Disabilities and the Law: The Evolution of Independence

By David Ferleger

Disabilities in Our Lives

Signing the Declaration of Independence on July 4, 1776, Stephen Hopkins referred to his cerebral palsy, saying "My hand trembles but my heart does not." During the Constitutional Convention of 1787, Benjamin Franklin was carried into sessions in a sedan chair because he was almost immobilized by gouty arthritis. More than two centuries later, thousands of people attended the 1990 White House signing ceremony for the Americans With Disabilities Act (ADA), at which President George H. W. Bush declared, "Today we're here to rejoice in and celebrate another 'independence day,' one that is long overdue."

People with disabilities influence and inspire our lives. Thomas Edison and Ludwig van Beethoven were deaf. Steven Hawking has a neurological condition. John Milton became blind at the age of 43, and Claude Monet became blind in later life. President Franklin Roosevelt, musician Teddy Pendergrass, "Superman" Christopher Reeve, and violinist Itzhak Perlman have used wheelchairs. The ballet dancer Vaslav Nijinsky had bipolar disorder, as does Patty Duke, who played Helen Keller in "The Miracle Worker." The actress Sarah Bernhardt had to have her leg amputated. Cher is dyslexic.

We are all extremely familiar with disabilities. We may have been born with a disability. If we are not disabled ourselves, we know people who are.

So-called temporarily able-bodied people may well lose their sight or speech or mobility. Baby boomers who are currently healthy will almost certainly become frail as they age. People with one challenge or limitation today often acquire another.

Currently, about 54 million people in the United States are disabled at present. This number accounts for about 19 percent of the U.S. population. Among families in America, 20,874,130 families—29 percent—have a family member with a disability.

Of the people with disabilities who are 15 years and older:

- 3.3 million use a wheelchair;
- 10.2 million use a mobility aid such as a cane, crutches, or a walker;
- 1.8 million are unable to see printed words or are blind;
- 1 million are deaf or unable to hear conversations;
- 2.5 million have difficulty having their speech understood by others; and
- 16.1 million have limitations in cognitive functioning or have a mental or emotional illness or developmental disability.

Snapshot numbers do not tell the whole story, of course. Someone 25 years old has a 44 percent likelihood of having at least one long-term disability that lasts three months or longer before the person reaches the age of 65. One out of two women and one out of three men will spend some time in a nursing home. The baby boomer generation, which makes up an increasing proportion of

the U.S. population, has 76 million members. In addition, in 2010, 13 percent of the United States population was over 65; by 2040, this percentage will rise to 20.4 percent. By 2050, there will be 88.5 million Americans over 65, more than doubling the 2008 figure. Most adults plan to keep working, even during so-called retirement.

People with disabilities live in relative social isolation. Compared to people without disabilities, disabled individuals are much less likely to work full- or part-time (35 percent versus 78 percent); less likely to socialize with close friends or relatives; less likely to go to church, synagogue, or mosque; and less likely to go out to eat. Physical isolation is also common in the lives of people with disabilities. Tens of thousands of residential institutions in the United States house people with disabilities. For example, in 2002 there were 69,136 nursing facilities and 28,448 facilities that serve people with developmental disabilities, mental health issues, or substance abuse. As of June 30, 2008, 42 states operated 2,614 residential settings that house people with intellectual or developmental disabilities. Currently, 1.8 million people live in nursing facilities. In 2008, at least 35,741 people lived in large state-operated institutions that cared for people with developmental disabilities.

Disabilities in History

The ancient Greeks called people with intellectual deficiencies "idiots" and intended the term to refer to their inferiority. Aristotle, who lived in the fourth century B.C., recommended the establishment of laws "to prevent the rearing of deformed children." He claimed that "no deformed child shall live." In ancient Rome, children who were blind, deaf, or mentally retarded were publicly persecuted and reported to have been thrown in the Tiber River by their parents. Some children born with disabilities were mutilated to increase their value as beggars.

In the Middle Ages, as leprosy began to disappear, leprosariums were converted to houses to be used by all sorts of people considered deviant: orphans, vagabonds, prostitutes, widows, and people with mental illness and intellectual disabilities. During this time, "idiot cages" became common in town centers and were used to keep people with disabilities "out of trouble." These facilities may also have served as entertainment for townspeople. Some people with disabilities were shipped off to other countries. Sailors were paid to take these individuals away in what were called "ships of Fools," which sailed from port to port. The sailors charged admission to view their cargo and eventually abandoned their passengers.

