

“Places of Such Towering Misery”: The History of the Institutionalization of Disabled
People and Deinstitutionalization

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From 1920 to 1970 hundreds of thousands of disabled people were institutionalized in America. People were institutionalized if they were mentally ill, developmentally disabled, physically disabled, or judged to be disabled by society. Institutionalization is when disabled people are placed in facilities away from their communities and do not have control over their lives. In 1904, 17.3 developmentally disabled people per 100,000 people in the general population had been institutionalized. By 1923, the number had risen to 46.7.¹ People with varying disabilities were institutionalized. The definition of disability has changed over time. Often people have been considered disabled if they did not conform to societal standards. This paper will focus on the institutionalization of people who were physically disabled, developmentally disabled, mentally ill, had posttraumatic stress disorder, were Deaf, or were considered by society to be disabled. The way disabled people were expected to be cared for changed throughout history. Institutionalization became common at the beginning of the twentieth century because of the belief that disabled people need to be kept away from the rest of society and the growing reliance on scientific ideas. Many disabled people experienced abuse in institutions. William Bronston, a former doctor at Willowbrook State School in New York City and advocate for the rights of disabled people, described institutions as “places of such towering misery and human humiliation and violence. It's incalculable even to describe and litanize the magnitude of the anti-human, cruel circumstances, even in its most essential form.”²

Disabled people were institutionalized because they did not fit into social norms and because able-bodied people did not think they were capable of participating in society. Despite

¹ Steven Noll. *Feeble-Minded in our Midst: Institutions for the Mentally Retarded in the South, 1900–1940* (Chapel Hill, North Carolina: The University of North Carolina Press, 1995), 4.

² William Bronston, 2001-2, interview by Kathy Cowan. Disability Rights and Independent Living Movement Oral History Project, Regional Oral History Office, University of California. The Bancroft Library, Berkeley, CA. 68.

this, disabled people affirmed their humanity. Ed Murphy, who was developmentally disabled and was institutionalized at Empire State School (a pseudonym) in the 1960s said that “People think that those that are worse off, like those on the worse wards at Empire, don't know anything...The people can't see what it is like inside. There is a brain. They know when they are being abused. That is a human being. They have a heart, there is tissue that makes them a human being. They are creatures of God, regardless.”³ While some disabled people had positive experiences in institutions, many institutionalized people experienced physical abuse, sexual abuse, being controlled, and neglect. Institutions harmed disabled people and made their lives more difficult. Institutionalized people were aware of the abuse they faced and attempted to leave institutions, receive better ways of care, and shut down institutions. Fred Pelka argues that disabled people “have generally been seen as objects of scorn or pity, ‘cases’ to be cured or ‘managed,’ problems to be confronted or ignored... Advocates have had to raise their voices, often in frustration and anger, sometimes in desperation, to a society that assumes they have no voice at all.”⁴ The numbers of disabled people in institutions fell because of deinstitutionalization. Deinstitutionalization is the reduction and elimination of large state hospitals where disabled people were expected to stay permanently and replacing these institutions with independent living or community services. By 1981 the number of people in institutions had dropped to 125,000 from when it had reached its peak at 559,000 in 1955.⁵ Disabled people were instrumental in bringing about deinstitutionalization. Disabled people

³ Robert Bogdan and Steven. J. Taylor, *The Social Meaning of Mental Retardation: Two Life Stories* (New York: Teachers College Press, 1994), 56.

⁴ Fred Pelka, *What We Have Done: An Oral History of the Disability Rights Movement* (Amherst, Massachusetts: University of Massachusetts Press, 2012), ix.

⁵ George Paulson, *Closing the Asylums: Causes and Consequences of the Deinstitutionalization Movement* (Jefferson, North Carolina: McFarland & Company, 2012), 167.

experienced abuse in institutions and as a result of this treatment contributed to deinstitutionalization.

Historiography

The history of institutions for disabled people and disability in general has been written about before, though a complete history of the institutionalization and deinstitutionalization movements has not been written. Several books and articles have been written that discuss what people's lives were like in institutions. In 1978 Charles Steir published *Blue Jolts: True Stories from the Cuckoo's Nest*, a collection of writings by residents, doctors, and families on their experiences with institutionalization from the 1940s to 1970s. Steir questions the right society has to define people as mentally ill and the ethics of the way institutions treat their residents. He also highlights the experiences of residents. *The Social Meaning of Mental Retardation: Two Life Stories* by Robert Bogdan and Steven Taylor, published in 1982, briefly discusses the current issues of developmental disability, but most of the book tells the life stories of two formerly institutionalized and developmentally disabled adults, Ed Murphy and Pattie Burt (both pseudonyms), in their own words. Bogdan and Taylor argue for the importance of highlighting the experiences of developmentally disabled people, which I will do in this paper, in addition to discussing the experiences of physically disabled and mentally ill people.⁶ In 1995, Steven Noll published *Feeble-Minded in our Midst: Institutions for the Mentally Retarded in the South, 1900–1940* which details what institutions were like in the South and how they were different from institutions in the North. He argues that institutions were originally meant to help disabled people participate in society but, due to cultural shifts in how disabled people were expected to

⁶ Bogdan and Taylor, *The Social Meaning of Mental Retardation*.

be treated, they began to focus on controlling their residents. He also discusses the abuse disabled people experienced in institutions.⁷ *The Disability Rights Movement: From Charity to Confrontation* by Doris Zames Fleischer and Frieda Zames, published in 2001, is an overview of the history of the disability rights movement. Fleischer and Zames argue, as Bogdan and Taylor did, that it is necessary to center disabled people in conversations about them.⁸ *Talking Back to Psychiatry: The Psychiatric Consumer/Survivor/Ex-Patient Movement*, by Linda Morrison, published in 2005, is a sociological look at the ex-psychiatric patient movement. She discusses the history of the movement and activists work to resist and reform the mental health system. She also interviews twelve former psychiatric patients about their experiences with the mental health system and institutions.⁹ I will also highlight the activism of former and psychiatric patients in my paper, in addition to discussing the activism of physically disabled and developmentally disabled people. In "The Savage Heart beneath the Civilized Exterior": Race, Citizenship, and Mental Illness in Washington, D.C., 1900-1940," published in 2008, Matthew Gambino also explores the experiences of institutionalized people. He focuses on the African American patients at St. Elizabeth's Hospital in Washington, D.C. His argument is that the white doctors at St. Elizabeth's gave African American patients substandard care because they believed African American were biologically inferior to whites.¹⁰ My paper will also address the racism institutionalized people of color experienced. "Disability and Life Writing Reports from the Nineteenth-century Asylum" by Sara Newman, published in 2011, includes writings from seven

⁷ Noll, *Feeble-Minded in our Midst*.

⁸ Fleischer, Doris Zames, and Zames, Frieda. *The Disability Rights Movement: From Charity to Confrontation*. (Philadelphia: Temple University Press, 2011).

⁹ Linda Joy Morrison, *Talking Back to Psychiatry: The Psychiatric Consumer/Survivor/Ex-Patient Movement* (New York: Routledge, 2005).

¹⁰ Matthew Gambino, "'The Savage Heart Beneath the Civilized Exterior': Race, Citizenship, and Mental Illness in Washington, D.C., 1900-1940," *Disability studies quarterly* 28, no. 3 (July 31, 2008).

people who had been considered disabled and institutionalized. This article focuses on how they felt about institutionalization, which was overwhelmingly negative, and their attempts to advocate for change. Newman examines their writings in the context of literature, specifically life writing.¹¹ In 2012, Kim E. Nielsen wrote *A Disability History of the United States* which chronicles disability history from before European colonization of North America to the present day. This book provides an overview of disability history. Nielsen touches on institutionalization briefly but does not go into depth about how and why it came about and later fell out of fashion. She argues that disabled people were institutionalized as a form of social control.¹² In *What We Have Done: An Oral History of the Disability Rights Movement*, published in 2012, Fred Pelka compiles the oral histories of multiple people involved in the disability rights movement. He shows how disability became seen as a political issue and how disabled people formed the disability rights movement. He argues for the importance of emphasizing the achievements and abilities of disabled people.¹³ In “Closing the Asylums: Causes and Consequences of the Deinstitutionalization Movement”, published in 2012, George Paulson discusses what he believes to be the major causes and impacts of institutionalization. Paulson worked at two institutions as a doctor and drew on his experiences. He argues that the reasons for deinstitutionalization were, to varying degrees, an increasing number of lawsuits against institutions; changing societal views of disability, including that disabled people could be better served in their communities and that institutions could exacerbate people’s disabilities; an increased emphasis in society on personal freedom; medical advances in how disabilities were treated; and the development of community services and support groups to help disabled

¹¹ Sara Newman, “Disability and Life Writing: Reports from the Nineteenth-century Asylum,” *Journal of Literary & Cultural Disability Studies* 5, no. 3 (2011): <https://doi.org/10.3828/jlcds.2011.22>.

¹² Kim E. Nielsen, *A Disability History of the United States*. (Boston: Beacon Press, 2012), 134.

¹³ Pelka, *What We Have Done*.

people.¹⁴ I will also argue that these factors contributed to deinstitutionalization, particularly the destigmatization of disability, the development of community services, and lawsuits against institutions. Paulson ignores how disabled people were influential in bringing about deinstitutionalization and wrote “The patients themselves tended to be silent.”¹⁵ This is in contrast to the evidence I have found which shows how disabled people were vocal about how they were mistreated in institutions, wanted change, and worked to bring it about, which I will highlight in my paper. The lack of attention to disabled people’s beliefs and actions regarding deinstitutionalization is a frequent theme in the literature on this topic

The History of Institutionalization

The treatment of disabled people in America has changed throughout its history. Until the mid-nineteenth century, disabled people were cared for by their families or towns.¹⁶ It was common for disabled people to be housed with criminals and the poor.¹⁷ Social reformers such as Dorothea Dix and Samuel Gridley Howe pressured states to open institutions that would house disabled people, out of a desire to care for disabled people and alleviate the oppression they were facing. In 1843, after Dorothea Dix witnessed the conditions that disabled people faced, she spoke to the Massachusetts state legislature and implored them to help. She said, “I proceed, Gentlemen, briefly to call your attention to the present state of Insane Persons confined within this Commonwealth, in cages, closets, cellars, stalls, pens! Chained, naked, beaten with rods, and lashed into obedience!”¹⁸ She worked to establish state-run institutions that would

¹⁴ Paulson, *Closing the Asylums*.

¹⁵ *Ibid.*, 165.

¹⁶ *Nomination Form of National Register of Historic Places: Commonwealth of Massachusetts State Hospital and State School System*, (December 9, 1993), 1.

¹⁷ Dorothea Dix, *Memorial to the Legislature of Massachusetts*, (Boston: Munroe & Francis, 1843).

¹⁸ Dix, *Memorial to the Legislature*.

improve disabled people's lives and was responsible for the construction of thirty-two public insane asylums.¹⁹ Samuel Gridley Howe established the Massachusetts School for Idiotic and Feeble-Minded Youth, an experimental boarding school for children with developmental disabilities that would prepare its students to live with the rest of society.²⁰ Many institutions at this time cared for their patients with what was called moral treatment, which "included removal of the afflicted one from an increasingly complex society to an ideal physical and social environment created within the boundaries of an asylum."²¹ Other institutions took a more medical approach to treating their patients and used drug therapy or a homeopathic approach that emphasized rest, nutrition, massage, and hydrotherapy.²² Training schools, which educated disabled people and helped them return to their community, find employment, and lead productive lives, were also popular. These training schools were successful in educating disabled people, but because of the struggling economy and the aftermath of the Civil War there were few jobs available for disabled people. The demand for training schools increased because parents had heard of the success they had. As more students enrolled, the schools did not have the ability to teach all of them, so they shifted their focus to providing custodial care and only teaching skills that disabled people could use as laborers at the school.²³ Samuel Gridley Howe was aware of the changing nature of institutions and warned against it. In 1866, he was asked to speak the groundbreaking of a new institution for blind people in New York and he asked them not to open the institution. He said of the institution's founders:

instead of first carefully inquiring whether an institution is absolutely necessary, that is, whether there is no more natural and effectual manner of relieving the class; and

¹⁹ *Nomination Form, Commonwealth of Massachusetts*, 32.

²⁰ "The Rise of Institutions: 1800-1950," The Minnesota Governor's Council on Developmental Disabilities, <https://mn.gov/mnddc/parallels/four/4b/5.html>.

²¹ *Nomination Form, Commonwealth of Massachusetts*, 10-11.

²² *Ibid.*, 15.

