

“The Greatest Discovery of My Generation:” The Disability Rights Movement in 1960s America



Michelle L. Erstad

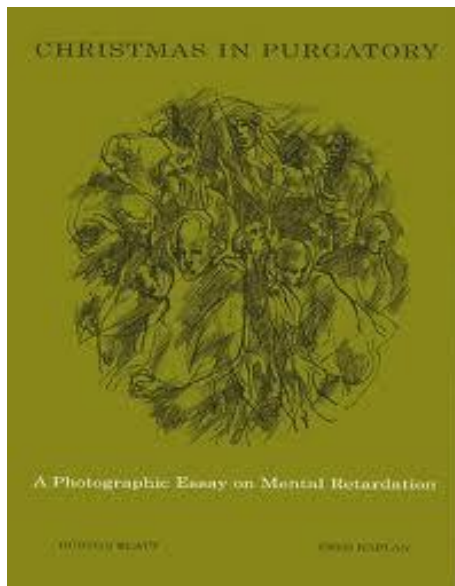
HIST 490: Historical Research and Writing

Jeffery Livingston

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To Steve Taylor, whose decades of research and advocacy made this project possible.

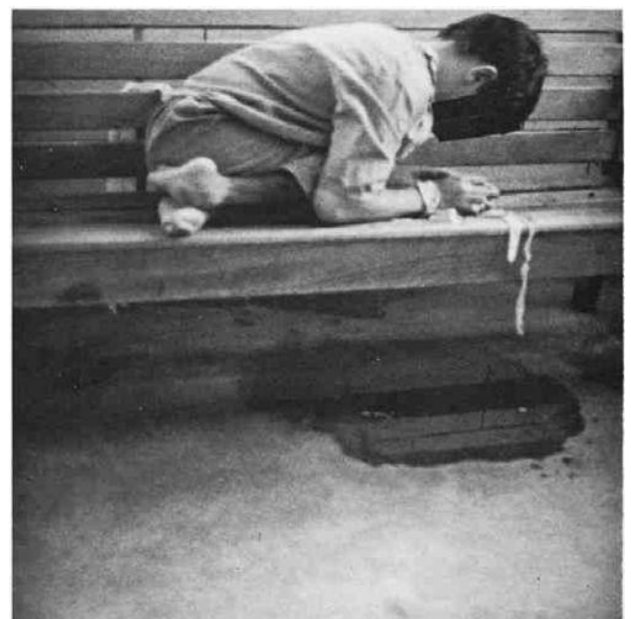
“The greatest discovery of my generation,” wrote the philosopher William James, “is that human beings can alter their lives by altering their attitudes of mind.”<sup>1</sup> Although penned decades before the tumultuous 1960s, these words expertly summarize the considerable changes that started to take place in America at that time. The disability rights movement grew from generations of inhumane treatment that was finally illuminated by a series of exposés published in the 1960s.



As advocates called for dramatic restructuring of the system that served those with special needs, parallel movements emerged in which the disabled explored their own identities.

**Cover—Christmas in Purgatory: A photographic Expose on Mental Retardation**

The richness of the disability rights movement has had far reaching implications. In the spirit of advocacy dominating the 1960s, the civil rights movement for people with disabilities emerged as a powerful opposition to inhumane treatment and social marginalization, and began the process of reshaping what is considered possible for those with even the most profound disabilities.



Institutionalized Child tied at hands and waist. From: *Christmas In Purgatory: A Photographic Essay On Mental Retardation*

## Background

An understanding of the civil rights movement for people with disabilities in the 1960s and 1970s cannot be understood separate from the historical views on and corresponding treatment of those with intellectual and developmental disabilities (ID and DD, respectively).



### **The civil rights movement for people with disabilities**

The study of those with disabilities first took shape in the mid-19<sup>th</sup> century, when social scientists began to explore the wide array of social problems plaguing the nation because of

industrialization, urbanization, and immigration. Several researchers in the

1850s used the new theory of evolution to attempt to understand their society, and concluded that poverty and crime were linked to those with “defective genes.” People with disabilities were the most obvious carriers of such defects. These theories spawned a body of research that only supported these findings. In the early 1900s Robert Dugdale and Henry Goddard conducted studies on two different families and their lineages, and concluded that feeble-mindedness was not only heritable, but directly responsible for such problems as alcoholism and poverty.

Goddard’s study was especially influential in the field of disability research, and his findings led him to conclude in 1915: "For many generations we have recognized and pitied the idiot. Of late we have recognized a higher type of defective, the moron, and have discovered that he is a burden; that he is a menace to society and civilization; that he is responsible to a large degree for

many, if not all, of our social problems." Around the same time, another early leader in this field, Walter Fernald, concluded, "Feeble-minded women are almost invariably immoral, and if at large usually become carriers of venereal disease or give birth to children who are as defective as themselves." Theories like these played a central role in shaping the attitudes of the general population toward those with disabilities.<sup>2</sup>

Institutionalization was the earliest response to caring for those with disabilities in America. Efforts at rehabilitation and reintegration of those with

disabilities punctuated the first half of the 19<sup>th</sup> century, and advocates like Dorothea Dix called for their humane treatment. However, the second half of the 19<sup>th</sup> century saw an increase in urbanization and industrialization, and a decrease in the belief those with ID and DD could be



A state run institution for people with mental retardation. From: *Christmas In Purgatory: A Photographic Essay On Mental Retardation*

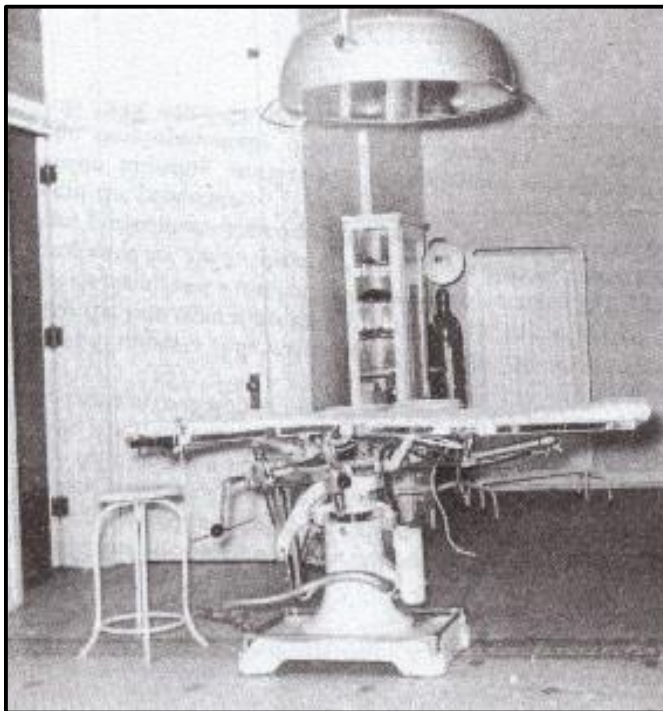


From: *Christmas In Purgatory: A Photographic Essay On Mental Retardation*

educated, or their condition improved. Factory work required greater amounts of skill than those with disabilities could provide, and the generation of progressive leaders died. Institutionalization evolved into a means of isolating the disabled from society entirely. Its popularity