With the Age of Enlightenment, a more humane educational motive in services developed, with professionals observing that people with disabilities were able to grow and develop. The "moral treatment" movement was influenced by the Quakers in England and post-French Revolution reformers in France in the late 1700s and into the 1800s. Reformers in the United States included activists like Dorothea Dix and Clifford Beers, whose personal crusades were rewarded with attention from legislators.

The first schools for students who were deaf opened

in Europe in the mid-1700s and in the United States in 1817. A school for students who were blind opened in Boston in 1832. In the mid-1800s, so-called training schools for people with developmental disabilities were established. Sadly, rapidly increasing enrollment and, eventually, the eugenics movement and a perception that residents of these schools were dangerous, resulted in a shift from "training" to custodial care in overcrowded and understaffed institutions.

The turn-of-the-century institution was aptly described by Louis Brandeis. Years before his appointment to the U.S. Supreme Court, Brandeis once represented Alice N. Lincoln, a Boston philanthropist and noted crusader for the poor. In 1894, Brandeis appeared at public hearings, which were held to investigate conditions in the public poorhouses. Brandeis' summation at one of these hearings emphasized the nature of segregation for those whom he described as "the outcasts of society":

They call this a Home for Paupers. That place may be as clean today, or any day, as any place in Christendom; the food may be as good, the air may be perfect; you may have beds in woven-wire mattresses as good as any that can be found; the attendants and the discipline and work may all be there. But that place as it presented itself to us is as far from a home as one pole is from another. It is the very opposite of a home in every particular.

Documents of the City of Boston for the Year 1894, Vol. 6, p. 3632-3633 (Boston: Rockwell & Churchhill. City Printers, 1895). The "out of sight, out of mind" approach adopted by institutions was echoed in society at large in the late 1800s: laws were passed to keep people with cerebral palsy and other visible disabilities from even appearing in public. These laws were sometimes called the "ugly laws" or "unsightly beggar ordinances," and the most famous was the City of Chicago Municipal Code, § 36034 (1911), which provided the following: "No person who is diseased, maimed, mutilated or in any way deformed so as to be an unsightly or disgusting object or improper person to be allowed in or on the public ways or other public places in this city, or shall therein or thereon expose himself to public view, under a penalty of not less than one dollar nor more than fifty dollars for each offense."

The Chicago law was not repealed until 1974, and it took other communities decades to eliminate similar ordinances as well. The grim history also includes medical experimentation focused on people with disabilities and forced sterilization. Even today, people with disabilities whether they are living in institutions or in the community—are sometimes abused or subjected to degrading use of physical restraints and seclusion.

Disability Rights in the United States

The disability rights movement has transformed the "social good" of services into a "rights model." When we trace existing legal rights back to their origins in social

values, we find that it takes 15 to 20 years for this change to occur. Change has not occurred simply as a result of successful advocacy by people with disabilities. "Rights" today have often evolved from what had been found to be the most effective and humane professional practices and by those who were defendants in litigation. Often, consent orders in disability cases resulted in reforms to services for people with disabilities. Sometimes the need for those changes was first advanced by the state and local officials who were (or later became) defendants in the actions.

In the last 25 years, we have witnessed an explosion of federal legislative action designed to protect people with disabilities from facing discrimination in their everyday lives. In addition to the most visible statute, the Americans With Disabilities Act—legislation that covers employment, public accommodations, and state and local government—Congress has passed the Air Carrier Access Act, the Architectural Barriers Act, the Fair Housing Amendments, the Individuals with Disabilities Education Act, the Telecommunications Act, the Urban Mass Transportation Act of 1964, the Help America Vote Act, and the Rehabilitation Act. More than 100 regulations have been attached to federally assisted or conducted programs that promote accessibility for people with disabilities.

Although these laws have a modern feel, they have grown out of a long-standing recognition that there is positive social, political, and perhaps spiritual value in serving the needs of people with disabilities. The nondiscrimination rights we recognize today were first seen as merely good federal or state policy. For example, social welfare policy favoring community services for people confined in institutions developed into a right to community services in succeeding decades.