²³ "The Rise of Institutions," <https://mn.gov/mnddc/parallels/four/4c/1.html>.

afterwards, taking care that no vicious principle be incorporated into the establishment; they hastily build a great showy building, and father within its walls a crowd of persons of like conditioned infirmity; and organize as community where everything goes by clock-work and steam.²⁴

By 1890 the number of “mentally retarded” people had risen to 95,571 from 24,527 in 1870.²⁵

According to Sara Newman, at this time the term insanity was applied to more characteristics, including “fever, delirium, melancholy, nervous movements, speech, and excitability.”²⁶ The number of people diagnosed as insane rose. This led to more institutions being built and gave more power to doctors to treat people. The increased medicalization of institutions fostered the belief that disabled people were sick and needed to be cured. It also encouraged the use of dangerous medical procedures, such as electroshock therapy. The number of institutions and the number of people in institutions rose throughout the beginning of the 20th century. In 1900, there were around 10 private institutions for disabled people and in 1923 there were 80.²⁷ The number of people in institutions nationwide peaked at 559,000 in 1955.²⁸

Defining Disability

Many disabled people were institutionalized because of apparent physical or developmental disabilities. However, how disability is defined is determined by societal standard of normalcy. One example of this is IQ testing. Many people were determined to be intellectually disabled if they had an IQ score below a certain number, but IQ tests only reflect how well someone answers the specific questions they were asked, not how intelligent they are. Early IQ tests reflected white American middle-class values. Working-class people, racial minorities, and

²⁴ Ibid., <https://mn.gov/mnddc/parallels/four/4c/5.html>.

²⁵ Ibid., <https://mn.gov/mnddc/parallels/four/4b/8.html>.

²⁶ Newman, “Disability and Life Writing,” 265.

²⁷ “The Rise of Institutions,” <https://mn.gov/mnddc/parallels/four/4d/1.html>.

²⁸ *Nomination Form, Commonwealth of Massachusetts*, 21.

immigrants made up a large proportion of people considered intellectually challenged based on their IQ test scores because they were not as familiar with white American middle-class values.²⁹ Ed Murphy, who was developmentally disabled and was institutionalized at Empire State School for four years in the 1960s, said “[An IQ test] wasn't a question of how intelligent I was. It was a question of how this guy was grading me. I don't think an IQ goes deep enough as far as the individual. It can only score the answers to the questions. It doesn't tell anything about the individual.”³⁰ Societal norms can also shape who is categorized as disabled or mentally ill. In the 1830s, Phebe Davis was institutionalized “all because I could not fall in with every vulgar belief that was fashionable.”³¹ Over a hundred years later, in 1962, Leonard Roy Frank was diagnosed as a paranoid schizophrenic, institutionalized for eight months, and subjected to fifty rounds of electroshock therapy against his will because he did not follow the norms of Cold War America.³² He became a vegetarian, grew a beard, did not look for a job, and read the works of Mohandas Gandhi, Henry David Thoreau, and Arnold Toynbee. His parents did not approve of his behavior and were worried about how he would affect their reputations. They encouraged him to meet with a psychiatrist who agreed that there was something wrong with him and said his treatment would be to go back to the person he used to be. Leonard Roy Frank said, “I was not interested in that. I liked the person I was becoming.”³³ Despite his beliefs, he was committed to the Twin Pines Sanitarium in Belmont, California. Phebe Davis, Leonard Roy Frank, and many other people were diagnosed as mentally ill and institutionalized because they did not conform to society's standards of how normal people should behave.

²⁹ Noll, *Feeble-Minded in our Midst*, 2.

³⁰ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 88.

³¹ Newman, “Disability and Life Writing,” 261.

³² Pelka, *What We Have Done*, 77.

³³ *Ibid.*, 78.

Women were especially vulnerable to being institutionalized for not fitting into societal norms. Men had the ability to legally institutionalize their wives. This happened to Elizabeth Packard, who was institutionalized at the behest of her husband who believed her religious beliefs were dangerous to their children and community.³⁴ This also happened to people of color and activists. In the 1960s, a young Black civil rights activist was sent to a mental hospital to be observed for “possible delinquent and sociopathic trends.”³⁵ He said, “We protest our inability to vote, go into a movie or restaurant everyone else uses, and they call us crazy, and send us away to be looked over by psychiatrists and psychologists and social workers.”³⁶ A psychiatrist named Robert Coles, who met with this activist, wrote that “I was not so prepared to see how convenient it would be for that judge, and many others like him, to...summon all the authority of medicine and science to the task of defending the status quo – which meant putting firmly in their place (a hospital or a clinic) those who choose to wage a struggle against that status quo.”³⁷ Some disability rights activists questioned the existence of disability and mental illness. In the mid-1970s, Leonard Roy Frank said that he and his fellow activists “didn’t believe that there was any such thing [as mental illness], in the medical sense of the term. We thought that it was just a construct that was developed as a rationale for depriving certain troubled or troubling people of their rights.”³⁸ Seymour Krim, who was institutionalized after a suicide attempt, also questioned the psychiatrist diagnosed people as mentally ill. He wrote that “I saw now that nine-tenths of the people I was quartered with were not ‘insane’ by any of the standards a normally intelligent person would use...Some of them may have been ‘sick,’ you say. I answer: who cannot be

³⁴ Newman, “Disability and Life Writing,” 268.

³⁵ Robert Cole, “A Need to Disrupt the Lives of Others,” in *Blue Jolts: True Stories from the Cuckoo's Nest*, ed. Charles Steir (Washington D.C.: New Republic Books, 1978), 61.

³⁶ Cole, “A Need to Disrupt the Lives of Others,” 61.

³⁷ *Ibid.*, 63.

³⁸ Pelka, *What We Have Done*, 235.

conceived as such in a world so complex?"³⁹ The existence of institutions for disabled people were an example of social norms. Disabled people were considered deviant and not fit to be around "normal" people. Society could not think of a way to integrate them into society. Putting them in institutions was a way of declaring what was normal and policing behaviors. William Bronston said that institutionalized disabled people were "there because society doesn't know what to do with this population. The message to all the people working there is that this is a highly devalued, stigmatized, less than human, and that is crucially important, less than human population of people that after a while all merge into one big mush of humanity that has to be somehow maintained."⁴⁰ Oftentimes, people were determined to be disabled as a form of social control.

Positive Experiences at Institutions

While many disabled people faced abuse and neglect in institutions, some disabled people in institutions had positive experiences. The largest benefit disabled people found was that they were able to interact with people who shared their disabilities and learn how to navigate the world from them. Fred Fay, a disability rights activist, who was paralyzed after a spinal cord injury in 1960, stayed at Roosevelt Warm Springs, a rehabilitation center for people with physical disabilities that was founded by Franklin Roosevelt. Roosevelt Warm Springs was originally founded to treat polio survivors and employed polio survivors on its staff. Fay appreciated his time at Roosevelt Warm Springs because "The staff seemed very knowledgeable, very friendly. The second day I was there, I realized that some of the teachers were in

³⁹ Seymour Krim, "The Insanity Bit," in *Blue Jolts: True Stories from the Cuckoo's Nest*, ed. Charles Steir (Washington D.C.: New Republic Books, 1978), 47-8.

⁴⁰ Bronston, 2001-2, interview by Kathy Cowan, 87.

wheelchairs: my English teacher, my physics teacher, and German teacher. That had an impact: There was a lot of stuff you could do from a wheelchair.”⁴¹ Meeting disabled adults showed him that he could live and thrive as a physically disabled person. He also formed important relations with his fellow patients. His roommate Larry, who was a quadriplegic, taught him to accept that his disability would never be cured and that he should accept his disability. Fay believed that “Larry's role model had a more profound impact on me than I think anything else in the whole course of my rehabilitation. Generally, I've learned more from other people with disabilities than I've learned from all the other doctors and nurses and physical therapists, occupational therapists that I've seen over the years.”⁴² The relationships disabled people formed with each other were important and gave them experiences they were unable to have with able-bodied people. Marilyn Saviola, who contracted polio as a child, went to Goldwater Memorial Hospital for checkups. As a teenager she decided to stay at the hospital permanently because she enjoyed spending time with other people and participating in activities with them that she had been unable to do with people at her home. The other patients there became her “family of choice.”⁴³ Sarah Uhlberg, who was Deaf, created affirming friendships with her fellow students at New York City's Lexington School for the Deaf in the early 1920s. She was able to talk with them in sign language at all hours of the day, while she was unable to communicate with her family, who did not know how to sign. She said, “the ability to communicate with one another was like the water of life, our oasis of language and meaning, in the midst of the huge expanse of desert silence and incomprehension that was the greater hearing world.”⁴⁴

⁴¹ Frederick Fay, 2001. Interview by Fred Pelka. Disability Rights and Independent Living Movement Oral History Project, Regional Oral History Office, University of California. The Bancroft Library, Berkeley, CA. 9.

⁴² Fay, 2001, interview by Fred Pelka, 11.

⁴³ Pelka, *What We Have Done*, 93.

⁴⁴ Nielsen, *A Disability History*, 134.

During World War II the National Park Service leased the Ahwahnee Hotel at Yosemite National Park to the Navy to be used as a military hospital. Doctors initially believed that the isolated nature of Ahwahnee would help their patients but instead they were bored and lost in their traumatic memories of war. The doctors then focused on physical rehabilitation and preparing the patients for a return to society. To boost patients' morale, the hospital provided classes, workshops, visits to Yosemite National Park, a library, bowling alley, pool hall, and transportation facilities. Visits from family members were encouraged. The Ahwahnee's methods of treating patients was successful. Roughly 65 percent of patients returned to active duty.⁴⁵ Another person who did not have a negative experience while institutionalized was Marle Woodson, a journalist whose friends committed him to an Oklahoma institution in the early 1930s because of his alcoholism. He later wrote a book about his experiences called *Behind the Door of Delusion* where he expressed his respect for the doctors and attendants at the institutions where he was a patient. He wrote, "There are some brutal attendants in most insane asylums, I have since learned, reliably. But usually they are weeded out as soon as they are detected in any brutality by the hospital authorities. I have never found but one on this ward. From patients on other wards I have learned of some rough handling of patients by attendants who have since been discharged."⁴⁶ While Woodson did not experience or witness abuse while institutionalized, the potential for abuse was present in all institutions because the patients were under the control of doctors, nurses, and other staff. Many workers at institutions had internalized the negative beliefs about disabled people present in society that led to their dehumanization and mistreatment. Even Woodson, who said he did not find the institution he was in abusive, recounted how an attendant

⁴⁵ "Yosemite's World War II Hospital," National Park Service, <https://www.nps.gov/articles/yosemitemilitaryhospitalwwii.html>.

⁴⁶ Marle Woodson, *Behind the Door of Delusion*, (Boulder, CO: University Press of Colorado, 1994), 9.

told him, "There will be many things here that you do not like. You will have to do some things that you do not want to do. But the thing to do is just to be a man and do them, whether they please you or not."⁴⁷ This attendant did not respect Woodson or the other patients as people capable of making their own decisions because of beliefs that disabled people were not capable of thinking for themselves and needed to be controlled. While disabled people may have had some positive experiences at institutions, they were also aware that there were few other options for them. If they did not have family members that were willing or able to care for them there was nowhere else to receive care, as they did not have the resources to allow themselves to live independently. Ed Murphy, was developmentally disabled and had epilepsy, was institutionalized at Empire State School for four years in the 1960s. He did not enjoy his time there but when a doctor asked him if he wanted to leave, he said "'No thank you.' I mean I was happy. I didn't know what was out there, I didn't want to risk it...For people getting out it's hard to live."⁴⁸ He knew he did not have the skills to survive outside of an institution because he had never been taught them. While some disabled people did have positive experiences at institutions, the concept of institutionalizing disabled people was harmful because it took away disabled people's rights to make their own decisions and live independently. People's positive experiences also do not negate the abuse many other people suffered at institutions.

Physical Abuse

Disabled people faced similar types of abuse in institutions across the 20th century. It was common for institutions to use physical abuse to punish patients for perceived misbehavior. Pattie Burt, who was developmentally disabled and institutionalized at Empire State School

⁴⁷ Woodson, *Behind the Door of Delusion*, 10.

⁴⁸ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 62.

recounted how one attendant made her and other patients kneel on logs for two hours whenever she wanted, even if they had not done anything.⁴⁹ Burt also remembered how she was often made to scrub all of the stairs in the building, would get hit in the mouth when attendants thought she talked back and was made to wear a straitjacket “plenty of times.”⁵⁰ A doctor had to order placing a patient in a straitjacket, so an attendant would call a doctor to ask if they could restrain a patient and the doctor would agree without even speaking to the patient. Patients at institutions were also physically abused even without the supposed excuse of punishing bad behavior. Abuse was very common at Willowbrook State School, an institution for developmentally disabled people in New York, where a patient was statistically more likely to be assaulted, raped, or murdered than in any neighborhood in New York City.⁵¹ William Bronston, a doctor at Willowbrook who later worked to shut the hospital down, said that at Willowbrook:

kid[s] [were] literally being ground into misshapen--I mean, cauliflower ears, smashed and disfigured noses, blinded eyes, teeth all knocked out, scars everywhere, huge weight gains, huge weight losses, constantly being drugged, no clothes, no soap, no suture material, two or three different doctors overseeing their kid, who don't care at all about the kid, don't want to touch the kid, don't want to be in the same room with the kid.⁵²

He also said that it was common for staff members to “[get] another resident, who's slightly more capable to take out some other resident, or murder them, or rape them, or hit them with a ball of keys, or whatever has to be done in order to make the time pass... You have a situation of living death.”⁵³ Another hospital where patients were physically abused was the Lima State Hospital for the Criminally Insane, where in 1971 thirty-one employees and former employees were arrested on charges of physically or sexually abusing inmates. The charges included “lewdness,

⁴⁹ Ibid., 131.