as a model of care grew significantly, and institutional populations soared, outpacing the growth of even the rapidly expanding American general populace. In 1880 approximately 4.8 people per 100,000 were institutionalized, but by 1926 that number skyrocketed to 47.8 per 100,000. In that same timeframe, the number of state-run facilities grew from 10 to 77, and the number of residents climbed from 2,429 to 55,466. This number peaked in 1967 when nearly 195,000 people with mental retardation called state-run institutions home.<sup>3</sup>

Because of the desire to remove those with disabilities from society, and because of the pervasive belief that heritable defects caused so many social problems, institutionalization was accompanied by a new and even more frightful treatment. Known as America's *eugenics*



The operating table at the Northern Wisconsin Center for the Developmentally Disabled where sterilizations were performed.

*movement*, thousands of adults with disabilities were involuntarily sterilized, prevented from marrying, engaging in sexual relations, or otherwise restricted, with the idea of “cutting off the defective germ plasm in the American population.” According to Henry Hamilton Laughlin, the nation's most prominent advocate of eugenics in the early 20<sup>th</sup> century, eugenics was the best way of removing the burden upon and danger posed to the general populace by those with disabilities.



**Henry Hamilton Laughlin**  
 (March 11, 1880 – January 26, 1943)  
 Leading American eugenicist in the first half of  
 the 20th century.

Sentiments like Laughlin's caught on and the popularity of the eugenics argument peaked in 1910; the movement tremendously impacted public policy toward those with disabilities. Between 1905 and 1917 17 state legislatures passed sterilization laws, many of which made sterilization a condition of a person's release from an institutional setting. Additionally, some 39 states outlawed marriage between two adults with mental retardation. However, the popularity of eugenics began to fade in the 1920s. New theories emerged that

challenged eugenics as a treatment, and the stance of the United States Supreme Court brought the constitutionality of such laws into question. Still, eugenic practices continued through the 1950s, and while the estimates of the total number of victims vary, it is no less than 30,000.<sup>4</sup>

While the eugenics movement lost some of its clout, institutionalization for those with ID and DD continued to be a given. Interestingly, the 1920s and 30s saw a renewed interest in community-based supports for those with disabilities. This "swing" held and proved to be the seed of a new movement that grew with each decade. By the 1950s, groups of parents with

special needs children began to form, and they expressed their desires for change.<sup>5</sup> As we will see, 1960s America was the perfect time and place for such a civil rights revolution to take place.

### **“The Times They Are a-Changin’:” The Era of Exposés and New Philosophies in the 1960s**

Nothing got the civil rights movement for people with disabilities jumpstarted like the wave of exposés that were published in the 1960s. *Christmas in Purgatory*, a photographic exposé published in 1966, is amongst the most impactful. Penned by Burton Blatt with photographs by Fred Kaplan, *Christmas in Purgatory* documents the horrific conditions in the “back wards” of several unnamed state-run institutions for people with disabilities in the Northeastern United States.

What they saw, and what Kaplan captured with a small, hidden camera affixed to his belt, Blatt accurately described as “a hell on Earth.” Men, women, and children were hidden behind barred windows and heavy doors like dangerous prisoners. They wandered the halls of decaying buildings, many nude or only partially clothed, with no purpose, no stimulation. Instead of being taught how to use a toilet, the residents were gathered in large common areas where waste could be hosed off down a drain in the middle of the floor. People were locked away in solitary cells,

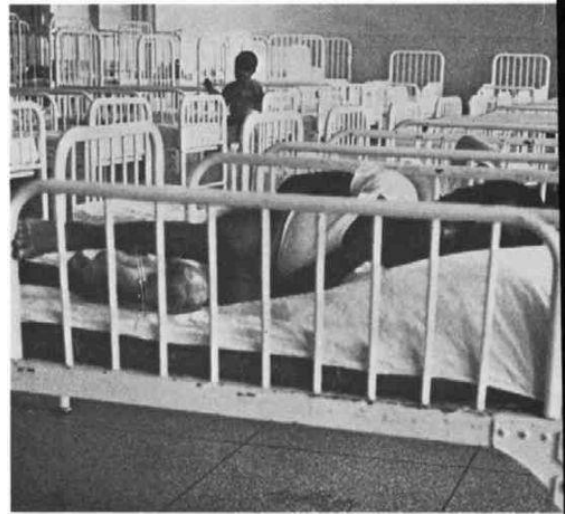


From: *Christmas In Purgatory: A Photographic Essay On Mental Retardation*



often without even a pillow or blanket, for days on end in the name of “therapeutic isolation.”

Children were bound to benches and left to wallow in their own excrement, and infants were left in their cribs day and night with no adult interaction. The abuse and neglect was unimaginable. *Look* magazine published a version of the exposé a year later under the title, “The Tragedy and Hope of Retarded Children,” and placed what Blatt called “our most indefensible practices” in the laps of the American public. The article stunned and outraged the public, and the October 1967 edition of *Look* generated the largest reader response in the magazine’s history.<sup>6</sup>



From: *Christmas In Purgatory: A Photographic Essay On Mental Retardation*

Burton Blatt, a professor at Boston University, and later the founder of The Center on



Solitary. From: *Christmas In Purgatory: A Photographic Essay On Mental Retardation*

Human Policy at Syracuse University, was instrumental in reshaping attitudes toward and expectations of people with ID and DD. Profoundly affected by the Holocaust and shocked by man’s ability to abuse his fellow man, Blatt’s outlook was shaped by his attempts to answer difficult questions about humanity. During a visit to Germany in the 1960s, Blatt grappled with how so many good people could come from a nation responsible for such

atrocities. He compared Germany and America and wondered how our society could allow the horrors of institutionalization to happen.<sup>7</sup> His advocacy challenged practically everything in the field of care for those with disabilities.