In addition, partly in response to criticism of the nation's poor response to the disability-based problems of Civil War veterans, the United States began to address the issue of disability when soldiers returned from service during World War I. In 1916, the National Defense Act provided for soldiers to receive funds for instruction as a way to facilitate their return to civilian life; this was the first time the country recognized and responded legislatively to its obligation to persons injured in military service. In 1917, the Smith-Hughes Act established the federal-state program in vocational education and a year later, the Smith-Sears Veterans Rehabilitation Act expanded the role of the Federal Board of Vocational Education to provide services for vocational rehabilitation of veterans disabled during World War I; this was also called the Soldiers' Rehabilitation Act.

These veteran-based laws were succeeded by civilianbased laws. In 1920, the Smith-Fess Act (also called the Civilian Rehabilitation Act) established rehabilitation programs for all Americans with disabilities. During the Great Depression, the 1935 Social Security Act was established as an income maintenance system for those unable to work and included medical and therapeutic services for children with physical disabilities as well as assistance to people who are blind. After 1945, emerging disability rights movements were typically led by parents' groups and reform-minded professionals who promoted deinstitutionalization and community services for people with developmental disabilities; access to American sign language and cultural self-determination for people who are deaf; and selfdirected, community-based living for people with physical disabilities. The organized movement for the visually handicapped lobbied for the right to use white canes and guide dogs in public places and for policies to advance the economic well-being of the blind.

The Challenge of Disability Rights Legislation

Enforcement of these laws ensuring rights to the disabled has been challenging for the courts and the parties before them. For every claim, there is a defense. For every rule, there is an exception. The "right to education" and the "right to community services" are informative exemplars.

First, in the United States, individuals with a wide range of disabilities are legally entitled to education and other support services under federal law. In 1975, the Education for All Handicapped Children Act (known since 1990 as the Individuals with Disabilities Education Act, or IDEA) became the legal basis for public education for all children, including those with severe and multiple disabilities. The IDEA requires an "individualized education program" for each child and establishes a right to "free appropriate public education" in the "least restrictive environment."

Defining the meaning of "appropriate" education and the meaning of the "least restrictive environment" has been fodder for a great deal of commentary and litigation. A major issue has been the extent to which children can be educated in an age-appropriate school setting alongside nondisabled peers. In school districts in rural areas, organizing sufficient resources without compelling excessive travel time is problematic. Other issues have been the parameters of other aspects, such as the following:

- summer educational programs to reduce or prevent skill regression;
- interventions that enable students to stay in school (providing catheterization for those unable to urinate voluntarily, for example);
- services and technology to assist with movement, positioning, speech, and augmentative forms of communication;
- education that is not limited by an assessment of educational potential; and
- provision of regular opportunities for interaction with nondisabled peers and inclusion in general education classrooms.

Another example of challenges in interpretation and enforcement is the Americans With Disabilities Act. The intricacies of enforcing the ADA's ban on employment discrimination are familiar to most readers: thousands of cases involve determination of whether a person is disabled and, if so, what employment accommodation is required. Less familiar is the ADA's application to institutionalization.

Eleven years ago, the Supreme Court in *Olmstead v*. *L.C.*¹ held that unjustified institutionalization is discrimination that is forbidden by the Americans With Disabilities Act. In this case, the Court held that the ADA proscribes "[u]njustified isolation of the disabled."² A five-justice majority held that a failure to provide care for individuals with mental disabilities in the most integrated setting appropriate to their needs may be viewed as discrimination in violation of the ADA, unless the state or another public entity can demonstrate an inability to provide less restrictive care without "fundamentally altering" the nature of its programs.

The *Olmstead* decision was heralded as a potentially "revolutionary" advance for people with disabilities. Although other courts had previously found the same protections in the ADA, *Olmstead*'s conclusion that Title II of the ADA forbids unjustified isolation of people with disabilities was a defining moment for the law.

Legal advocates and scholars are perhaps prone to overstate the impact of particular cases on the world generally, as well as on the law. That has been *Olmstead*'s fortune. Although one might have expected the *Olmstead* decision to accelerate community placement for people with disabilities, this did not happen. In addition, the decision is fraught with ambiguities that have frustrated achievement of the right articulated by the Court: an end to unjustified isolation.