⁵⁰ Ibid.

⁵¹ Pelka, *What We Have Done*, 175.

⁵² Bronston, 2001-2, interview by Kathy Cowan, 71.

⁵³ Ibid.

assault, torture and sodomy.”⁵⁴ Among the employees arrested was the hospital personnel director. Most of the inmates at the Lima State Hospital were people who had been arrested or convicted of crimes and were judged to be mentally ill. They were supposed to receive treatment but many never did. Employees at the hospital used electric shock treatment to punish inmates, drugged them to make them compliant, and beat them while they were tied to their cell doors.⁵⁵ One of the inmates who was abused was a Vietnam veteran who not been convicted of any crimes. He was beaten daily and kept in isolation for three years. Other employees of the hospital were angry at the arrests and planned to wear black ribbons to work in sympathy and solidarity with the arrested employees.

Patients at institutions had no protection from abuse. Terry Schwartz was institutionalized at Fairview Training Center in Salem, Oregon and said that “there was a lot of abuse out there too, that was not supposed to be done. If they wanted to hurt us, they could hurt us. If they wanted to slap us down, spank us, why, it doesn’t matter. If they done something real wrong, it’s no big deal. They could do what they wanted and abuse people, whatever they wanted to do.”⁵⁶ Ed Murphy mentioned that at Empire State School an attendant killed a patient.⁵⁷ He did not mention if the attendant was ever punished and did not act like this occurrence was out of the ordinary. In 1974, at Boulder River School and Hospital in Montana, a number of patients died because of what officials said was “poor conditions spurred by staff shortages.”⁵⁸ Robert Perske,

⁵⁴ "31 Accused of Abusing Asylum Inmates," *New York Times*, November 25, 1971, <https://www.nytimes.com/1971/11/25/archives/31-accused-of-abusing-asylum-inmates.html?searchResultPosition=1>.

⁵⁵ Jerry M. Flint, “31 Ex-Employees at Ohio Hospital Appear in Court,” *New York Times*, November 27 1971, <https://www.nytimes.com/1971/11/27/archives/31-exemployees-at-ohio-hospital-appear-in-court.html?searchResultPosition=13>.

⁵⁶ Pelka, *What We Have Done*, 58.

⁵⁷ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 58.

⁵⁸ *Nomination Form of National Register of Historic Places: Montana State Training School Historic District*, (October 10, 2014), 32.

who was the chaplain at the Kansas Neurological Institute from 1959 to 1970, remembered how a child died in the dental chair after a dentist over-sedated him. The child had been acting hyperactive and the dentist didn't know how else to control him.⁵⁹

Medical Abuse

Patients at institutions were also physically abused under the guise of providing them care or conducting medical experiments. At Willowbrook doctors gave patients tropical diseases in order for the doctors to study them. They “inoculat[ed] kids with Hepatitis A in order to study how to develop a possible hepatitis vaccine.”⁶⁰ At the Kansas Neurological Institute, doctors kept the brains of patients in jars to do research on. This area was off-limits to patients, but they were aware of it. Robert Perske, the chaplain at the Kansas Neurological Institute, remembered how, after the child had died in the dental chair, another child named Shotgun “kind of nudge[d] me and sa[id], ‘They got his brain in there yet?’”⁶¹ Electroshock therapy was a common way for doctors to treat patients at institutions. Ted Chabasinski was diagnosed with childhood schizophrenia when he was six and was committed to Bellevue Hospital and later Rockland State Hospital. He believed that this diagnosis was due to the belief that mental illness was hereditary and because his mother had been diagnosed with schizophrenia. He said that “Psychiatrists and social workers had already decided before I was born that I was going to be a mental patient.”⁶² When he was six, in 1944, he was one of the first children to be treated with electric shock “as part of an experiment to see what effect they would have on a child.”⁶³ When he wasn't being given electric shocks he was kept in isolation in his room. Some of the attendants would turn off

⁵⁹ Pelka, *What We Have Done*, 56.

⁶⁰ Bronston, 2001-2, interview by Kathy Cowan, 69.

⁶¹ Pelka, *What We Have Done*, 56.

⁶² *Ibid.*, 59.

⁶³ *Ibid.*

the radiator in his room and keep the window open, even in the winter. One of his doctors said that it was a sign of his sickness that he did not like fresh air. The doctors allowed him to leave when he was seventeen and “the shrinks thought they had destroyed [him].”⁶⁴ Chabasinski later became a leader in the psychiatric survivor movement. Leonard Roy Frank was also subject to shock therapy. For a month after he was committed to Twin Pines Sanitarium in Belmont, the psychiatrists pressured him to consent to electroshock treatment. When he refused, they obtained a court order that allowed them to use electroshock treatment without his consent.⁶⁵ The electroshock treatment put him in an insulin coma where:

There is a lead-up period [to the insulin coma] lasting about four hours during which the subject experiences increasingly intense hunger as well as heavy perspiration, chills, tremors, headache, sometimes convulsions, and what I would describe as the pangs of dying. All the while, the insulin is absorbing sugar in the subject's body, including the brain. Starved of sugar, the brain goes on strike and begins to feed on itself, eventually causing brain-cell death and coma. The coma lasts about an hour, at which point emergency measures are used to bring the subject out of the coma.⁶⁶

The sociologist Ivan Belknap observed how the staff decided which residents would receive electroshock treatment at an institution in Texas. He witnessed that “On the day before the shock team is scheduled, the charge attendant makes out the EST List, as it called. He lists for treatment those patients he feels needs the treatment because they are ‘acting up,’ are causing trouble, have become disturbed, or show strong evidence of becoming disturbed or violent.”⁶⁷ Doctors and nurses had the ability to treat institutionalized people however they wanted, and many used their power to abuse their patients.

⁶⁴ Ibid.

⁶⁵ Ibid., 80.

⁶⁶ Ibid., 80.

⁶⁷ Ivan Belknap, “Worry Warts,” in *Blue Jolts: True Stories from the Cuckoo's Nest*, ed. Charles Steir (Washington D.C.: New Republic Books, 1978), 98.

Sexual Abuse

Sexual abuse was also common in institutions. William Bronston noted that at Willowbrook “Lots of residents in the institution got pregnant” with at least some most likely becoming pregnant after being raped by staff or fellow patients.⁶⁸ At the Kansas Neurological Institute the chaplain Robert Perske remembered that a staff member molesting a child “and the kid kept saying he was doing it, and nobody would believe it because, after all, he was disabled. And then the guy was caught. I gotta tell you, they didn’t call the police. They fired him, quietly, and he turned up in another institution in the system.”⁶⁹ Lucy Gwin, who was institutionalized at New Medico in Cortland, New York in 1989 after receiving a head injury in a car accident, also noted that the staff at institutions did not listen to patients who said they were being sexually abused. She witnessed an attendant repeatedly rape a woman named Delores who was aphasic and could not speak. At night, he would bring his friends into the institution and they would rape her as well. Gwin would say, “‘Stop that right now!’ And they’d say, ‘Nobody will ever believe you.’ And they were right, nobody did. I reported it. The first time, I thought they’d do me next. I...tried to tell the attendant, and tried to tell the guy who ran the day care center, and tried to tell the case manager. ‘No, no, no, you’re imagining things.’”⁷⁰ Ed Murphy was also aware that sexual abuse was common at Empire State School where he was institutionalized. When a parent found out that their child had been molested by a male attendant, Murphy’s response was “Big deal. If they knew what was going on it wouldn't be that big a deal one incident of sodomy.”⁷¹ Patients, especially female ones, also faced the threat of sexual abuse from their fellow patients.

⁶⁸ Bronston, 2001-2, interview by Kathy Cowan, 86.

⁶⁹ Pelka, *What We Have Done*, 56.

⁷⁰ *Ibid.*, 87.

⁷¹ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 60.

At Empire State School “the girls all had to be supervised. They were locked up a lot.”⁷² This was to protect them from being assaulted and also to prevent them from engaging in consensual sexual relationships. Murphy also witnessed how older male patients would groom younger teenagers or boys into a sexual relationship.⁷³ If a male patient molested another male patient, or if two men had a consensual relationship, “sometimes [the staff] would lock them up, put them in isolation or up on the detention ward. Locking them up. Sometimes the attendants would dress residents up with a dress and parade you around the ward.”⁷⁴

Another way institutions tried to control the sexuality of patients was through sterilization, which deprived them of their reproductive rights. In the 1920s sterilization became more popular because of the growing belief in eugenics, the practice of breeding out undesirable characteristics, such as disability, from society. This was based on the belief that disabilities were hereditary. Indiana passed the world's first eugenic sterilization law in 1907 which allowed doctors at institutions to sterilize patients who they believed had disabilities that would harm society. From 1907 to 1937, thirty-two states passed eugenic sterilization laws.⁷⁵ Doctors believed that they had to sterilize institutionalized people to prevent them from reproducing and creating more disabled people. In many states, patients had to be sterilized in order to be released.⁷⁶ During the six decades that sterilization laws were in place, over 60,000 sterilizations were officially recorded. Most of these took place in institutions. Robert Perske, the chaplain at Kansas Neurological Institute, met a patient from Winfield State Institution and found that all of

⁷² Ibid., 46.

⁷³ Ibid., 44.

⁷⁴ Ibid., 46.

⁷⁵ Siobán Harlow, Sharon Kardia, Natalie Lira, Katie O'Connor, Nicole L. Novak, and Alexandra Minna Stern, "California's Sterilization Survivors: An Estimate and Call for Redress," *American Journal of Public Health* 107, no. 1 (January 2017): <https://doi.org/https://doi-org.huaryu.kl.oakland.edu/10.2105/AJPH.2016.303489>. 51.

⁷⁶ Noll, *Feeble-Minded in our Midst*, 28.

the males there had been castrated. They also “had a place there where they used to keep the gonads in jars.”⁷⁷ Aside from having disabilities that doctors believed were hereditary, people were also sterilized at institutions if they were thought to be a danger to society in other ways. In 1926, Marsha (all names are pseudonyms), who was a patient at the Sonoma State Home in California, was sterilized because her IQ was 56 and because she was perceived as “sly, profane, [and] obstinate.”⁷⁸ Sarah, who was also a patient at the Sonoma State Home in the 1940s, was admitted there after her family became unable to care for her. She was sterilized “because of her supposed sexual delinquency and poor family attributes, including poverty and alcoholism.”⁷⁹ Joseph, a patient at Pacific State Hospital, was sterilized because of his “recklessness [and] familial history of adultery.”⁸⁰ In Marle Woodson’s book, *Behind the Door of Delusion*, he wrote about the sterilization law passed in Oklahoma while he was institutionalized and how other patients reacted to it. The law allowed doctors at institutions to sterilize patients before they were released and gave the superintendent of an institution the authority to decide who to sterilize. Some patients feared that their superintendent would sterilize them because of preexisting grudges. Patients were frightened and angry of being sterilized. One patient said, “Well if they do that to me I’ll kill them [*sic*] man who orders it done even if it takes me the rest of my life.”⁸¹ Another patient said, because of the fear of sterilization, “I’m not agoing [*sic*] to stay here.”⁸² At least one patient successfully escaped.

⁷⁷ Pelka, *What We Have Done*, 56.

⁷⁸ Harlow et al., “California’s Sterilization Survivors,” 50.

⁷⁹ *Ibid.*, 52.

⁸⁰ *Ibid.*, 52.

⁸¹ Woodson, *Behind the Door of Delusion*, 126.

⁸² *Ibid.*

Control

Another way institution abused residents was through constantly observing them and controlling their actions. At many institutions residents were told what to do, even for ordinary tasks, such as when to eat or sleep. Terry Schwartz was institutionalized at Fairview Training Center for most of his childhood and young adulthood. At the Fairview Training Center “we didn’t have no freedom, we didn’t have no rights at all. They decided when we go to bed. We weren’t allowed to take naps. We couldn’t go to lie down on your own bed if you wanted to relax or take a little nap or something. They controlled everything we did.”⁸³ At Fairview people were only allowed to leave to work at a job that Fairview selected for them. They were not even allowed to go for a walk outside of the institution’s grounds.⁸⁴ Residents were told that they were being controlled for their own good because they were not capable of making decisions for themselves due to being disabled. This contributed to feelings of depression and insecurity among institutionalized people. The staff at institutions watched patients at all times. Ed Murphy said that “at Empire [State School] everybody watched you. There is a belief that practically everybody is watching from the teachers to the attendants to the gardener to the dentist.”⁸⁵ Maria Bell lived in institutions in New York City where “you were constantly being watched over and they only let you know what they thought you needed to know.”⁸⁶ The staff at institutions watched patients because they wanted to ensure they were acting the way they wanted them to and to punish them if they were not. When intuitions controlled their residents they made them

⁸³ Pelka, *What We Have Done*, 57.

⁸⁴ *Ibid.*, 58.