He believed in being humane, and felt his membership in humanity held him accountable for the treatment of the most vulnerable: “I could no longer ignore the probability that, unless I struggled to understand inhuman treatment of humans, I would become either insensitive to such treatment (as I believe I had become) or I would not be able to tolerate my own relatively pleasurable life in the face of the Holocaust surrounding those of us unaffected.” He thought everyone bore such responsibility. When Blatt published *Christmas in Purgatory*, he saw institutionalization as viable, so long as the facilities were made smaller, provided with more resources, and accountability measures

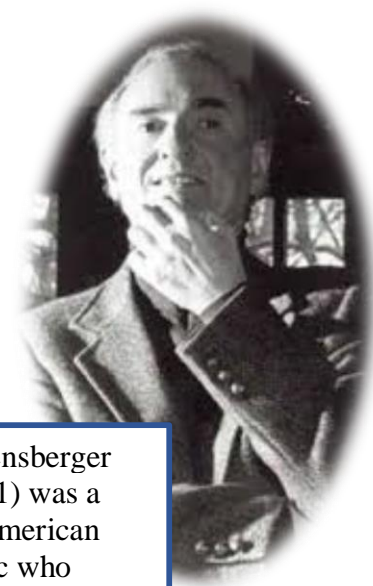


Burton Blatt (1927-1985) He believed in being humane, and felt his membership in humanity held him accountable for the treatment of the most vulnerable.

were in place. Within a few years, however, Blatt abandoned any hope institutionalization could be reformed and called for the removal of people from state-run facilities in favor of community-based supports. Blatt’s reasons were two-fold--not only did he want to save innocent lives, but he wanted to change humanity: “To have a decent society we must behave as decent individuals.”<sup>8</sup>

Exposés accompanied new theories that emerged regarding those with ID and DD. For the first time, social scientists usurped psychologists and medical scientists in developing models

of care, care that now focused on the humanity of the person, rather than on a label that prescribed a course of “treatment.” *Normalization*, as first introduced by Bengt Nirje, and then expanded upon by Wolf Wolfensberger in the 1970s, represented this paradigm shift—instead of needing “treatment,” people with disabilities needed to be treated “normally.” As Wolfensberger defined it, “Normalization implies, as much as possible, the use of culturally valued means in order to enable, establish, and/or maintain valued social roles for people.” In other words, people with special needs can participate in society when they have not been devalued through inferior treatment.<sup>9</sup>



Wolf Wolfensberger (1934-2011) was a German-American academic who influenced disability policy and practice in the United States and elsewhere.

### ***Litigation***

By the end of the 1960s, public concern over the maltreatment of those with disabilities had grown, and increasingly the courts weighed in on these pressing issues. A series of class action lawsuits targeting institutional conditions brought sweeping reforms, and three cases in particular set precedents for other cases to follow.<sup>10</sup>

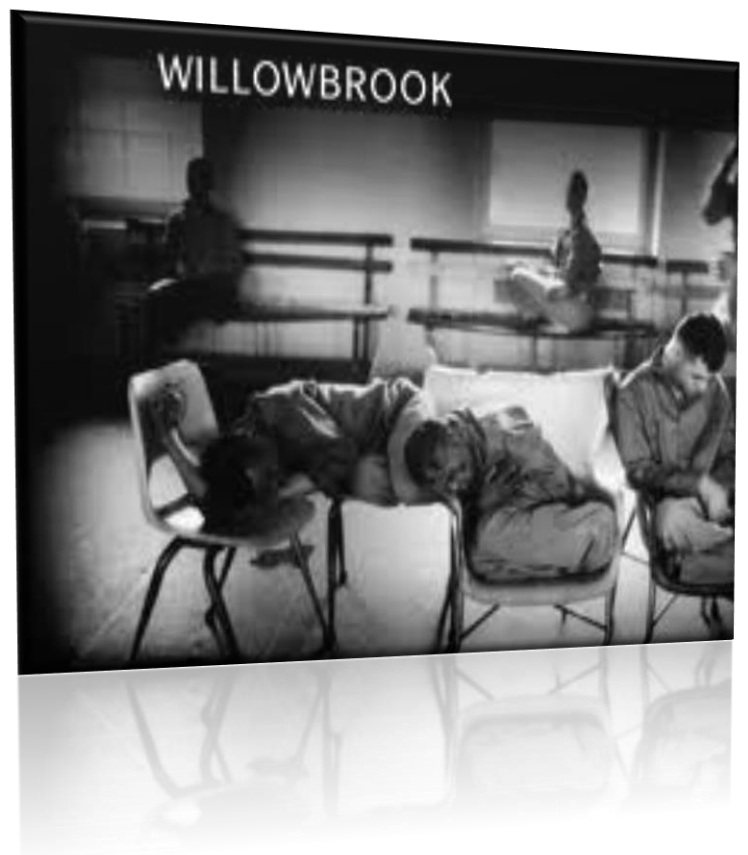
One of the first cases to grab widespread public and professional attention was Alabama’s *Wyatt v. Stickney* (1972). Judge Frank Johnson declared that state-run facilities for those with mental retardation violated the individuals’ civil liberties, but that those living in an institution had a right to live in a place that met “Minimum Constitutional Standards” that could be offered in the “least restrictive circumstances.” These standards were 49 very strict and specific mandates that covered practically every aspect of care, including “habilitation programs,” a point on which Judge Johnson was very clear: “The mentally retarded person has a

right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.”<sup>11</sup> Judge Johnson’s ruling set in motion sweeping changes to Alabama’s system of care for the mentally ill and retarded.

Another case that received much attention was the 1973 *Willowbrook* case in New York State. Judge Orrin Judd ruled that the facility, the largest in the world at that time for those with mental retardation, had failed to protect its residents’ right to *protection from harm*. Although



Willowbrook, a New York State Run Institution for the Mentally Handicapped



Judd did not agree with Johnson that residents of such facilities had the constitutional right to habilitation, the ultimate agreement both parties in *Willowbrook* reached in 1975 mirrored many of the same provisions included in Judge Johnson’s ruling. It even went so far as to call for deinstitutionalization, mandating the population of Willowbrook be reduced to no more than 250 residents by 1981.<sup>12</sup> Both *Wyatt* and *Willowbrook* brought about tremendous reforms to the system of institutionalization.