Since the *Olmstead* decision, the movement of residents from both public and private institutions has actually slowed down, according to an analysis marking the 10th anniversary of the ruling. *Olmstead* alone has proven insufficient to provide significant motivation for the increased attention to community integration that the decision mandates.

Apart from its lack of constitutional teeth, *Olmstead* suffers from several internal deficiencies that weaken the force of its integration mandate. These flaws include an unclear fundamental alteration defense, an ambiguous nonaccountable "working plan" option to demonstrate compliance, lack of guidance on standard of care, and lack of direction on the respective roles of the courts and legislatures.

The Fundamental Alteration Defense

The obligation of public entities to make reasonable modifications of their policies, practices, and procedures to avoid the discrimination of unjustified segregation is limited by the "fundamental alteration" defense found in federal regulations.³ Courts must consider whether "in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with … disabilities."⁴ Additional cost alone does not constitute a fundamental alteration, however. The difficulty is that there is no clear guidance in *Olmstead* on meaningful parameters

for the defense of fundamental alteration.

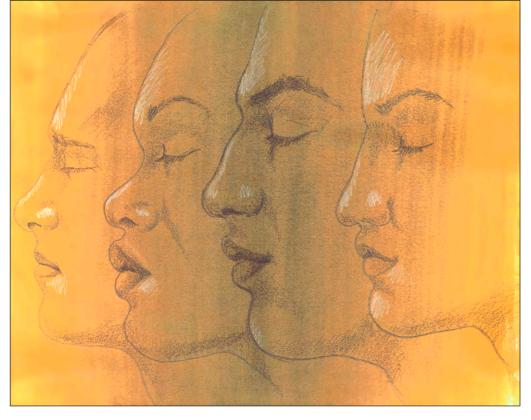
Clear and Nonaccountable Working Plan

Justice Ginsburg's plurality opinion in Olmstead gives states "leeway" to adopt "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."5 Each element of this operational testa "comprehensive, effectively working plan," a waiting list moving "at a reasonable pace," and a plan that is "not controlled" by a state's effort to keep institutions filled-raises difficult interpretive questions. It is a challenge to define these terms clearly.

One thing is certain. Any change to

a complex system necessitates careful planning, which will typically include analysis; development of a mission, goals, and objectives; expected outcomes, tasks, and timelines; deadlines; identification of persons responsible for tasks; quality assurance and accountability mechanisms; and evaluation. When done well, a self-adjusting system will be in place, with sufficient feedback and flexibility to adapt to changing conditions. Absent unusual circumstances or prolonged violations of rights, a state should generally be given the first opportunity to come forward with a plan. An unimplemented or vague plan, however, is insufficient to satisfy parties' or courts' concerns that the court's involvement will someday come to an end.

Courts are certainly limited in their ability and resources needed to shepherd all the details of compliance,⁶ but courts are capable of ensuring compliance with the law-even in the most complex situations.7 A case in point is United States v. State of Connecticut, in which Senior U.S. District Judge Ellen Bree Burns found the state in contempt of a consent decree intended to reform Southbury Training School (STS), an institution for people with developmental disabilities.8 The court found deficiencies in such areas as medical care, psychiatric services, psychological programs, physical therapy, treatment of injuries, and protection from harm, concluding that "STS's systemic flaws have caused many residents to suffer grave harm, and, in several instances, death." The court appointed the author of this article as special master to review the care provided by the STS, to determine the changes needed, to "formulate specific methods to implement the required changes," and to help "effectuate those changes."9 In this position, I actively oversaw a detailed remedial plan and held hearings where necessary; after nine years, the state achieved compliance with the law at the institution and was purged of contempt.¹⁰ Such special mastership, especially under the 2008 Amendment to



Federal Rule of Civil Procedure 53, works well in securing compliance.