⁸⁵ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 48.

⁸⁶ "History from Institutionalization to Independent Living | Move to Include," PBS, <https://dptv.pbslearningmedia.org/resource/mti17.history.institutionalization.independence/history-from-institutionalization-to-independent-living-move-to-include/#.X9rNNNhKjIV>.

feel powerless. Institutionalized people were prevented from making their own decisions.

Richard Gould, who received a spinal cord injury from a diving accident, was a resident at a nursing home in Massachusetts in the late 1960s. He wanted to attend a local community college but was not able to because the nursing home he was in would not let him leave out of a fear that they would lose Medicaid funding. He “had to stay within the facility, otherwise--the logic behind that is that if you're able to go to school, you don't really need this level of care...But it wasn't really a question, once I got there, that they were not going to permit it no matter what I did.”⁸⁷

Judi Chamberlin, who was institutionalized after being diagnosed with depression and schizophrenia, believed that “Institutions with lots of staff members (expensive hospitals with good reputations) were particularly oppressive, because they were able to control virtually every move patients made.”⁸⁸ She knew a man named David who was a resident at one of those hospitals. He was a vegetarian, but the hospital thought it would be therapeutic that he eat meat, which he resisted. He began to eat peanut butter frequently to ensure that he received enough protein but “It was decreed that he be limited to one ounce of peanut butter per meal, a ruling that was enforced by a staff member assigned to be there to watch him eat.”⁸⁹ Institutions believed they were controlling residents for their own good, but the residents viewed these treatments as harmful.

⁸⁷ Gould, Richard, 2001, interview by Fred Pelka. Disability Rights and Independent Living Movement Oral History Project, Regional Oral History Office, University of California. The Bancroft Library, Berkeley, CA. 168.

⁸⁸Judi Chamberlin, *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, (New York: Hawthorn Books, 1978), 74.

⁸⁹ Chamberlin, *On Our Own*, 74.

Racism

Institutions tried to control people of color, particularly Native Americans and African Americans. At St. Elizabeth's Hospital in Washington, D.C., which was segregated and one of only two federal insane asylums in the United States, white doctors were more likely to view Black patients as inferior. White doctors created treatment for African Americans that was based on the belief that they were biologically inferior. According to Matthew Gambino, "When it came to dementia precox, a conceptual precursor of schizophrenia and the most common diagnosis among patients of both races...blacks' inferiority entailed a distinctive presentation of the disease."⁹⁰ Black patients received worse treatment from doctors. Black men were occasionally transferred to Howard Hall, which was the most secure part of the hospital, when they were suspected of being dangerous, while white patients were rarely assigned there even if they had been violent.⁹¹ Black patients were forced to work at the hospital without pay. While white patients worked without pay as well, they were more likely to supervise other patients, which Black patients rarely did. Starting in the early 1900s, the Black patients, most of whom were the descendants of enslaved people, recognized the racial implications of their unpaid labor and asked to be paid.⁹² When Black patients protested their unfair treatment at St. Elizabeth's, they also protested the legitimacy of the racism doctors were using to control them. When Eileen Walkenstein was in medical school in the 1940s, she witnessed a doctor give an eighteen-year-old Black man diagnosed with schizophrenia a lobotomy as part of a demonstration for her class. The man was given electroshocks to anesthetize him for the surgery. The doctor remarked that he had difficulty placing the icepick used to perform the lobotomy (which was unsterilized, as he

⁹⁰ Gambino, "The Savage Heart Beneath the Civilized Exterior."

⁹¹ Ibid.

⁹² Ibid.

used it after removing it from his pocket) through the patient's skull because of its "thickness", a racial dog whistle that several of the students laughed at.⁹³ Walkenstein rhetorically asked "This patient – if he were not poor, not black, not welfare-experimental-animal material – what treatment would then have been meted out to him?"⁹⁴

Another institution that tried to control people of color was the Hiawatha Asylum for Insane Indians. The Hiawatha Asylum was the second federal insane asylum in the United States. From 1903 to 1933 over three hundred Native Americans from at least fifty-three different tribes were patients at Hiawatha.⁹⁵ Kim Nielsen speculated that Hiawatha was founded specifically to control Native Americans because Native Americans were under the control of federal authorities and state institutions were under no legal obligation to accept them as patients.⁹⁶ Hiawatha also could have been seen as a way to create jobs and earn the state money. White agents of the Bureau of Indian Affairs (BIA) could send someone to Hiawatha for any reason without the advice of doctors. Some of the reasons people were sent to Hiawatha were resisting, arguing with BIA agents, practicing their religion, and refusing to send their children to residential schools.⁹⁷ At Hiawatha inmates were not allowed to practice their traditions. The staff also frequently cut off inmates' hair, which was disrespectful in their culture. The Hiawatha Asylum attempted to control Native Americans by cutting off their access to their culture and trying to assimilate them into white American culture, which was perceived to be normal. After Hiawatha closed in 1933, sixteen patients were released because they were determined to not need to be institutionalized. Sixty-nine other people were transported to St. Elizabeth's Hospital

⁹³ Eileen Walkenstein, "Vegetables Don't Cry," in *Blue Jolts: True Stories from the Cuckoo's Nest*, ed. Charles Steir (Washington D.C.: New Republic Books, 1978), 132.

⁹⁴ Walkenstein, "Vegetables Don't Cry," 131.

⁹⁵ Nielsen, *A Disability History*, 122.

⁹⁶ *Ibid.*

⁹⁷ *Ibid.*

in Washington, D.C. where they undoubtedly encountered more mistreatment based on their race and perceived disability. People of color in institutions received racist treatment and abuse.

Neglect

While many institutions tried to cure disabled people or treat their disabilities – whether through positive techniques, such as physical therapy, or abusive techniques, such as electroshock therapy – it was also common for institutions to neglect their patients. The *New York Times* reported that the Lima State Hospital for the Criminally Insane “ha[d] been run with a minimum of medical supervision or direction...[and] lacked professional leadership at top levels.”⁹⁸ Lucy Gwin was institutionalized at New Medico, and she wrote

The whole time I was there, I never saw a doctor. I never saw a nurse. I never had any “therapy.” There was nothing to do, so we all sat around the picnic tables talking. The only time I got therapy was when I complained that there wasn’t any, and then they made up this silly game that was a rip-off of Trivial Pursuit, where the staff would quiz the inmates on whether or not something was “appropriate behavior.”⁹⁹

Gwin had lost her memory after she suffered a traumatic brain injury. When she got her memory back on her fourth day at New Medico, she recalled, she “went downstairs to the person who was on duty and I said, ‘I just remembered my whole life. I remember my name and my children and my home, I remember everything.’ And she said, ‘Oh, that’s nice honey, now what do you want on your pancakes?’”¹⁰⁰ Many doctors who had worked at institutions admitted that part of the reason for their neglect was because they did not have the ability or knowledge to treat patients. Robert Perske, the chaplain at the Kansas Neurological Institute, said, “We didn’t understand people with autistic spectrum disorders, but we had them all over the place. We didn’t know

⁹⁸ “31 Accused of Abusing Asylum Inmates.”

⁹⁹ Pelka, *What We Have Done*, 85.

¹⁰⁰ *Ibid.*, 86.

what autism was. We didn't know what ADHD was. We certainly didn't know what fetal alcohol syndrome was, and Lord knows our institution had a lot of them... They all pretty much got the label 'mental retardation.'"¹⁰¹ William Bronston, a doctor at Willowbrook State Hospital, believed that he was hired simply because he "knew penicillin from aspirin. That was about all they cared about."¹⁰² Willowbrook was so desperate for doctors because they were understaffed.

Willowbrook had:

"five to six thousand people with between two and three thousand workers, split among three shifts. So at no time were there ever more than three people on a ward to take care of fifty residents. There was no program. People never got outside of the buildings because there wasn't enough supervision to take a group of people, and we couldn't take all fifty, some had to stay behind."¹⁰³

Because of the neglect and lack of staff, Ed Murphy believed that "Some of the patients at the [Empire State] school could be the director, for that matter. They would know the needs of the people more than the people that run it."¹⁰⁴ Institutionalized people understood their needs better than the staff and did work that the staff would not. At Empire State School there was "shit all over the floor. After a while people who work there just don't see it. To keep up with it would be a full-time job. Just to keep changing those poor people would be a full-time job. The attendants were supposed to do the changing but, let's face it, the residents did it."¹⁰⁵ Some intuitions did not have enough staff to care for all of the patients, but some doctors and staff purposefully neglected their patients. Lucy Gwin said that New Medico "was a total scam, and everybody working there knew it."¹⁰⁶ The staff lied on their insurance paperwork to ensure that they would get money from insurance companies. They would "sit down at the end of the day, the little

¹⁰¹ Ibid., 55.

¹⁰² Bronston, 2001-2, interview by Kathy Cowan, 66.

¹⁰³ Ibid., 68.

¹⁰⁴ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 58.

¹⁰⁵ Ibid., 57.

¹⁰⁶ Pelka, *What We Have Done*, 87.

front-line workers, and say, 'Can I say I spent six hours with Juan today, or did you say you spent six hours with him? We can't both say it.' And they would figure out their lies while they were doing their paperwork, because nobody spent six hours with anybody."¹⁰⁷ The neglect disabled people experienced at institutions led to negative outcomes for them.

Negative Outcomes of Institutionalization

Being institutionalized harmed disabled people and in many cases made their lives worse than what they would have been if they had never been institutionalized. In the 1970s Ed Murphy said that institutions "have taken millions of dollars and spent them and never rehabilitated who they were supposed to. If you looked at individuals to see what they said they were supposed to do for that person and then what they actually did, you would find that many of them were actually hurt, not helped."¹⁰⁸ Being institutionalized caused many disabled people to behave in ways that society did not consider normal. William Bronston argued that "the very manifestation of bestial behavior is really a learned coping behavior that flows from the very organization of the place."¹⁰⁹ People viewed disabled people as insane for acting erratically, but in most cases, they were acting that because of the brutal treatment they experienced. Being institutionalized also made disabled people think less of themselves and negatively affected their self-worth. Pattie Burt described how when she was ten at Empire State School "they put me in a highchair, and they tied a bib around me. They made me feel just like a baby. I really did. What I did was I messed in my food. I played with it and took the food out and played in it. I threw it...When they put me in the highchair it was like an instinct to act like a baby."¹¹⁰ Judi

¹⁰⁷ Ibid.

¹⁰⁸ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 41.

¹⁰⁹ Bronston, 2001-2, interview by Kathy Cowan, 70.

¹¹⁰ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 115.

Chamberlain, a disability rights activist, spent five months in six different institutions, having been diagnosed with depression after a miscarriage. She wrote that “after hospitalization, I was convinced of my own worthlessness. I had been told that I could not exist outside an institution. I was terrified that people would find out that I was an ex-patient and look down on me as much as I looked down on myself.”¹¹¹ Bronston believed that

human expectations, conscious and unconscious, are the absolute determinants of behavior and development...What happens in the developmental delay field, the mental retardation, developmental disability institutional reality world is that this whole world has ratcheted down their expectations. It trades on the thesis that people are what they appear though appearance is completely misleading.¹¹²

Moreover, institutions did not prepare disabled people for what life would be like after they left. Murphy said that “going into the state school is like being sucked up a vacuum cleaner. The state takes you over.”¹¹³ Even though he knew this, he was afraid to leave the state school he was at because he didn't know how he would survive outside of it. Pattie Burt, who was institutionalized at Empire State School, believed that “the major problem with people leaving the state school is that you are so used to everything being handed to you...When you get out, it is no fun because you don't know what the outside is all about...When you get out you're lost. You gotta go 'round asking people and you feel kind of stupid.”¹¹⁴ Being institutionalized affected the way people were treated and the opportunities they had after leaving institutions. This also affected the opportunities they could have after leaving institutions. Pattie Burt said that “you tell people you have been in the state school and they think I am retarded.”¹¹⁵ Nancy

¹¹¹ Chamberlin, *On Our Own*, 5.

¹¹² Bronston, 2001-2, interview by Kathy Cowan, 37.

¹¹³ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 58.

¹¹⁴ *Ibid.*, 184.

¹¹⁵ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 200.

was an eighteen-year-old activist who began to hear her former girlfriend's voice, who was sick, asking her for help. She told this to doctors at Cambridge City Hospital in Boston and was hospitalized. As Nancy recalled, after she left the hospital, "Women in the women's movement, in the lesbian movement, women I had known for a long time and worked with, started treating me differently after I had been in the hospital. They were oppressing me. They wouldn't tell me things, wouldn't ask me to do any work, because they thought I couldn't handle stuff....they would look at me as if I was crazy."¹¹⁶ People who had been institutionalized were judged and this made it harder for them to return to society.