The *Pennhurst* case (1974), however, challenged institutionalization itself. Judge Raymond Broderick determined that Pennsylvania’s Pennhurst State School and Hospital violated its residents’ civil liberties and failed to meet any sort of minimum standard for care. Building upon the rulings of both the *Wyatt* and *Willowbrook* cases, Broderick considered mandates from the 1973 Rehabilitation Act as well as the equal protection clause of the 14<sup>th</sup> Amendment of the Constitution in his ruling. Citing language from *Brown v. Board of Education* (1954), he declared that Pennhurst is “a facility that clearly is separate and Not equal.” He determined Pennhurst had an obligation to provide community-based living, and as a result of this case, the facility shut down. Much like exposés, litigation played an important role in uncovering the abuse of those with disabilities. However, it had much greater power to affect nationwide change in what Samuel Walker calls “a new strategy of social reform: to change public institutions through constitutional litigation.”<sup>13</sup>

The *Brown v. Board of Education* (1954) ruling also set the precedent for achieving greater educational rights for children with special needs. In both *PARC v. Commonwealth of Pennsylvania* (1971) and *Mills v. Board of Education of the District of Columbia* (1972), the district judges ruled that students, regardless of disability, had the right to a free, public education in the most inclusive setting possible. The rulings in both of these cases became the basis upon which important legislation on behalf of those with disabilities was designed.<sup>14</sup>

### ***Legislation***

Legislation on behalf of those with ID and DD first took form in the 1960s, and John F. Kennedy was the first president to express support for such legislation.<sup>15</sup> However, the most significant legislation emerged in the mid-1970s.

The first of such significant laws is Public Law (PL) 94-142, or the Individuals with Disabilities Education Act (IDEA), which was signed into law by President Gerald R. Ford in



1975. IDEA guarantees all children with disabilities a free and “appropriate” public education with access to services to meet their specific needs. Additionally, IDEA requires assessments to ensure the effectiveness of the teaching strategies, it protects the rights of both the children and their parents, and it authorizes federal money to support states in complying with its provisions.<sup>16</sup>



Because of IDEA, thousands of children with special needs attended school for the first time.

Another huge milestone was the passage, also in 1975, of the Developmentally Disabled Assistance and Bill of Rights Act (DD Act). An amendment to the Mental Retardation Facilities and Community Mental Health Centers Act of 1963, the DD Act provided some government funds to states to conduct research and provide services for

those with disabilities. Its most significant feature is its Bill of Rights, whose language reflected a growing belief in the dignity and value of those with special needs. It states that those with ID and DD “have a right to appropriate treatment, services, and habilitation in the least restrictive setting that maximizes developmental potential. Additionally, it prohibited public funds from being spent on programs and services that do not meet minimum standards for care.<sup>17</sup> The law has been amended a number of times since, reflective of the evolutionary process that is serving those with disabilities.

Another important piece of legislation is California's Lanterman Act of 1969, which states that people with disabilities have the right to services that allow them to live as their non-disabled peers. It established a system of regional centers, which connected disabled Californians with those services, and provided resources and support to families as they transitioned their loved one from state-run institutions to the community. The Lanterman Act effectively began the process of deinstitutionalization in California.<sup>18</sup>



**Assemblyman Frank  
D. Lanterman**

Disability Studies at Syracuse University, and Blatt's successor, such legislation as IDEA "is not a sign that we've arrived. It's a sign of how much further we need to go—that the ideal society [is] where we don't have to have these laws protecting the rights of people with disabilities. And while I think these laws are critically important, we have to change our society and our culture."<sup>19</sup>

Even though Blatt commended progressive legislation, and called IDEA a "great and wonderful federal law," the need for such legislation at all must give us pause. According to Steven Taylor, the co-Director of The Center on Human Policy, Law, and



*Photos of Assemblyman Frank D. Lanterman (upper left) and Frank Lanterman with Governor Ronald Reagan are courtesy of the Department of Developmental Services, Office of Legislation and Communication.*



### *Parallel Movements*

Advocacy, litigation, and legislation created fertile ground from which a number of “parallel” movements for those with disabilities sprang up in tumultuous 1960s America. One of the most prolific was the Independent Living Movement (ILM), whose first center was established in Berkeley, California in 1972. Started by a student named Ed Roberts in the early 1960s, the ILM says that even those with the most severe disabilities can and have the right to live in the community with the proper supports.<sup>20</sup>



Ed Roberts, contracted polio at 14 years old. Ed, a student at Berkeley, California in 1972 started the Independent Living Movement.

Roberts contracted polio at 14 years old and was almost instantly paralyzed from the neck down. He needed to be in an 800 pound iron lung 24 hours a day to breathe. Despite doctor’s grim prognosis, Roberts attended his first three years of high school over the telephone. Concerned he would never realize his independence, Roberts’ mother encouraged him to attend school in person his senior year. Because

portable ventilators did not exist at this time, Roberts taught himself how to breathe outside the iron lung by “frog breathing,” or swallowing air into his lungs.<sup>21</sup>

After he received his high school diploma, he set his sights on a political science degree from UC Berkeley. However, Roberts’ dream met much opposition from the university’s

administration. After being told, “We tried cripples, and they don’t work,” he sued the school and won the right to be a student and live on campus—iron lung and all. As a student, Roberts participated in the Civil Rights Movement for African-Americans, and learned from the women’s rights movement. He realized how much the tenets of these revolutions applied to him and other people with disabilities. Over the course of many years, Roberts worked with other students with disabilities to not only make UC Berkeley more accessible, but to change attitudes.



He expanded his advocacy beyond the confines of the campus and founded the Center for Independent Living in 1972, which still provides resources to “enhance the rights and abilities of people with disabilities to actively

participate in their communities and to live self-determined lives.” Roberts was even appointed by California governor Jerry Brown to be the Director of the Department of Rehabilitation, a position Roberts held for nine years.<sup>22</sup>

Roberts passed away in 1995, but in his lifetime of advocacy he was a leader and an example of what was possible for



Gov. Jerry Brown swears Ed Roberts in as director of California’s Department of Rehabilitation.

even those with the most severe disabilities. He knew that everyone has something to offer, and that “there are very few people even with the most severe disabilities who can't take control of their own life. The problem is that people around us don't expect us to. We built a system, a political system, and a system of public policy based on old attitudes that actually allow us off the hook, to have no expectations, that believe that we will not work or participate in our... in our communities when in fact we've discovered that the reality is just the opposite.”<sup>23</sup> The revolution that was 1960s America allowed leaders like Roberts to challenge the traditional ways of thinking that had long dominated popular thought regarding those with disabilities.

### Analysis

There was perhaps no better time and place for this civil rights movement to happen than 1960s America. Several factors worked to create an environment conducive to the tremendous change that took place in the area of disability rights. Firstly, the groundwork for civil rights had already been laid, partially by the *Brown vs. Board of Education* (1954) ruling.