Standard of Care

The Olmstead Court stated the following in footnote 14 to the opinion: "We do not in this opinion hold that the ADA imposes on the States a 'standard of care' for whatever medical services they render, or that the ADA requires States to 'provide a certain level of benefits to individuals with disabilities." Justice Kennedy's concurrence is stated more strongly. He concluded that, given states' need to weigh their priorities, "[i]t follows that a State may not be forced to create a community-treatment program where none exists." Justice Kennedy did not explain how one distinguishes between "creation" and "expansion" of community programs, however. The multiplicity of opinions and the weak language cited above is another weakness in the decision. The language does not appear to support even the minimally adequate level of habilitation that the Supreme Court's 1982 Youngberg v. Romeo decision held is required.11

Respective Roles of the Courts and Legislatures

Constrained perhaps by internal divisions, the Supreme Court was muted in its endorsement of vigorous efforts to move to a fully community-oriented system. *Olmstead* holds that institutional settings may be "terminated" but not for people "unable to handle or benefit" thereby. According to the ruling, institutions may be "phased out" so long as this does not place "patients in need of close care at risk."

This limited closure mandate appears calculated to appeal both to those who do not favor institutions and to those concerned that some residents may not be well served in the community. Obviously, no one would intentionally adopt a "phase out" effort or place even a single person into the community if the move would predictably cause harm, but analysis of risk and benefit is a complex calculus in human services. Missing from the Court's discussion is the nature of the balance in this sensitive area between the legislative policy-setting role and the judicial role in the definition and enforcement of rights. Also missing is the question of what weight to give the constitutional liberty interests of the individual and his or her desires or those of parents or guardians. One wishes for clearer guidance from the Court on these issues.

The Future of Disability Rights

The two legislatively created rights discussed above (education and community integration) have been vitally important to administrators, government policy-makers, and the courts in defining and providing services to people with disabilities. The prohibition on employment discrimination enables employers to have the benefit of able workers who, in the past, would have been excluded from the workplace. One could cite examples of disability rights in other domains as well.

As in any such effort to address societal needs, legislation falls short of resolving all the complex elements of the issue. In the disabilities arena, where fundamental needs are at the forefront, there are two additional approaches that may assist in resolving the nuanced challenges posed by the legislation's language.

First, the Fourteenth Amendment of the Constitution may provide assistance on this issue. Prior to the enactment of the "right to education" IDEA and prior to the "community integration" concept in the ADA, the federal courts had enunciated two related constitutional rights on two occasions: (1) a constitutional right to education in 1972 and (2) a constitutional right to community services in the 1970s.

With the statutes in the forefront, constitutional analysis took a backseat to the law. It may be, however, that a comprehensive legal theory embodying both constitutional and statutory rights is more likely to serve private and public needs than a theory including just one or the other. This may be a time to circle back to those constitutional principles on which the rights of people with disabilities were recognized decades ago. Restoring the constitutional dimension to the conversation encourages reasoned discussion of both the opportunities and the deficits in the statutory solutions.¹²

Another avenue is one that neither Congress nor the courts have explored thus far. Universal design—also called "inclusive design"—refers to the design of services, products, and environments that all people can use, to the greatest extent possible, without the need for adaptation or specialized design. Early writers in the field cite the *Brown v. Board of Education* conclusion that "separate is not equal" as the "milestone that marks the beginning of an approach to design that respects all users."

The effort to address societal needs involves making things in the world more usable by as many people as possible at little or no extra cost, regardless of the person's level of ability or disability. We all know the familiar examples in the barrier-free and accessibility context. However, the inclusive design concept refers to a broader issue than physical access. The concept encompasses every field in which disability rights has been asserted, including education, community integration, telecommunications, health care, and others. The benefits of universal design include elimination of discrimination, empowerment of individuals, increased fairness, and justice. It is essential, however, that the concept not be undermined by implementation without standards and by mandates without enforcement.

One example is mobility. The two-wheeled, selfbalancing transportation device known as the Segway[®] is visible in many cities during commercial tours of historic sites; the devices are used by police in downtown Orlando, by shopping mall security guards, and for recreation by people who can afford these devices. For many people with disabilities, the Segway has become an essential everyday mode of mobility, which allows people with a wide variety of disabilities a means to "walk" alongside family and colleagues and to meet the world at eye level. Using the Segway has mitigated or eliminated painful movement for these users. Hundreds of veterans have benefited from the universal design inherent in the Segway thanks to donations and training by Segs4Vets, a national charity that donates the mobility device to American veterans who have been permanently disabled in Iraq and Afghanistan.