Institutions also caused physical hardships for institutionalized people. At Willowbrook, Bronston witnessed that many patients received amputations due to circulatory problems and chronic infections in their thirties that people did not normally get until they were in their eighties. Bronston realized that this was because:

these people were developing these incredible fungal infections from the athlete's feet that was just in here on the floor everywhere, coupled with the erosion of their skin from the caustic detergents scum used on the floors, creating fissures, and they were beginning to develop cellulitis of their feet and legs and then superficial vein thrombosis and then deep vein thrombosis until finally the leg and the circulation was destroyed within a decade from being in these buildings.¹¹⁷

Since institutions did not expect disabled people to achieve anything or live independently, many disabled people did not think they were capable of thinking and acting for themselves. In institutions many people lost skills and abilities they had previously possessed. In 1978 the court case *Halderman v. Pennhurst* revealed that Pennhurst State School and Hospital was "not only not conducive to learning new skills, but it is so poor that it contributes to losing skills already

¹¹⁶ Chamberlin, *On Our Own*, 71.

¹¹⁷ Bronston, 2001-2, interview by Kathy Cowan, 72.

learned.”¹¹⁸ The original plaintiff in the case, Terri Lee Halderman, had been admitted to Pennhurst in 1966 when she was twelve and in her eleven years there she lost the ability to speak.¹¹⁹ The parents of Robert Hight, another plaintiff in the case, visited him two weeks after he had been admitted to Pennhurst and found that he was unable to recognize them and had lost skills he previously had.¹²⁰ In the 1960s David Vail, a doctor and advocate for the reform of institutions, met with a patient named Jane. Jane had been diagnosed with schizophrenia and was institutionalized for thirty-four years. When they came to a locked door Vail asked her if she would like to unlock the door had difficulty doing so, because she had not had to unlock a door while institutionalized. When Vail asked her what kind of candy bar she would like, she did not choose a specific one until Vail told her to choose. He surmised that the reason Jane was unable to make her own decisions was because had never been allowed to do so for the thirty-four years she had been institutionalized. Vail explained that she

had been herded sheep-like from one building to another, and on the hour told when to eat (food chosen by others), what to wear (clothing selected by others) when to take a walk and where, when to wash, when to take a pill, when to go to church and where, when to go see a movie or a television program (chosen by others), when to go to work and where...and so on in every aspect of her existence!¹²¹

Jack McCabe brought his uncle Ken to live with him after he was released from an institution after twenty-nine years. McCabe, who had also been institutionalized, found that Ken had a difficult time adjusting to living outside an institution. He was reluctant to go anywhere by himself, had a difficult time finding a job, and never asked for anything, but waited until it was offered to him. Ken's doctor said that “The prospect of undoing the hardened accretion of those

¹¹⁸ *Halderman et al. v. Pennhurst State School & Hospital et al.*, 446 F. Supp. 1295 (U.S. District Court, E.D. PA, 1978).

¹¹⁹ Halderman, 446.

¹²⁰ *Ibid.*

¹²¹ David Vail, “Vertical Extraction,” in *Blue Jolts: True Stories from the Cuckoo's Nest*, ed. Charles Steir (Washington D.C.: New Republic Books, 1978), 141.

years of hospital life, of dissolving the 'institutional syndrome,' of eradicating the 'brain-washing' effect of patienthood, was bleak."¹²² His doctor believed that "The condition was a definable pathology all by itself, overshadowing in the end whatever malady had made hospitalization seem necessary to begin with."¹²³

Attempting to Leave Institutions

Oftentimes, institutionalized disabled people were aware of the abuse they suffered and how they were disadvantaged because of the time they spent in institutions. This made them attempt to leave. Many disabled people who had been institutionalized went to great lengths to keep from going back. In the late 1970s in California, Lyn Thompson, who had muscular dystrophy, was told that Medicaid would no longer pay for her health insurance and personal attendant. According to Medicaid law she was not truly disabled because she made over two hundred and forty dollars a month from the answering service she ran at her house, and thus was not eligible for Medicaid disability benefits. She would have to be institutionalized, which had happened when she was younger, and she did not want to go through again. She took her own life in February 1978.¹²⁴ Institutionalized people protested their situation and the way they were treated. At Caswell Training School in North Carolina three female patients burned down their dormitories in December 1918 and January 1919.¹²⁵ In the early 1900s, at St. Elizabeth's Hospital in Washington D.C. patients often refused to work, asked to be paid for their labor, damaged property, assaulted the staff, and attempted to escape.¹²⁶ Many institutionalized people

¹²² John Neary, "Institutionalism," in *Blue Jolts: True Stories from the Cuckoo's Nest*, ed. Charles Steir (Washington D.C.: New Republic Books, 1978), 225.

¹²³ Neary, "Institutionalism," 225.

¹²⁴ Fleischer and Zames, *The Disability Rights Movement*, 34-5.

¹²⁵ Noll, *Feeble-Minded in our Midst*, 131.

¹²⁶ Gambino, "The Savage Heart Beneath the Civilized Exterior."

tried to leave institutions. Karen Gorr, who had cerebral palsy, was institutionalized at the South Dakota State School and Hospital for the Feebleminded for ten years in the 1940s and 1950s. There she was beaten by the staff frequently, often because she was unable to finish eating her food in fifteen minutes. She begged her mother Mabel to take her home because she was afraid she would be killed. When she was thirteen, her mother promised to let her come home and promised she could stay if she learned to walk. Karen was determined to earn her freedom and learned to walk. She learned because she was allowed to eat her food slowly and she gained weight and physical strength.¹²⁷ Lucy Gwin, who was institutionalized at New Medico after a traumatic brain injury, escaped New Medico after hearing that she was scheduled for brain surgery to cure her of her supposed seizures, even though she did not have seizures. When a friend came to visit her she had him drive her away.¹²⁸ Russell Daniels was sent to a state school in 1958 when he was twelve where “they treat you like dirt. You don't get treated like a human being. They treat you mean, like, you know, you do something, they slap you.”¹²⁹ He escaped when he was seventeen. The police found him and brought him back, where he was put into isolation. He did not leave permanently until he was twenty-eight.

Disabled people and Deinstitutionalization

The majority of institutionalized disabled people and the greater disability rights movement supported deinstitutionalization because they believed institutions to be abusive and harmful. They knew that many disabled people still needed support, so they supported community-based programs that reinforced disabled people's humanity and fostered

¹²⁷ “The Self-Advocacy Movement 1980 -,” The Minnesota Governor's Council on Developmental Disabilities, <https://mn.gov/mnddc/parallels/six/6d3/2.html>.

¹²⁸ Pelka, *What We Have Done*, 87.

¹²⁹ “The Self-Advocacy Movement,” <https://mn.gov/mnddc/parallels/seven/7d3/1.html>.

independence. Deborah Kaplan is a disability rights activist and attorney who became paralyzed after a car accident. She believed that what makes community services for disabled people successful “depends on how much resources go into the community services and how supportive they can be. Some people need--because they lack a lot of the ability to make their own decisions--more support in making decisions and in how they live their daily lives, but that can be provided in a small group setting as well as in an institution.”¹³⁰ This belief was reflected in the experiences of disabled people. In 1992 Maria Bell moved to a group home with People Inc. Agency, which helped to integrate disabled people into their communities. At People Inc., Bella recalled, “There’s nobody to tell me what to do, when to eat, when to go to bed, when to wake up, when to take medicine. There’s nobody there to tell me that. I do it all myself. I like living by myself.”¹³¹

However, not all group homes were positive experiences for disabled people. James Meadours, a developmentally disabled disability rights activist, lived in a group home that he disliked because it was controlling. There he was only allowed to go into the community if he earned a certain number of tickets for so-called good behavior. They took away his computer if he didn’t keep his area of the group home clean. He was only able to leave the group home to go to mass at the nearby Catholic Church, until the manager of the group home stopped him from doing that too.¹³² Group homes are not inherently positive, but what many disabled people said they liked about them was that they had freedom to make their own choices and to be treated with the same respect as able-bodied people and what they disliked was being controlled. Kaplan

¹³⁰ Deborah Kaplan, 1998, interview by Sharon Bonney. Disability Rights and Independent Living Movement Oral History Project, Regional Oral History Office, University of California. The Bancroft Library, Berkeley, CA.

¹³¹ "History from Institutionalization to Independent Living."

¹³² Self Advocacy History, “James Meadours on Group Home Experiences.”

argued that the quality of care disabled people receive in group homes “depends on how much resources the state puts into the group home and how much monitoring they do of the quality there. A group home doesn't guarantee anything, it's just a better way to go, provided that there's oversight and there's clear standards of quality that relate to choice and freedom for people.”¹³³ Because the majority of disabled people opposed institutions, they worked to achieve deinstitutionalization. Disabled people were able to bring about deinstitutionalization through their work to destigmatize disability, their efforts to create independent living communities, their activism, and their participation in lawsuits against institutions.

Destigmatization of Disability

During the 1960s and 1970s the way disability was seen in society changed and disability became less stigmatized. This change occurred because disabled people became more visible and active in society. This affected the way society viewed disability, the way parents viewed their disabled children, and the way disabled people viewed themselves. One example of the destigmatization of disability was the changing perception of posttraumatic stress disorder. Posttraumatic stress disorder first appeared in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in 1980.¹³⁴ It was meant to only refer to soldiers' experiences. During World War I, British soldiers who appeared to suffer from the stress of combat were originally diagnosed with shell shock, though this diagnosis was later discouraged to limit the number of cases.¹³⁵ There was a controversy among doctors and psychiatrists as to what caused this disorder to appear in certain people. Some believed that people pretended to

¹³³ Kaplan, 1998, interview by Sharon Bonney, 83.

¹³⁴ Marc-Antoine Crocq and Louis Crocq, “From Shell Shock and War Neurosis to Posttraumatic Stress Disorder: A History of Psychotraumatology,” *Dialogues in Clinical Neuroscience* 2, no. 1 (2000): 47. doi: 10.31887/DCNS.2000.2.1/macroq.

¹³⁵ Crocq, “From Shell Shock and War Neurosis to Posttraumatic Stress Disorder,” 50.

have posttraumatic symptoms to be removed from combat, while some others thought that there were physical explanations, such as concussions or nerve injuries. Others thought that the posttraumatic symptoms were psychological, but there was to debate on if they were solely caused by combat or if people who had these symptoms were predisposed to mental illness because of personal weakness or childhood traumas.¹³⁶ Suffering from posttraumatic stress was heavily stigmatized and victims of shell shock were thought of as cowards. The Vietnam War brought more attention to what would be called posttraumatic stress disorder. During World War II and the Vietnam War attempts were made to keep people who had pre-existing psychological problems from enlisting in the army in hopes that this would prevent soldiers from developing PTSD. Despite these efforts, soldiers continued to develop psychological reactions to fighting in the war. Around 700,000 Vietnam veterans – nearly one fourth of all Vietnam veterans – needed psychological help after returning from the war.¹³⁷ Fifteen years after the war, 480,000 Vietnam veterans suffered from PTSD.¹³⁸ This proved that all men in combat were vulnerable to experiencing psychological responses to trauma. Eventually people came to believe that anyone who experienced trauma could develop posttraumatic stress disorder. This led to a growing awareness and destigmatization of PTSD. Disability came to be more commonly seen as something that could affect anyone and did not need to be hidden. This belief gave support to community services for disabled people and independent living, while deemphasizing institutionalization. George Paulson, a doctor at institutions, believed that “the renewed emphasis on trauma and stress as a factor involved in mental health and illness may even have enhanced

¹³⁶ Ibid., 51.

¹³⁷ Ibid., 53.

¹³⁸ Hans Pols and Stephanie Oak, “WAR & Military Mental Health: The US Psychiatric Response in the 20th Century,” *American Journal of Public Health* (1971) 97, no. 12 (2007): 2137-8.
 doi:10.31887/DCNS.2000.2.1/macroq.

the demedicalization of mental illness.”¹³⁹ Paulson argues that the demedicalization of disability contributed to deinstitutionalization. The destigmatization of disability helped to lead to deinstitutionalization.

Parents were affected by the changing way disability was perceived. Until the 1960s, parents were taught to institutionalize their children and feel ashamed of them. Parents were urged to send their children to institutions and were brushed off by doctors when they expressed concerns about their children. At many institutions they were not allowed to see their children often or at all. It was also difficult for parents to receive support besides institutionalizing their children. A doctor told a poor, single mother named Mabel Gorr, whose daughter Karen had cerebral palsy and son David suffered a traumatic brain injury that caused him to have blackouts to “take [her children] to a high cliff and push them over the side.”¹⁴⁰ In the 1940s Karen and David were placed in the South Dakota State School and Hospital for the Feeble-minded where David died during a blackout and Karen was abused. In the 1960s, a poor, rural family in Tennessee did not want their disabled son to be institutionalized, but they were coerced into sending him to the Arlington Developmental Center. The “staff had to practically rip him away from the family.”¹⁴¹ He later died at Arlington from gangrene from an untreated infection.

Some parents were unwilling to care for their disabled children. Pattie Burt said, “I think me going to Empire was just plain ignorance and laziness and stupidity from my family. They didn't want to help me. Throw me in a stupid school like that.”¹⁴² In 1983, during the middle of

¹³⁹ Paulson, *Closing the Asylums*, 63.

¹⁴⁰ “The Independent Living Movement 1970 -,” The Minnesota Governor's Council on Developmental Disabilities, <https://mn.gov/mnddc/parallels/six/6d3/1.html>.