It was not a stretch to imagine separate facilities for people with ID and DD as unconstitutional also.

Secondly, Americans challenged the nature of institutions of all kinds, and consequently the validity of institutionalization for those disabilities was put on trial. Americans also approached

traditional views, definitions, and authority figures with great suspicion during this era. In much the same fashion that college students challenged the authority of their academic institutions and bucked against the leadership's traditional decisions, families of and advocates for those with ID and DD questioned the "authority of professional decision making." Certainly, the 1960s and 70s were also years of nonconformity, when many Americans sought to define their own identity separate from any institution. Many sociologists who published new theories on the care of those with ID and DD saw the traditional treatments offered by doctors and psychologists as attempts to stifle the nonconformity of those with special needs. Additionally, some sectors of society not only welcomed nonconformity, they reveled in the unusual. After generations of isolation, those with disabilities were amongst society's most unusual. The Supreme Court's greater involvement in what was traditionally considered states' affairs, and the federal government's greater funding of social programs also contributed to the success and longevity of this movement.<sup>24</sup> This confluence of events and circumstances ripened America into a hotbed of progressive advocacy that changed everything for those with special needs.

### **Legacy of Blatt & the Movement**

The impact of Blatt's and Roberts' advocacy, as well as the civil rights movement for those with ID and DD in the 1960s is very difficult to overstate. Not only did the immediate circumstances for many of our nation's most marginalized population change, but precedents were set that enabled future generations of those with special needs to gain even greater status in our society. They have gained greater legal recognition and society expects their participation.

Several important legal precedents emerged from the legacy of the tumultuous 1960s. In 1990 the United States passed the Americans with Disabilities Act (ADA), which prohibits discrimination against and "ensures equal opportunity for persons with disabilities in

employment, state and local government services, public accommodations, commercial facilities, and transportation.”<sup>25</sup> So, every wheelchair ramp into a business, every accessible bathroom stall, and every bus that kneels to accommodate passengers with physical disabilities is a manifestation of our culture’s shift from exclusive to inclusive.



**President Bush  
signs the  
American’s  
with  
Disabilities Act  
of 1990 into  
law.**

In much the same fashion that the ADA grew from the legacies of the 1960s and the DD Act, the Supreme Court ruling in the 1999 *Olmstead* case built upon the ADA. The Court concluded that unjustified segregation of those with ID and DD violates Title II of the ADA, and that appropriate community-based

services must be provided to those who want them. The most significant part of this ruling,



**Before** the American's with Disabilities Act of 1990 became law.

assumptions that persons so isolated are incapable of or unworthy of participating in community life;" and "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."<sup>26</sup> The United States finally articulated what advocates like Blatt and Roberts had known for decades. *Olmstead* was a human rights victory and the impetus for many states to deinstitutionalize those with disabilities in favor of community living.

The closure of state-run institutions is another legacy of this movement. Since 1967, the population residing in institutional settings has declined an average of 4% per year, and resulted in the closure of 140 facilities across 40 states.<sup>27</sup> In California, the systematic closure of such

however, is why the Supreme Court ruled the way it did. According to the ruling, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted



**After** the American's with Disabilities Act of 1990 became law.

facilities began after the passage of the Lanterman Act in 1969, with a renewed effort beginning in 1994 following the *Coffelt* lawsuit.<sup>28</sup> As a result, the population in developmental centers has steadily declined from its peak of 13,000 in 1968 to 1,385 as of October 30, 2013. To cite only a few examples, New York has a plan in place to close four state-run institutions in the next four years; in New Jersey, 204 residents moved from institutional settings into community-based supports over the course of two years, with a 94% success rate; and in Louisiana, 428 were moved between December 2003 and February 28, 2007.<sup>29</sup> It is tragic that in our modern society there are still people with special needs living in the forced isolation of institutional settings. However, if it were not for people like Blatt and Roberts, America may never have made it this far.

It is hard to believe that our grandparents can remember a time when the educational system excluded students with special needs. But, because of the Disability Rights Movement, kids with disabilities are included in their neighborhood schools across the country. As of 2009, some 95% of American students with disabilities are educated in regular schools, and roughly three in five spend 80% or more of their school day in the regular classroom.<sup>30</sup> Mainstreaming is the new norm. It reflects the belief that all children can learn and that those with special needs contribute just as much to the classroom as their peers in general education.



The late Burton Blatt's legacy defies simple summation and cannot be pigeonholed. In his few short decades of national advocacy, Blatt helped to change expectations for those with disabilities. Seymour Sarason of Yale University believes part of Blatt's legacy rests in the demise of institutionalization: "For all practical purposes, there is no controversy today about deinstitutionalization; we do not hear individuals and groups say that individuals with mental retardation should be removed from the communities and placed in institutions . . . no *individual* more than Burt played as crucial a role in changing public attitudes and policy." But, even more than that was what Blatt left to humanity. He challenged silence when it meant suffering would continue, because "when privacy contributes to suffering, it loses its significance as a cherished privilege." He lived by a strict moral code that empowered him to share his knowledge with the world, so that evil would not persist unopposed. He challenged the idea that ID and DD were diseases and saw all treatments for such as abusive because they imply those with special needs require a "cure." He believed in the dignity and abilities of everyone, regardless of diagnosis: "Don't tell me what retarded people cannot do, tell me under what conditions they can learn and do more." Indeed, Burton Blatt's advocacy is not bound to "a certain historical era," but is critical "to understand the age-old problem of human abuse, of inhumanity, that continues to plague us today."<sup>31</sup>

## **Conclusions**

Less than 100 years ago, people with intellectual and developmental disabilities were locked away in human warehouses, deprived of even the most basic rights, and blamed for alcoholism, poverty, and other social problems. Society considered them abnormal, diseased, and defective, and the advocacy of only a few made forced sterilization of thousands popular. How far the United States has advanced in its care for those with intellectual and developmental



disabilities is almost unreal. Today, the millions of Americans with intellectual and developmental disabilities have the federally guaranteed right to receive an education that best

**Michelle Erstad with her brother, Ben and his dog, Bob.**



meets their needs, to seek employment without discrimination, and to live in the community of their choosing and lead the lives they wish to have. Models for care are no longer about “curing” a person, but about recognizing their uniqueness and inherent value as a human being. These progressive and humanistic ideals were born and reared in the hotbed of 1960s America, when tradition and conformity was challenged by nearly all segments of society.