In addition to mobility, modern technology provides new domains in which the rights of people with disabilities must be protected. For example, work is under way to ensure that computer hardware, software, and the Internet are accessible to all. Federal law (§ 508 of the Rehabilitation Act) requires federal agencies to make their electronic and information technology accessible to people with disabilities.

Conclusion

The presence of disability in our communities is inescapable. As the population ages in the coming decades, the presence of people with disabilities and their participation in the nation's life will increase. The American legal community's response to disabilities has evolved from Louis Brandeis' compassionate concern expressed in his plea in 1864 to the statutory rights established by Congress in the last quarter century. State and local governments have played important roles both in defining rights locally and in implementing federal laws. The federal courts have both interpreted and enforced the rights of people with disabilities and have often been called upon to balance competing needs and interests in this field.

But the law's expanse consists of more than the statutes and the Constitution. It embodies our government and the nation's ideals. In 1977, Hubert Humphrey memorably reminded us of our duties to people with disabilities: "The moral test of government is how it treats those

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The California court has the following goals:

- Cooperative, therapeutic treatment strategy for veterans in the criminal justice system who suffer from post traumatic stress disorder (PTSD), psychological or substance abuse problems, as a result of having served in a combat theater.
- The goal and purpose of creating the Veterans Court is not to incarcerate defendants, but to give them access to the kind of treatment they need, which is often intense, depending on the circumstances they endured while at war.
- Veterans who will benefit from Veterans Court often suffer from addictions, mental illness and traumatic brain injuries. This newly-designed court does not follow the same procedures that Orange County courts follow, as these men and women who experience symptoms of PTSD need to be tried differently, according to their mental and physical condition.

Matthew B. Wallin, *Orange County, Creates a Veterans Court,* www.schools.com/news/law-criminal-justice/orangecounty-veterans-court_201001193008.html (last visited June 9, 2010).

The foregoing is just a small sampling of approaches to dealing with veterans who suffer from PTSD. A Google search on this topic will reveal that the idea of veterans courts is being discussed in many areas of the country. This is a promising sign that the country is beginning to understand the severity of the problems facing many of the veterans returning from war zones, including the problems associated with PTSD. We need to honor our veterans

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who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy, and the handicapped." **TFL**



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ferleger.com. Benjamin Johnson, William Mitchell College of Law (J.D. candidate, 2011), provided research assistance for this article. For full citations, readers can send an e-mail to the author. © 2010 David Ferleger. All rights reserved.

Endnotes

¹527 U.S. 581 (1999). ²*Id.* at 597. and give them the help they need without looking to incarceration first when drug addiction or other behavioral problems that lead to an arrest can clearly be associated with the effects of post-traumatic stress disorder or other traumatic physical and psychological injuries sustained when they rendered service to this country. **TFL**



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³28 C.F.R. § 35.130(b)(7).

⁴527 U.S. at 603–604, 615 (Kennedy, J. concurring). ⁵*Id.* at 605–606.

⁶See Samuel R. Bagenstos, *Justice Ginsburg and the Judicial Role in Expanding "We the People": The Disability Rights Cases*, 104 COLUM. L. REV. 49, 58 (2004).

⁷See David Ferleger, Special Master Rules: Federal Rule of Civil Procedure 53, The Role of Special Masters in the Judicial System, 2004 Special Masters Conference: Transcript of Proceedings, 31 WILLIAM MITCHELL L. REV. 1193 (2005); David Ferleger, Special Masters Under Rule 53: A Welcome Evolution, in ALI-ABA, THE ART AND SCIENCE OF SERVING AS A SPECIAL MASTER (2007).

⁸931 F. Supp. 974 (D. Conn. 1996), appeal dism'd, 116 F.3d 466 (table), 1997 WL 321594 (1997), cert. den. sub nom., *Connecticut v. United States*, 522 U.S. 1045 (1998).

⁹931 F. Supp. at 985.

¹⁰*Messier v. Southbury Training School*, 562 F. Supp. 2d 294, 299–300 (D. Conn. 2008) (describing the success of this judicial oversight in a parallel case involving the same institution).

¹¹Youngberg v. Romeo, 457 U.S. 307 (1982).

¹²David Ferleger, *The Constitutional Right to Community Services*, 26 Georgia State U. La. Rev. 763 (2010).