¹⁴¹ “The Threads that Came Together in the Pennhurst Case,” The Minnesota Governor's Council on Developmental Disabilities, .

¹⁴² Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 115.

the deinstitutionalization movement, a group of parents of developmentally disabled people founded The Voice of the Retarded, a national organization whose goal was to keep institutions open.¹⁴³ Judith Gran, a lawyer who worked on many court cases about deinstitutionalization, found that there were generally two groups of parents who institutionalized their children. One was typically upper middle class and white families who valued perfection and a cure for disabilities. They often attempted to cure their disabled children and when they failed, they became angry and hopeless. They would reject their child and institutionalize them. The other group was typically working-class families, who were often racial and ethnic minorities, who wanted to keep their children and home but did not have the resources to care for them. They generally only institutionalized their children when they had no other options.¹⁴⁴ When parents from the latter group realized that their disabled children could live in their community and were given resources to care for them, they often enthusiastically supported deinstitutionalization. Parents frequently learned of this possibility from disability rights activists and disabled people. Due to growing disability rights activism, parents found that their disabled children could lead productive and fulfilling lives. They also learned more about the abusive ways disabled people were treated in institutions and worked to put an end to it. Diane Lipton was an able-bodied disability rights activist whose daughter Chloe was born with cerebral palsy. When she went to the Berkeley Center for Independent Living in Berkeley, California (Berkeley CIL), which helped disabled adults live independently:

It was the first time in my life I'd ever seen people with disabilities, and pretty significant disabilities, like working, and on the phone, and just, kind of, doing a normal job kind of thing... Then to get to know a few of the people and realize they lived in their own

¹⁴³ "The Threads that Came Together in the Pennhurst Case."

¹⁴⁴ Ibid.

apartments, they had crazy relationships like everyone else. They were just living and working like everybody else. I never could even picture that for Chloe before that.¹⁴⁵

Diane Lipton became involved with the Disability Law Resource Center which was a legal advocacy unit connected with the Berkeley CIL. She helped parents advocate for their disabled children's rights to education and community services. Parents also learned from their disabled children that disabled people could have fulfilling lives. Nancy, who had been institutionalized for hearing the voice of her ex-girlfriend asking her for help, confronted her father about how he had been mistreating her since she had been institutionalized. He realized that he had been wrong and began to change. He told her, "It's been a privilege to watch you grow and change."¹⁴⁶ When parents advocated for their disabled children, they were able to bring awareness to the abuse and discrimination they faced and helped lead to deinstitutionalization.

While it had been encouraged to hide disabled people away in situations, by the 1970s it had become more acceptable for parents to care for their disabled children at home and for disabled adults to live independently in their communities. This shift occurred because of the greater visibility of disabled people who were able to live and thrive outside of institutions. The growing disability rights movement also showed society that disabled people were capable of thinking and acting for themselves. William Bronston, a doctor at Willowbrook who was involved in the disability rights movement, observed that this change occurred because "as the children with congenital disabilities...who are now in their twenties, in the early 1970s hit the street, you have the burgeoning of a whole new consciousness, a whole new youth movement that is speaking to needing to carve a major place, dignity, and a rightful role in society."¹⁴⁷ The

¹⁴⁵ Diane Lipton, 2001, interview by Denise Jacobson, Disability Rights and Independent Living Movement Oral History Project, Regional Oral History Office, University of California. The Bancroft Library, Berkeley, CA. 29.

¹⁴⁶ Chamberlin, *On Our Own*, 71.

¹⁴⁷ Bronston, 2001-2, interview by Kathy Cowan, 110.

disability rights movement was inspired by the Civil Rights movement, women's movement, and gay liberation movement. Disability rights activists used some of the same techniques that earlier civil rights movements had used, including consciousness-raising and focusing on self-determination.¹⁴⁸ The broader public was also inspired by these movements and realized that disabled people faced oppression in the same way that other groups did. According to Linda Morrison, "the notion that [disabled people] were human beings with human rights was resonant with the public outcry about rights for women, blacks, homosexuals...and other oppressed groups that were organizing for change."¹⁴⁹ Disability rights activists made society see disabled people as capable of acknowledging their oppression and demanding their rights. William Bronston observed that disabled people "didn't want to be 'dependent,' safely, dependent like the developmental disability movement. They didn't want to be patronized. They wanted to call their own shots, they wanted their own apartments, they wanted their own accessibility...they wanted to be part of America."¹⁵⁰ Ray Uzeta, who was quadriplegic, founded the Community Center for the Disabled in California. He said that by the 1970s, "Those of us with physical disabilities were getting kind of resentful, being treated as children, being treated as little crippled people who needed to be taken care of."¹⁵¹ Institutionalized disabled people also showed able-bodied people that they were intelligent and capable. In the early 1950s Terry Schwartz was institutionalized at Fairview Training Center in Oregon where he and other patients frequently did work that the staff would not or could not do. When "they found out we're smart enough—we took over

¹⁴⁸ Judi Chamberlin, "The Ex-Patients' Movement: Where We've Been and Where We're Going," *The Journal of Mind and Behavior* 11, no. 3/4 (1990): 1.
https://web.archive.org/web/20110727115541/http://ebp.networkofcare.org/uploads/Judi_Chamberlin_Article_9583578.pdf. 1.

¹⁴⁹ Morrison, *Talking Back to Psychiatry*, 67.

¹⁵⁰ Bronston, 2001-2, interview by Kathy Cowan, 112.

¹⁵¹ Pelka, *What We Have Done*, 119.

Fairview. When most staff don't know how to work, a lot of times we do. And so they said, 'Hey, these people are smarter than we think they are.'"¹⁵²

Disability rights activism also empowered disabled people to take pride in themselves and demand their own rights. Terry Schwartz was a leader in People First, a self-advocacy organization movement in Portland that was founded in 1974. He said that the goal of People First was "to let us know that we had just as much rights as anybody else. So if we can do a job, we have the right to do a job."¹⁵³ People First held a conference in 1974 and expected a few hundred people, but around 600 people came. People who had never spoken about their experiences publicly before did so at the conference and were listened to for the first time. Patrick Worth, who was developmentally disabled, said that "People First helped me...People First stands for active involvement, citizens, real jobs, doing real work, respect, being seen as people with power over our lives, learning new things, making friends...We want to be part of the community. People First taught me what real self-advocacy means."¹⁵⁴

For many disabled people, meeting with other disabled people contributed to their conscious raising. They learned how they faced oppression and what they could do about it. They also found a sense of community where they were not alone. Judi Chamberlin, who was diagnosed with schizophrenia after miscarrying a child and was committed to a series of hospitals in the mid-1960s including Bellevue and Rockland State, cofounded the Mental Patients' Liberation Front (MPLF) in 1971. Their goal was to improve the lives of formerly and currently institutionalized people who had been diagnosed with a mental illness. The MPLF

¹⁵² Ibid., 58.

¹⁵³ Ibid., 333.

¹⁵⁴ "The Self-Advocacy Movement," <https://mn.gov/mnddc/parallels/seven/7d2/1.html>.

organized inside hospitals, particularly Boston State Hospital, where they met with patients once a week. Chamberlin, who after being institutionalized felt demoralized and inferior, wrote that “Of enormous help in digging through the layers of mystification has been my involvement...in a number of mental patients’ liberation groups, in which ex-patients have come together to validate our own pain and anger.”¹⁵⁵ These support groups brought ex-patients together and empowered them. Nancy, who had been institutionalized, went to a conference the MPLF held. Listening to other former patients talk about their experiences and opinions made her feel connected to a wider movement. She realized she could advocate for her rights too. After Nancy went to the conference she said “Now I’m fighting—for myself and others. I found a place I could plug in, where I could address myself to my most immediate oppression. It made me so happy.”¹⁵⁶ Phyllis, who had been diagnosed with a mental illness and institutionalized, met with a group of other former mental patients at a restaurant where they discussed their experiences with mental illness, hospitals, and medication. She felt empowered by discussing these topics with other people like herself and realizing that she was not alone. She said “And it was like, ‘Oh, we don’t have to be ashamed of this, we don’t have to be quiet. We don’t have to whisper it. We don’t only have to say it in hospital corridors. We can say this in a public restaurant!’ And it was very freeing and very healing. And from that I came away with a sense of ‘I’m not alone.’”¹⁵⁷ Disabled people were empowered by the destigmatization of disability and engaging with other disabled people. They began to advocate for alternatives to institutionalization and deinstitutionalization.

¹⁵⁵ Chamberlin, *On Our Own*, 5.

¹⁵⁶ *Ibid.*, 71.

¹⁵⁷ Morrison, *Talking Back to Psychiatry*, 125.

Independent Living

With the destigmatization of disability came growing support for independent living, where disabled people are able to live on their own with accommodations and support services. Many disabled people saw independent living as a favorable option to institutionalization. Independent living allows disabled people self-determination and the ability to make their own decisions. Independent living also gives disabled people access to services to help them live independently. One of the first independent living centers in America, the Berkeley Center for Independent Living (Berkeley CIL), was founded by Ed Roberts in Berkeley, California in 1972. In 1953, when Roberts was fourteen, he contracted polio and was paralyzed in most of his lower body. He was accepted to the University of California, Berkeley but the school tried to reverse his acceptance after they learned he was disabled. He insisted on attending and became the first wheelchair user to study at UC Berkeley.¹⁵⁸ At the university, Roberts created a group of physically disabled students, who were admitted after him, called the Rolling Quads. They moved into a dorm together and pressured the university to make all facilities accessible. This experience inspired Roberts to create a community that would allow disabled people to live independently. According to Fred Pelka, the Berkeley CIL's driving belief "was the then-radical notion that people with disabilities were the experts on their experience and could best decide for themselves what services they needed and how to use them."¹⁵⁹ At least 51 percent of the staff and board of directors at the Berkeley CIL had to be disabled. Roberts explained that "Most people never thought of independence as a possibility when they thought of us. But we knew

¹⁵⁸ Edward V. Roberts, 1994, interview by Susan O'Hara, Disability Rights and Independent Living Movement Oral History Project, Regional Oral History Office, University of California. The Bancroft Library, Berkeley, CA. 3.

¹⁵⁹ Pelka, *What We Have Done*, 198.

what we wanted, and we set up CIL to provide the vision and resources to get people out and into the community. The Berkeley CIL was revolutionary as a model for advocacy-based organizations; no longer would we tolerate being spoken for... This was the vision we had for the future of the movement."¹⁶⁰ Many disabled people were inspired by the Berkeley CIL. Cathrine Caulfield, who was paralyzed, said that the Berkeley CIL "helped me realize a full and active life was possible."¹⁶¹ The Berkeley CIL inspired disabled people across the country to form their own independent living centers. One place this occurred was in Boston.

In 1974, the Boston Center for Independent Living (BCIL) was established by Fred Fay, a quadriplegic disability rights activist; Paul Corcoran, an able-bodied rehabilitation doctor; and Robert McHugh, an able-bodied rehabilitation counselor.¹⁶² Fred Fay worked at Lennox Hill Nursing Home and seeing the conditions there also inspired him to start an independent living community.¹⁶³ Before helping to establish the BCIL, Paul Corcoran realized the importance of listening to disabled people after meeting disability rights activists. He met paralyzed activist Julius Shaw at a bar and admitted that he had never had a social encounter with a disabled person before. Shaw "was pretty annoyed at me. He said, 'You call yourself a rehabilitation specialist? You've never even had a meal with a person with a disability? You've never been to the home of a person with a disability? What kind of a rehabilitation doctor are you, anyway?'"¹⁶⁴ Shaw also introduced Corcoran to a blind woman named Eunice Fiorito who "invited me over to her house for dinner, and I saw how a person who lives alone or who's totally blind can organize their

¹⁶⁰ Fleischer and Zames, *The Disability Rights Movement*, 39.

¹⁶¹ Pelka, *What We Have Done*, 205.

¹⁶² Fleischer and Zames, *The Disability Rights Movement*, 43.

¹⁶³ Fay, 2001, interview by Fred Pelka, 58.

¹⁶⁴ Paul Corcoran, 2001, interview by Fred Pelka, Disability Rights and Independent Living Movement Oral History Project, Regional Oral History Office, University of California. The Bancroft Library, Berkeley, CA. 116.

home and live independently.”¹⁶⁵ The BCIL was started in the dorms of Boston University and was paid for by Medicaid. The BCIL “had figured out a way to funnel Title XIX money out of nursing homes--which everyone thought of as the bad boy. Take the money away from the bad guys, and give it to the good guys; that was the wonderful thing, and we were aware of it.”¹⁶⁶

The BCIL received money from Medicaid for each of their clients and BCIL gave that money to the disabled client so they could pay their personal care assistant. This was important to them because it reinforced that the personal care assistant was working for the disabled person and helped empower the disabled person.¹⁶⁷

In New York City, in the 1970s, formerly institutionalized people founded Project Release which was an entirely patient-run group that helped formerly institutionalized people find safe and inexpensive places to live. Their housing program helped members find their own apartments, either by themselves or with other members. A member of Project Release said they liked this program because “we are always being shunted from one form of institution to another or just put back into the same living situation that caused many problems in the first place. Why can't we just live in our own apartments, like other people? Contrary to most 'experts' opinions we can and we are.”¹⁶⁸ In 1976 Project Release received a ten-thousand-dollar foundation grant and rented an apartment and opened a community center. The community center was a gathering place for members and prospective members of Project Release. People were there at all hours and every day of the week. Each night they had a community meal. A member said that “Project Release exists in opposition to the whole self-perpetuating bureaucracy of 'Mental Health' care

¹⁶⁵ Paul Corcoran, 2001, interview by Fred Pelka, 116.