## NOTES

<sup>1</sup> Burton Blatt and Fred Kaplan, *Christmas in Purgatory: A Photographic Essay on Mental Retardation* (Syracuse, NY: Human Policy Press, 1974), 95.

<sup>2</sup> Steven J. Taylor and Stanford J. Searl, "Disability in America: A History of Policies and Trends," in *Significant Disability: Issues Affecting People with Significant Disabilities from a Historical Policy, Leadership, and Systems Perspective*, ed. E. Davis Martin, (Springfield, IL: Charles C. Thomas Publisher Ltd, 2001), 26-27; Wolf Wolfensberger, "The Origin and Nature of Our Institutional Models," in *Changing Patterns in Residential Services for the Mentally Retarded* (Washington D.C.: President's Committee on Mental Retardation, 1969), 21.

<sup>3</sup> Taylor and Searl, "Disability," 20-34.

<sup>4</sup> Philip R. Reilly, "Involuntary Sterilization in the United States: A Surgical Solution," *The Quarterly Review of Biology* 62 (1987): 155-59, <http://www.jstor.org/stable/2829217>; Taylor and Searl, "Disability," 30-35.

<sup>5</sup> Taylor and Searl, "Disability," 35.

<sup>6</sup> Steven J. Taylor, *Encyclopedia of American Disability History*, 1<sup>st</sup> vol., s.v. "Christmas in Purgatory."; Blatt and Kaplan, "Christmas," v-121; James W. Trent, *Inventing the Feeblemind: A History of Mental Retardation in the United States* (Berkeley: University of California Press, 1994), 255.

<sup>7</sup> Steven Taylor, email message, December 4, 2013.

<sup>8</sup> Burton Blatt, "Preface to *Exodus from Pandemonium*," in *In Search of the Promised Land: The Collected Papers of Burton Blatt*, eds. Steven J. Taylor and Steven D. Blatt (Washington D.C.: American Association on Mental Retardation, 1999); Burton Blatt, "The Family Papers: A Return to Purgatory," in *In Search of the Promised Land: The Collected Papers of Burton Blatt*, eds. Steven J. Taylor and Steven D. Blatt (Washington D.C.: American Association on Mental Retardation, 1999).

<sup>9</sup> Taylor and Searl, "Disability," 44; Wolf Wolfensberger and Steven Tullman, "A Brief Outline of the Principle of Normalization," *Rehabilitation Psychology* 27 (1982): 131, doi: 10.1037/h0090973.

<sup>10</sup> Taylor and Searl, "Disability," 48

<sup>11</sup> Taylor and Searl, "Disability," 49; *Wyatt v. Stickney*, 344 F.Supp. 387 (1972).

<sup>12</sup> Taylor and Searl, "Disability," 50-51.

<sup>13</sup> *Pennhurst State School and Hospital v. Halderman*, 465 U.S. 89, 104 S.Ct. 900, 79 L.Ed.2d 67, (1984), [http://www.pilcop.org/wp-content/uploads/2012/04/Pennhurst\\_SCOTUS21.pdf](http://www.pilcop.org/wp-content/uploads/2012/04/Pennhurst_SCOTUS21.pdf); *Halderman v. Pennhurst State School and Hospital*, 612 F.2D 84 (1979) <https://www.casetext.com/case/halderman-v-pennhurst-state-school-hospital/>; Samuel Walker, *The Rights Revolution: Rights and Community in Modern America* (Oxford: Oxford University Press, 1998), 115.

<sup>14</sup> Taylor and Searl, "Disability," 46-47.

<sup>15</sup> Taylor and Searl, "Disability," 53.

<sup>16</sup> U.S. Department of Education, Office of Special Education and Rehabilitation Services, "Thirty-five Years of Progress in Educating Children with Disabilities Through IDEA," 2010, [http://www2.ed.gov/about/offices/list/osers/idea35/history/index\\_pg10.html](http://www2.ed.gov/about/offices/list/osers/idea35/history/index_pg10.html).

<sup>17</sup> U.S. Department of Health and Human Services, Administration for Community Living, Administration on Intellectual and Developmental Disabilities, "History of the DD Act," 2013, [http://www.acl.gov/Programs/AIDD/DD\\_History/index.aspx](http://www.acl.gov/Programs/AIDD/DD_History/index.aspx).

<sup>18</sup> Frank D. Lanterman Regional Center, "The Lanterman Developmental Disabilities Services Act," 2013, [http://www.lanterman.org/lanterman\\_act](http://www.lanterman.org/lanterman_act); Department of Developmental Services, "Lanterman Developmental Disabilities Services Act and Related Laws," 2013, [http://www.dds.ca.gov/Statutes/docs/LantermanAct\\_2013.pdf](http://www.dds.ca.gov/Statutes/docs/LantermanAct_2013.pdf).

<sup>19</sup> Steven Taylor, "On the Shoulders of Giants, Reflections on Great Leaders of Our Time: Burton Blatt, Gunnar Dybwad and Wolf Wolfensberger," *Revolutionary Leaders Webinar Series*, 2012, [https://connectpro95156488.adobeconnect.com/\\_a944643455/p4sb7kqusq/?launcher=false&fcsContent=true&pbM ode=normal](https://connectpro95156488.adobeconnect.com/_a944643455/p4sb7kqusq/?launcher=false&fcsContent=true&pbM ode=normal).

<sup>20</sup> University of California, Berkeley, *The Disability Rights and Independent Living Movement: Introduction*, 2013, <http://bancroft.berkeley.edu/collections/drilm/introduction.html>.

<sup>21</sup> Ed Roberts, "Autobiography," from *Parallels in Time: The Independent Living Movement*, " <http://mn.gov/mnddc/parallels/six/6b/1.html>, n.d., 1-3.

<sup>22</sup> Roberts, "Autobiography," 4-6; Ed Roberts, "Speech: The Emergence of the Civil Rights Movement," 1980, <http://www.oac.cdlib.org/view?docId=hb6m3nb1nw&brand=oac4>; Center for Independent Living, "Mission," 2012, <http://www.cilberkeley.org/mission/>.

<sup>23</sup> Ed Roberts, interview by Harry Reasoner, *60 Minutes*, CBS, April 1988, <http://mn.gov/mnddc/ed-roberts/sixtyMinutes.html>.

<sup>24</sup> Taylor and Searl, "Disability," 52; Steven J. Taylor, *Acts of Conscience: World War II, Mental Institutions, and Religious Objectors* (Syracuse, NY: Syracuse University Press, 2009), 392-93; Steven J. Taylor, "Christmas in Purgatory: A Retrospective Look," *Mental Retardation* 44 (2006): 147.

