of the physical health challenges was essential. In order to prevent further deterioration of Elaine's condition, the legal team filed a motion for preliminary injunction on her behalf to obtain the services she needed in a community setting.

Ultimately, Judge Marvin Shoob ruled in favor of Lois and Elaine and found that: “. . . under the ADA, unnecessary institutional segregation of the disabled constitutes discrimination *per se*, which cannot be justified by a lack of funding.”<sup>21</sup> Thus, Judge Shoob required that the state provide Elaine with an appropriate community placement and maintain Lois' community placement with appropriate supportive services.<sup>22</sup>

The State of Georgia appealed to the Eleventh Circuit. The panel consisted of Judges Tjoflat, Barkett, and Propst. The oral argument did not begin well as the first question from Judge Tjoflat suggested that the State could not afford to provide funding for community services, and, therefore, would not a ruling in favor of the Plaintiffs result in a contempt action to throw state officials into jail? Although the record showed that community services were cheaper to provide than institutional services, Judge Tjoflat's funding concern found its way into the Eleventh Circuit's decision.<sup>23</sup> In affirming the district court's opinion that the failure to provide community services for qualified persons, such as Lois and Elaine, is discriminatory under

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21. *L.C. v. Olmstead*, No. 1:95-cv-1210-MHS, 1997 WL 148674, at \*3 (N.D. Ga. Mar. 26, 1997).

22. *Id.* at \*5.

23. *See L.C.*, 138 F.3d at 905.

the ADA, the Court did not outright affirm the district court.<sup>24</sup> The case was remanded for a determination regarding whether the State could “prove that requiring it to make additional expenditures [for Lois and Elaine] would be so unreasonable given the demands of the State’s mental health budget that it would fundamentally alter the service it provides.”<sup>25</sup> If the state could not show such a fundamental alteration, the Eleventh Circuit held that the ADA would require those expenditures.<sup>26</sup>

The Supreme Court affirmed the Eleventh Circuit’s decision in substantial part. It specifically held that “[u]njustified isolation . . . is properly regarded as discrimination based on disability.”<sup>27</sup> The Supreme Court, however, found that the Eleventh Circuit’s remand instruction was “unduly restrictive” as follows:

In evaluating a State’s fundamental alteration defense [the funding issue], the District Court must consider, in view of the resources available to the state, not only the cost of providing community-based care to the litigants, but also the range of services the state provides to others with mental disabilities, and the state’s obligation to mete out those services equitably.<sup>28</sup>

The Court’s concern was based on the regulations under the ADA which provide that the State must make reasonable modifications to its programs to avoid discrimination unless those modifications entail a fundamental alteration of the state’s services.<sup>29</sup> The Court found that, as a practical matter, a state would never be able to show a fundamental alteration under the regulation if the “expense entailed in placing one or two people in a community-based treatment program is properly measured for reasonableness against the entire mental health budget” as required by the Eleventh Circuit.<sup>30</sup>

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24. *See id.* at 895.

25. *Id.* at 905.

26. *Id.*

27. *Olmstead v. L.C.*, 527 U.S. 581, 597 (1999).

28. *Id.*

29. *See* 28 C.F.R. § 35.130(b)(7) (1991).

30. *Olmstead*, 527 U.S. at 603.

APPLICATION OF THE *OLMSTEAD* DECISION

Near the end of its opinion, the Supreme Court provided a specific example of the intent of its holding with respect to the reasonable modification regulation:

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.<sup>31</sup>

The Court further explained as follows:

In such circumstances, a court would have no warrant effectively to order displacement of persons at the top of the community-based treatment waiting list by individuals lower down who commenced civil actions.<sup>32</sup>

Based upon the above language, the Supreme Court carefully qualified its holding that unnecessary institutionalization of the disabled constitutes discrimination under the ADA.

We are now beyond the ten year anniversary of the *Olmstead* decision and little has happened in Georgia and many other states to develop a "comprehensive, effectively working plan" and a "waiting list that move[s] at a reasonable pace." Persons with mental disabilities continue to languish in dangerous and inhumane institutions for many years. In many instances, no waiting lists exist at all, let alone ones that move at a reasonable pace. A reasonable pace simply does not mean confinement and segregation for several years in the locked ward of an institution. In the words of Senator Kennedy, it is time to end this "American apartheid."

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31. *Id.* at 606.

32. *Id.*

A return to Fourteenth Amendment constitutional claims, as some have suggested, is not the solution when the United States Supreme Court is more conservative now than when it issued the failed Fourteenth Amendment jurisprudence of *Youngberg v. Romeo* and its progeny. Although the *Olmstead* decision is not a perfect one, in states such as Georgia where little has been done, *Olmstead* still holds great promise. In those states, enforcement actions under *Olmstead* are long past due. It is time to act if *Olmstead*'s original promise is to be fully realized.