¹⁶⁶ Ibid., 132.

¹⁶⁷ Ibid.

¹⁶⁸ Chamberlin, *On Our Own*, 98.

in this society...Here, you can learn a whole different way of being; you begin to trust yourself and your reactions. Instead of feeling coldness at your core, you feel warmth and strength.”¹⁶⁹

Independent living showed society that disabled people were capable of living by themselves if they were given the resources. This led to less of a demand for institutions and contributed to deinstitutionalization.

Activism

With the notion that disabled people were capable of independent thought and action becoming more popular, able-bodied people became more horrified at the abuse disabled people faced in institutions. This, along with the activism of disabled people, also helped to bring about deinstitutionalization. Formerly institutionalized disabled people worked directly to shut down institutions. People who had survived abuse from psychiatrists on the basis of their supposed mental illnesses raised awareness of the abuse they had suffered and tried to stop it from happening again. Psychiatric survivors created support groups, such as “We Are Not Alone” in New York City, in the 1940s and 1950s but the infrastructure of the psychiatric survivor activism movement did not develop until the 1970s.¹⁷⁰ The Mental Patient Liberation Front was founded in 1971 by formerly institutionalized people who had been diagnosed with mental illnesses. The MPLF ran a weekly group discussing current events with patients at the Boston State Hospital, and Judi Chamberlin recalled “which informally developed into a patients’ rights meeting, since this was the main subject everyone wanted to discuss.”¹⁷¹ Because of this the hospital administration attempted to stop the MPLF from meeting with patients, but a group of patients

¹⁶⁹ Ibid., 97.

¹⁷⁰ Pelka, *What We Have Done*, 238.

¹⁷¹ Chamberlin, *On Our Own*, 194.

started a petition that over eighty percent of all patients signed. The MPLF and patients were allowed to continue meeting. The MPLF also operated a drop in center where former patients could come to connect with each other and find information about housing, welfare, and support.¹⁷²

Another advocacy group for survivors of institutions was the Network Against Psychiatric Assault (NAPA), which was cofounded by Leonard Roy Frank in California in 1974. Frank said they “wanted to make fundamental changes in the entire psychiatric system and were opposed to this whole notion of mental illness.”¹⁷³ In order to promote their message, they published a magazine called *Madness Network News* (MNN). The first issue of MNN was published in August 1972.¹⁷⁴ Early issues of MNN were written by former patients, current patients, mental health workers, lawyers, psychiatrists, and, according to an issue of MNN, “all those who shared common goals such as the abolishment of all forced ‘treatments’ and forced psychiatric incarceration and institutional psychiatry itself; and saw this as a part of a larger and broader movement to make basic changes in the nature of our world . . . one being the de-institutionalization of life.”¹⁷⁵ Later, the magazine was only written by former and current patients because they felt they were the most capable about writing about the issues they faced. The goal of MNN was “to ‘Break the Silence’: making private problems into public issues, exposing the abuses of psychiatry, educating people about the effects of psychiatric drugs, encouraging connections and dissent among those who had survived psychiatry and wanted to support each other both inside and outside the hospital.” NAPA distributed copies of MNN for

¹⁷² Ibid., 195.

¹⁷³ Pelka, *What We Have Done*, 235.

¹⁷⁴ Morrison, *Talking Back to Psychiatry*, 67.

¹⁷⁵ Ibid., 78.

free at local hospitals and psychiatric wards.¹⁷⁶ NAPA also lobbied for legislation to restrict the use of electroshock therapy and lobotomies. John Vasconcellos, a California assemblyman who was a friend of NAPA members, sponsored legislation that restricted the use of electroshock treatment and nearly eliminated the use of lobotomies.¹⁷⁷ In 1982, NAPA held a demonstration in front of Herrick hospital in Berkeley protesting their use of electroshock treatment. A city council member invited them to speak at a hearing with the Human Relations and Welfare Commission where survivors of electroshock treatment testified about how it had harmed them. This was covered by local television stations and newspapers. It turned people against doctors who practiced electroshock treatment.¹⁷⁸ NAPA lobbied to put a measure to ban electroshock treatment on the ballot. Doctors spent over \$15,000 on a campaign to gain support for electroshock treatment. Ted Chabasinski remembered that the doctors “couldn’t come up with anybody who liked shock treatment, that was their problem. So they would say, ‘Shock treatment is life-saving’ and, ‘Don’t deprive us of this wonderful tool to help people’ and blah blah blah. But the average person on the street thought it was barbaric.”¹⁷⁹ The measure passed with 62% of the vote and electroshock therapy was banned.¹⁸⁰

In 1975 Judi Chamberlin and other disability rights activists, the majority of whom had been institutionalized for mental illness, held a protest outside St. Mary’s Hospital in San Francisco. Judi Chamberlin recalled that the activists felt that they were “united in confronting an outside enemy—St. Mary’s ‘Hospital,’ both as an individual oppressive institution and as a symbol of the mental prisons nearly all of us had experienced...we listened to moving speeches

¹⁷⁶ Pelka, *What We Have Done*, 236.

¹⁷⁷ *Ibid.*, 236-7.

¹⁷⁸ *Ibid.*, 294.

¹⁷⁹ *Ibid.*, 296.

¹⁸⁰ *Ibid.*

by ex-patients from many parts of the country and practiced the chants that would resound all along the lengthy march route. 'What do you want? FREEDOM! When do you want it? NOW!' 'Two, four, six, eight. Smash the therapeutic state!'"¹⁸¹ The activists felt that this experience was unifying and a turning point for the movement. In 1977 President Carter created the President's Commission on Mental Health. In 1978 hearings were held where people, including activists for the rights of mentally ill and institutionalized people, testified on their experiences and recommendations about the mental health industry. Judi Chamberlin said that these activists "testif[ied] eloquently about the harmfulness of the psychiatric treatments they had experienced while pleading for enforcement of patients' rights and funding of patient-run alternatives to traditional treatment."¹⁸² The commission's final report acknowledged that many mentally ill people preferred treatments that did not involve institutionalization.¹⁸³

Another self-advocacy group was Speaking for Ourselves in Pennsylvania, which advocated for the rights of developmentally disabled people, raised awareness about the abusive conditions of institutions and helped to close them. In the late 1970s Mark Friedman, an able-bodied disability rights activist, watched a film that showed the conference People First had held in Oregon in 1974. Friedman recalled that he "was just extraordinarily moved to being teary eyed by that film and a notion that people who were perceived to be voiceless could gain a voice and the people could be organizing and could be in charge of having their own conference."¹⁸⁴ He decided to help start a similar group in Pennsylvania. He went to the local Association for Retarded Citizens and met with five intellectually disabled adults who "were very interested in

¹⁸¹ Morrison, *Talking Back to Psychiatry*, 77.

¹⁸² Chamberlin, "The Ex-Patients' Movement," 4.

¹⁸³ *Ibid.*

¹⁸⁴ Mark Friedman, January 20, 2012, interview by Lisa Sonneborn. *Visionary Voices*, Institute on Disabilities at Temple University, chapter 2.

the idea of putting on their own conference and bringing people together.”¹⁸⁵ One of the disabled members named the group Speaking for Ourselves. They continued to meet, and the number of members increased. Around 90 percent of Speaking For Ourselves’ members had been institutionalized.¹⁸⁶ Some members were residents of institutions while they were a part of Speaking For Ourselves. The president of the Philadelphia chapter, Roland Johnson, was central to the movement. Johnson had been institutionalized and abused at Pennhurst State School and Hospital for thirteen years. At a disability rights conference where the majority of participants were able-bodied, he told them he wanted to see more self-advocates at the next conference. The able-bodied people brought self-advocates to the next conference.¹⁸⁷

At this time, many able-bodied people were skeptical that developmentally disabled could be leaders in the disability rights movement. Steve Eidelman, the Director of Mental Retardation Services in Philadelphia, believed that “Roland showed us that people with an intellectual disability could lead, and could lead without being - someone pulling their strings, could lead from the heart, and could again articulate in a very clear way why things had to change.”¹⁸⁸ Johnson was also instrumental in Speaking For Ourselves’ work to close institutions. Debbie Robinson, a member of Speaking For Ourselves who became the president of the Philadelphia chapter after Johnson decided not to run for the position again, said that deinstitutionalization was “one of [Johnson’s] main goals and he’s always said it and it stuck to everybody’s mind that knew him: ‘Free my people. I want institutions closed, every single one’ ... There was no if, ands, butts about it and somebody had to take the lead and we did. We

¹⁸⁵ Mark Friedman, January 20, 2012, interview by Lisa Sonneborn, chapter 2.

¹⁸⁶ Debbie Robinson, September 15, 2011, interview by Lisa Sonneborn. Visionary Voices, Institute on Disabilities at Temple University, chapter 4.

¹⁸⁷ Debbie Robinson, September 15, 2011, interview by Lisa Sonneborn, chapter 2.

¹⁸⁸ Steve Eidelman, October 26, 2011, interview by Lisa Sonneborn. Visionary Voices, Institute on Disabilities at Temple University, chapter 3.

took the lead.”¹⁸⁹ Closing institutions became a primary goal of Speaking For Ourselves. They received a grant that allowed them to visit institutions across Pennsylvania and observed the conditions, heard the residents’ stories, asked them if they wanted to leave, and told them how they could receive help if they left. They also testified at hearings and shared the stories they had heard. Speaking For Ourselves later expanded their efforts to closing institutions in other states as well. Several members, including Debbie Robinson, formed a national group called Self-Advocates Becoming Empowered, which is dedicated to closing institutions, developing community services for disabled people, and improving their lives and is still active today.¹⁹⁰

Many formerly institutionalized disabled people attempted to shut down institutions. After Lucy Gwin escaped from New Medico in 1989, she attempted to expose their abuse and shut them down. Immediately after escaping she reported them to the local police and FBI, but nothing came of it. She wrote letters to members of Congress who referred her to the Health Insurance Association. She, alongside Vicki Stephans, a doctor, and Jim Spall, a lawyer and brain injury survivor, gave a presentation about what happened in the brain injury rehab industry to the Health Insurance Association of America. After the presentation, a man in attendance told her, “You don’t really understand our industry, do you? The more we pay out, the more we can charge. So you’re not going to find anybody here who’s working against fraud.”¹⁹¹ Gwin also brought people to testify to the Commission on Quality of Care in New York State, where

People really poured out their stories...the parents and the former inmates were weeping and telling terrible, terrible stories that would break your heart. And the commissioners sat there, all listening, and they took notes, and whatnot, but afterwards one of them took

¹⁸⁹ Debbie Robinson, September 15, 2011, interview by Lisa Sonneborn, chapter 3-4.

¹⁹⁰ Ibid., chapter 4.

¹⁹¹ Pelka, *What We Have Done*, 321.

me aside and he said, "Now, my daughter works for New Medico, she's in their marketing department, and none of this could be true."¹⁹²

Gwin wrote to Ted Weiss, a congressman from New York, detailing the abuse she had witnessed at New Medico, and he got the FBI to investigate and chaired a committee that held a hearing on the conditions at New Medico.¹⁹³ New Medico went out of business in 1992.¹⁹⁴ By the 1970s "a national public policy of deinstitutionalization was promoted by...alleged violations of patient rights and the perceived ill effects of long-term institutional care."¹⁹⁵ This occurred because of the activism of formerly institutionalized people.

Lawsuits

Lawsuits against institutions were also influential in bringing about deinstitutionalization. Most of these lawsuits were brought by residents or their families. Court cases established humane standards of treating people in institutions and showed the progression of how courts and society viewed the rights of disabled people. Many lawsuits were precipitated by media exposés of the abuse people faced in institutions. Institutionalized people were aware of the importance of raising awareness. Ed Murphy, who was institutionalized at Empire State School (a pseudonym) in the 1960s said that "You take a lot of crusaders, though, like local politicians, they go over to the state school and do a lot of yelling. They only do it when someone forces them to, like when someone gets something in the paper about someone being beaten, or is overdosed bad."¹⁹⁶ The increased awareness of abuse in institutions caused able-bodied people to understand the importance of closing institutions. Institutionalized people were aware of the

¹⁹² Ibid.

¹⁹³ Ibid., 322.

¹⁹⁴ Ibid., 538.

¹⁹⁵ *Nomination Form, Commonwealth of Massachusetts*, 21.