<sup>25</sup> United States Department of Justice Civil Rights Division, "Information and Technical Assistance on the Americans with Disabilities Act," 2010, [http://www.ada.gov/2010\\_regs.htm](http://www.ada.gov/2010_regs.htm).

<sup>26</sup> Department of Justice, "About *Olmstead*," 2013, [http://www.ada.gov/olmstead/olmstead\\_about.htm](http://www.ada.gov/olmstead/olmstead_about.htm).

<sup>27</sup> Amie Lulinski Norris, Mary Kay Rizzolo, and Tamar Heller, "An Analysis of Movement From State Operated Developmental Centers in Illinois," prepared for the *Illinois Department of Human Services Division of Developmental Disabilities*, 2010, 11: <http://www.dhs.state.il.us/OneNetLibrary/27897/documents/DD%20Reports/AnalysisofMovementfromSODCinILO92010.pdf>.

<sup>28</sup> The *Coffelt* lawsuit is a class-action suit brought against the California Department of Developmental Services in 1990 by William Coffelt whose son was nearly beaten to death during his residency in Sonoma Developmental Center. The lawsuit claimed that insufficient state funding prevented those with ID and DD from community living, and that residency in developmental centers heightened their risks for injury. The 1993 settlement ensured provisions for high-quality community-based supports. (Elizabeth Chilcoat, "Coffelt v. Dept. of Developmental Serv. Case Profile," for the Civil Rights Litigation Clearinghouse at the University of Michigan Law School, 2006, <http://www.clearinghouse.net/detail.php?id=433>.)

<sup>29</sup> California Health and Human Services Agency Department of Developmental Services, "Final Report on the Plan for the Closure of Agnews Developmental Center," 2010, 5: [http://www.dds.ca.gov/AgnewsClosure/docs/March2010\\_FinalReportAgnewsClosurePlan.pdf](http://www.dds.ca.gov/AgnewsClosure/docs/March2010_FinalReportAgnewsClosurePlan.pdf); State of California Department of Developmental Services, "Population of Developmental Centers and State-Operated Community Facilities," 2013: <http://www.dds.ca.gov/DevCtrs/AllFacPop.cfm>; NYSARC, "Politics as it Happens: State to Close Four Remaining Developmental Centers," 2013: <http://blog.nysarc.org/2013/07/29/politics-as-it-happens-state-to-close-4-remaining-developmental-centers/>; Task Force on the Closure of State Developmental Centers, "Final Report," 2012, 5: [http://www.state.nj.us/humanservices/news/hottopics/Final\\_Task\\_Force\\_Report.pdf](http://www.state.nj.us/humanservices/news/hottopics/Final_Task_Force_Report.pdf); Office for Citizens with Developmental Disabilities, "State of Louisiana: Plan for Transformation of Public Developmental Centers to Supports and Services Centers," 2007, 3: <http://new.dhh.louisiana.gov/assets/docs/OCDD/publications/PlanforTransformationofPublicDevCentersSupportsandServicesCenters.pdf>.

<sup>30</sup> National Center for Education Statistics, "Fast Facts: Students with Disabilities, inclusion of," 2009, <http://nces.ed.gov/fastfacts/display.asp?id=59>.

<sup>31</sup> Seymour B. Sarason, Foreword to *In Search of the Promised Land: The Collected Papers of Burton Blatt*, eds. Steven J. Taylor and Steven D. Blatt (Washington D.C.: American Association on Mental Retardation, 1999), xviii; Blatt and Kaplan, "Christmas," 120; Burton Blatt, "How to Destroy Lives by Telling Stories," in *In Search of the Promised Land: The Collected Papers of Burton Blatt*, eds. Steven J. Taylor and Steven D. Blatt (Washington D.C.: American Association on Mental Retardation, 1999), 95; Steven J. Taylor and Steven D. Blatt, Introduction to *In Search of the Promised Land: The Collected Papers of Burton Blatt*, eds. Steven J. Taylor and Steven D. Blatt (Washington D.C.: American Association on Mental Retardation, 1999).

## Bibliography

### Primary Sources

- Blatt, Burton. "The Family Papers: A Return to Purgatory." In *In Search of the Promised Land: The Collected Papers of Burton Blatt*, edited by Steven J. Taylor and Steven D. Blatt. Washington D.C.: American Association on Mental Retardation, 1999.
- Blatt, Burton. "How to Destroy Lives by Telling Stories." In *In Search of the Promised Land: The Collected Papers of Burton Blatt*, edited by Steven J. Taylor and Steven D. Blatt. Washington D.C.: American Association on Mental Retardation, 1999.
- Blatt, Burton. "Preface to Exodus from Pandemonium." In *In Search of the Promised Land: The Collected Papers of Burton Blatt*, edited by Steven J. Taylor and Steven D. Blatt. Washington D.C.: American Association on Mental Retardation, 1999.
- Blatt, Burton, and Fred Kaplan. *Christmas in Purgatory: A Photographic Essay on Mental Retardation*. Syracuse: Human Policy Press, 1974.
- California Health and Human Services Agency Department of Developmental Services. "Final Report on the Plan for the Closure of Agnews Developmental Center." 2010.  
[http://www.dds.ca.gov/AgnewsClosure/docs/March2010\\_FinalReportAgnewsClosurePlan.pdf](http://www.dds.ca.gov/AgnewsClosure/docs/March2010_FinalReportAgnewsClosurePlan.pdf)
- Department of Justice. "About *Olmstead*." 2013.  
[http://www.ada.gov/olmstead/olmstead\\_about.htm](http://www.ada.gov/olmstead/olmstead_about.htm).
- Halderman v. Pennhurst State School and Hospital 612 F.2D 84 (3D Cir. 1979).  
<https://www.casetext.com/case/halderman-v-pennhurst-state-school-hospital/>.
- Lulinski Norris, Amie, Mary Kay Rizzolo, and Tamar Heller. "An Analysis of Movement from State Operated Developmental Centers in Illinois." Prepared for the *Illinois Department of Human Services Division of Developmental Disabilities*. 2010.  
<http://www.dhs.state.il.us/OneNetLibrary/27897/documents/DD%20Reports/AnalysisofMovementfromSODCinIL092010.pdf>.
- National Center for Education Statistics. "Fast Facts: Students with Disabilities, inclusion of." 2009. <http://nces.ed.gov/fastfacts/display.asp?id=59>.
- Office for Citizens with Developmental Disabilities. "State of Louisiana: Plan for Transformation of Public Developmental Centers to Supports and Services Centers." 2007.  
<http://new.dhh.louisiana.gov/assets/docs/OCDD/publications/PlanforTransformationofPublicDevCentersSupportsandServicesCenters.pdf>.
- Pennhurst State School and Hospital v. Halderman, 465 U.S. 89, 104 S.Ct. 900, 79 L.Ed.2d 67 (1984). [http://www.pilcop.org/wp-content/uploads/2012/04/Pennhurst\\_SCOTUS21.pdf](http://www.pilcop.org/wp-content/uploads/2012/04/Pennhurst_SCOTUS21.pdf).
- Roberts, Ed. "Autobiography." From *Parallels in Time: The Independent Living Movement*. n.d.  
<http://mn.gov/mnddc/parallels/six/6b/1.html>
- Roberts, Ed. "Ed Roberts, Activist." By Harry Reasoner. *60 Minutes*, (April 1988):  
<http://mn.gov/mnddc/ed-roberts/sixtyMinutes.html>.
- Roberts, Ed. "Speech: The Emergence of the Civil Rights Movement." 1980.  
<http://www.oac.cdlib.org/view?docId=hb6m3nb1nw&brand=oac4>.
- State of California Department of Developmental Services. "Population of Developmental Centers and State-Operated Community Facilities." 2013.  
<http://www.dds.ca.gov/DevCtrs/AllFacPop.cfm>.
- Task Force on the Closure of State Developmental Centers. "Final Report." 2012.  
[http://www.state.nj.us/humanservices/news/hottopics/Final\\_Task\\_Force\\_Report.pdf](http://www.state.nj.us/humanservices/news/hottopics/Final_Task_Force_Report.pdf).

United States Department of Justice Civil Rights Division. "Information and Technical Assistance on the Americans with Disabilities Act." 2010.

[http://www.ada.gov/2010\\_regs.htm](http://www.ada.gov/2010_regs.htm).

Wolfensberger, Wolf, and Stephen Tullman. "A Brief Outline of the Principle of Normalization." *Rehabilitation Psychology* 27 (1982): 131-45. doi:10.1037/h0090973

## Secondary Sources

Center for Independent Living. "Mission." 2012. <http://www.cilberkeley.org/mission/>.

Chilcoat, Elizabeth. "Coffelt v. Dept. of Developmental Serv. Case Profile." For the *Civil Rights Litigation Clearing House* at the University of Michigan Law School. 2006.

<http://www.clearinghouse.net/detail.php?id=433>

Department of Developmental Services. "Lanterman Developmental Disabilities Services Act and Related Laws." Published January 2013.

[http://www.dds.ca.gov/Statutes/docs/LantermanAct\\_2013.pdf](http://www.dds.ca.gov/Statutes/docs/LantermanAct_2013.pdf)

Frank D. Lanterman Regional Center. "The Lanterman Developmental Disabilities Services Act." Last modified 2013. [http://www.lanterman.org/lanterman\\_act](http://www.lanterman.org/lanterman_act).

NYSARC. "Politics as it Happens: States to Close Four Remaining Developmental Centers." 2013. <http://blog.nysarc.org/2013/07/29/politics-as-it-happens-state-to-close-4-remaining-developmental-centers/>.

Reilly, Philip R. "Involuntary Sterilization in the United States: A Surgical Solution." *The Quarterly Review of Biology* 62 (1987): 153-70. <http://www.jstor.org/stable/2829217>

Sarason, Seymour B. Foreword to *In Search of the Promised Land: The Collected Papers of Burton Blatt*. Washington D.C.: American Association on Mental Retardation, 1999.

Taylor, Steven J. "Christmas in Purgatory." In *Encyclopedia of American Disability History*, edited by Susan Burch. Facts on File, 2009.

Taylor, Steven J. "Christmas in Purgatory: A Retrospective Look." *Mental Retardation* 44 (2006): 145-49.

Taylor, Steven J. Conclusion to *Acts of Conscience: World War II, Mental Institutions, and Religious Objectors*, 381-95. Syracuse, NY: Syracuse University Press, 2009.

Taylor, Steven J., and Stanford J. Searl. "Disability in America: A History of Policies and Trends." In *Significant Disability: Issues Affecting People with Significant Disabilities from a Historical Policy, Leadership, and Systems Perspective*, edited by E. Davis Martin. Springfield, IL: Charles C. Thomas Publisher Ltd, 2001.

Taylor, Steven J., and Steven D. Blatt. Introduction to *In Search of the Promised Land: The Collected Papers of Burton Blatt*, xix-xxi. Washington D.C.: American Association on Mental Retardation, 1999.

Taylor, Steven J. "On the Shoulders of Giants, Reflections on Great Leaders of Our Time: Burton Blatt, Gunnar Dybwad, and Wolf Wolfensberger." *Revolutionary Leaders Webinar Series*. 2012.

[https://connectpro95156488.adobeconnect.com/\\_a944643455/p4sb7kqusqe/?launcher=false&fcsContent=true&pbMode=normal](https://connectpro95156488.adobeconnect.com/_a944643455/p4sb7kqusqe/?launcher=false&fcsContent=true&pbMode=normal).

Trent, James W. *Inventing the Feeblemind: A History of Mental Retardation in the US*. Berkeley: University of California Press, 1994.

University of California, Berkeley. *The Disability Rights and Independent Living Movement: Introduction*. 2013. <http://bancroft.berkeley.edu/collections/drilm/introduction.html>.

U.S. Department of Education, Office of Special Education and Rehabilitation Services. "Thirty-five Years of Progress in Educating Children with Disabilities Through IDEA." Last modified November 22, 2010.

[http://www2.ed.gov/about/offices/list/osers/idea35/history/index\\_pg10.html](http://www2.ed.gov/about/offices/list/osers/idea35/history/index_pg10.html).

U.S. Department of Health and Human Services, Administration for Community Living, Administration on Intellectual and Developmental Disabilities. "History of the DD Act." Last modified September 19, 2013. [http://www.acl.gov/Programs/AIDD/DD\\_History/index.aspx](http://www.acl.gov/Programs/AIDD/DD_History/index.aspx).

Walker, Samuel. *The Rights Revolution: Rights and Community in Modern America*. Oxford: Oxford University Press, 1998.

Wolfensberger, Wolf. "The Origin And Nature Of Our Institutional Models." *Changing Patterns in Residential Services for the Mentally Retarded*. Washington D.C.: President's Committee on Mental Retardation, 1969. Online edition.