¹⁹⁶ Bogdan and Taylor, *The Social Meaning of Mental Retardation*, 60.

courts' importance. Seymour Krim, who was institutionalized, said "Had I to [be institutionalized] over again, I believe I would now have the guts to threaten such an institution or psychologist with a lawsuit, ugly as such a procedure can be to a person already vulnerable with the harsh-marks of one legally defined 'psychotic episode' and the contemplation of the criminal act of suicide."¹⁹⁷ George Paulson, a former doctor at two institutions, wrote that "The fear of personal lawsuits, some of which are now initiated by patient advocacy groups, has not affected psychiatrists to the extent it affected surgeons, but awareness of such threats served to enhance the phenomenon of early release and served to prevent extended hospitalizations."¹⁹⁸ Deborah Kaplan, a disability rights activist and lawyer, worked at the Disability Rights Center in Washington in the 1970s where she taught people how to file complaints against institutions.¹⁹⁹ The Mental Patient Liberation Front helped seven patients at Boston State Hospital to bring a lawsuit against the hospital "to try to improve conditions in the hospital, mainly around the issues of forced medication, restraint, and seclusion."²⁰⁰ All of the plaintiffs in the lawsuit were members of the group that met with the MPLF. The plaintiffs won the lawsuit and it established Massachusetts' patients right to refuse treatment.²⁰¹ In the 1970s, at Boulder River School and Hospital in Montana, people began calling for the hospital to be shut down after several patients had died. Janice Frisch, the Chief of Social Services at Boulder, wrote that "Boulder River School and Hospital, as an institution, should be closed. Institutions are not fit places for people to live. Institutions serve society, not the people they are stated to serve. They only remove from society problems with which it does not want to contend."²⁰² She also encouraged people to

¹⁹⁷ Krim, "The Insanity Bit," 49-50.

¹⁹⁸ Paulson, *Closing the Asylums*, 68.

¹⁹⁹ Kaplan, 1998, interview by Sharon Bonney, 61.

²⁰⁰ Pelka, *What We Have Done*, 289.

²⁰¹ Chamberlin, "The Ex-Patients' Movement," 5.

²⁰² *Nomination Form, Montana State Training School*. 32.

contact their legislators and urge them to close the hospital. In 1983, there were only 209 patients in the hospital, and it closed.

An influential case that shaped how disabled people were allowed to be treated in institutions was *Wyatt v. Stickney*. The first plaintiff in the case was Ricky Wyatt, a fifteen-year-old who was not mentally ill. He was committed to the Bryce State Hospital in Alabama because he was considered to be a juvenile delinquent. Patients from other hospitals in Alabama, Searcy Hospital and the Partlow State School and Hospital, later became other plaintiffs in the lawsuit.²⁰³ On April 13, 1972, U.S. District Court Judge Frank M. Johnson, Jr issued an opinion that required that the hospitals involved in the case implement standards on how to treat their residents. These standards said that residents would have the right to treatment that would “maximize [their] human abilities.”²⁰⁴ According to the standards, residents also had the right to dignity, privacy, and humane care. The institution would prohibit abuse of residents and investigate all accusations of abuse. The judge also required that a human rights committee oversee the institution and ensure that the standards were followed. The standards also outlined how no one would “be admitted to the institution unless a prior determination shall have been made that residence in the institution is the least restrictive habilitation setting feasible for that person [and] no mentally retarded person shall be admitted to the institution if services and programs in the community can afford adequate habilitation to such person.”²⁰⁵ All residents would have an individualized habilitation plan which listed their limitations and needs, their short-term and long-term goals, their plan for meeting these goals, a post-institutionalization plan, and criteria for release. These standards would come to be known as the Wyatt Standards

²⁰³ *Wyatt et al v. Stickney et al.*, 344 F. Supp. 387 (United States District Court, M. D., AL, 1972).

²⁰⁴ *Wyatt et al v. Stickney et al.*

²⁰⁵ *Ibid.*

and eventually became the standards for how to treat disabled people across the country.

According to a news report in 2003, *Wyatt v. Stickney* “placed emphasis on the downsizing of state institutions and the proliferation of community services.”²⁰⁶ The number of residents at the Partlow State School and Hospital decreased from around 2,200 in 1972 to under 400 in 1986. *Wyatt v. Stickney* remained in the courts until 2003, when U.S. District Court Judge Myron H. Thompson approved the original settlement and dismissed the appeal. When giving his final opinion Judge Thompson said “the enormity of what this case has accomplished cannot be overstated. The principles of humane treatment of people with mental illness and mental retardation embodied in this litigation have become part of the fabric of law in this country and, indeed, international law.”²⁰⁷

Another influential lawsuit was *New York State Association for Retarded Children v. Carey*, in which parents of residents at Willowbrook State School filed suit against the institution. In 1972, ABC News investigative reporter Geraldo Rivera headlined a television program called *Willowbrook: The Last Disgrace*. It exposed the abusive and dehumanizing conditions at Willowbrook and was watched by millions. William Bronston recalled that the exposé

hit TV New York and national ABC News audiences like a bomb...it was the world's worst thing that possibly could've happened from [Willowbrook's] perspective and possibly life saving for the "hostage" population. It was like the planes flying in on September 11 to the World Trade Center. It was the same kind of outrage and consternation of how can this be, right here under our noses, so many thousands of people violated.²⁰⁸

²⁰⁶ “The Legacy of Wyatt,” The Minnesota Governor's Council on Developmental Disabilities, <https://mn.gov/mnddc/parallels2/one/video/wyatt.html>.

²⁰⁷ *Wyatt et al. v. Sawyer et al.*, 219 F.R.D. 529 (United States District Court, M.D., AL, 2004).

²⁰⁸ Bronston, 2001-2, interview by Kathy Cowan, 101-3.

The program provoked anger among the public and parents of Willowbrook residents. In response to the public outrage, Willowbrook acted as if they would improve, but nothing fundamentally changed. According to William Bronston, Willowbrook “made a lot of cosmetic changes. They brought in a little more soap--but, you know, nothing significant really happened.”²⁰⁹ The state gave Willowbrook more money so it could fix its problems, which advocates for closing Willowbrook, including William Bronston, a doctor at Willowbrook, were disgusted by because “we didn't want it fixed, we wanted it closed once and for all. It was a concentration camp, you weren't going to rehabilitate this place. I was clear that what was missing was individualized, integrated community-based services.”²¹⁰ Parents of Willowbrook residents filed a lawsuit against the institution on March 17, 1972. The plaintiffs claimed that Willowbrook fostered an abusive and neglectful environment for its residents and violated their constitutional rights. In April 1973, U.S. District Court Judge Orrin G. Judd found that Willowbrook violated its residents’ constitutional right to protection from harm and granted an injunction which required Willowbrook to increase their number of staff, stop using restraints and seclusion, and provide regular reports on their progress meeting these conditions.²¹¹ The case proceeded to trial and was settled on April 30, 1975. Judge Judd signed the Willowbrook Consent Judgment which outlined how resident at Willowbrook had to be treated. According to the Consent Judgement, residents at Willowbrook were required to be provided with "the least restrictive and most normal living conditions possible."²¹² They were to be given individualized care, medical services, and opportunities for education and recreation. Willowbrook was

²⁰⁹ Ibid., 105.

²¹⁰ Ibid.

²¹¹ *New York State Association For Retarded Children, Inc., et al. v. Nelson A. Rockefeller, et al.*, 357 F. Supp. 752 (United States District Court, E. D. New York, 1973).

²¹² *New York State Association For Retarded Children, Inc., et al., v. Hugh L. Carey, et al.*, 706 F.2d 956 (United States Court of Appeals, 2nd Circuit, 1983).

prohibited from using physical restraints, having residents work to take care of the institution, and experimenting on residents. The Consent Judgement also required that Willowbrook's population be reduced from 5,700 to 250. This was done by relocating residents to community placements which would "ready each resident, with due regard for his or her own disabilities and with full appreciation for his or her own capabilities for development, for life in the community at large."²¹³ On September 17, 1987 Willowbrook closed. In the following ten years, nine more institutions in New York closed. By July 1998, in New York, nearly 31,900 developmentally disabled people lived in their communities, more than 58,600 received day services, and only 2,100 were in institutions.²¹⁴

In August 1972, six developmentally disabled residents of Minnesota state hospitals filed a lawsuit, *Welsch v. Likins*, alleging that the institutions they were in violated their constitutional rights. They argued that the abusive conditions in institutions violated the Cruel and Unusual Punishment Clause of the Eighth Amendment and that the institutions' failure to provide individualized programs of habilitation and community-based care violated the due process clause of the Fourteenth Amendment.²¹⁵ The Plaintiffs argued that "Hospitalization [should be used] only as a last resort... [because of] a right of least restrictive alternatives under the due process clause. They contend that defendants are obligated to seek out and develop community-based facilities for the placement of involuntarily committed retarded persons." In February 1974 U.S. District Court Judge Earl Larson ruled in favor of the plaintiffs. He drew on the decisions of *Wyatt v. Stickney* and *New York State Association for Retarded Children v. Carey* and said that

²¹³ *New York State Association For Retarded Children, Inc., et al., v. Hugh L. Carey, et al.*

²¹⁴ "Milestones in OMRDD's History Related to Willowbrook," The Minnesota Governor's Council on Developmental Disabilities, <https://mn.gov/mnddc/extra/wbrook/wbrook-timeline.html>.

²¹⁵ *Welsch et al. v. Likins et al.*, 373 F. Supp. 487 (U.S. District Court, D. MN, 1974).

Welsch v. Likins joined the “growing body of law recognizing a constitutional right to treatment for persons confined in various settings without having been found culpable of criminal conduct.”²¹⁶ Legal scholars Bruce Mason and Frank Menolascino wrote that “the logic of normalization and the developmental model which *Wyatt* and *Welsch* recognized suggests full implementation of habilitation can only be achieved in a non-institutional setting.

Institutions...can rarely normalize and habilitate the mentally retarded citizen to the extent of community programs created and modeled upon the normalization and developmental approach components of habilitation.”²¹⁷ These court cases provided the legal framework for shifting the idea of treatment for disabled people away from institutionalization and towards community services.

On May 30, 1974 former and current residents of Pennhurst State School and Hospital, in Spring Hill, Pennsylvania, filed a lawsuit against the institution. The abusive conditions at Pennhurst were brought to the public's attention because of a television exposé in 1968 by Bill Baldini called *Suffer the Little Children*.²¹⁸ The plaintiffs argued that the institution had violated their constitutional rights under the First, Eighth, Ninth and Fourteenth Amendments, as well as under federal civil rights laws and the Pennsylvania Mental Health and Mental Retardation Act of 1966. The plaintiffs “sought damages and broad equitable relief, including individualized habilitation and the relocation of all class members from Pennhurst into their communities.”²¹⁹ On December 23, 1977, U.S. District Court Judge Raymond J. Broderick ruled in favor of the

²¹⁶ *Welsch et al. v. Likins et al.*

²¹⁷ Bruce Mason, Frank Menolascino, and Lorin Galvin, “Mental Health - The Right to Treatment for Mentally Retarded Citizens: An Evolving Legal and Scientific Interface,” *Creighton Law Review*, no. 10 (1977): 156. <http://hdl.handle.net/10504/38948>.

²¹⁸ “The Threads that Came Together in the Pennhurst Case.”

²¹⁹ *Halderman et al. v. Pennhurst State School & Hospital et al.*, 995 F. Supp. 534 (U.S. District Court, E.D. PA, 1998).

plaintiffs. He found that the residents at Penhurst had constitutional rights to minimally adequate habilitation, to be free from harm, and to non-discriminatory habilitation.²²⁰ Judge Broderick's ruling was appealed several times in the following decade. In 1984, the parties settled, and under the terms Pennsylvania agreed to close Pennhurst by July 1, 1986.²²¹ Judith Gran, a disability rights lawyer, said that before the Pennhurst lawsuit "There were no community services for people with significant disabilities [in Pennsylvania] and actually the Pennhurst orders had the effect of developing the system for everybody."²²² In Judge Broderick's initial ruling in 1977, he drew on the decisions of *Wyatt v. Stickney*, *New York State Association for Retarded Children v. Carey*, and *Welsch v. Likins*.²²³ These lawsuits represented a turning point in how disabled people were treated in institutions and helped to cause deinstitutionalization. After Pennhurst began the process of deinstitutionalization, Department of Health and Human Services studied how deinstitutionalization had affected the former residents, their families, and their communities. The Pennhurst Longitudinal Study found that while 63 percent of families were strongly opposed to the relocation of their family members to their communities before the relocation, but afterwards, only four percent of these same respondents were strongly opposed, and 66 percent were strongly supportive.²²⁴ The study also found that the former residents who had moved to their community were "better off in every way we know how to measure."²²⁵

²²⁰ *Halderman et al. v. Pennhurst State School & Hospital et al.*, 446 F. Supp. 1295 (U.S. District Court, E.D. PA, 1978).

²²¹ *Halderman et al. v. Pennhurst State School & Hospital et al.*, 995 F. Supp. 534.

²²² Judith Gran, February 17, 2011, interview by Lisa Sonneborn. Visionary Voices, Institute on Disabilities at Temple University, chapter 3.

²²³ *Halderman et al. v. Pennhurst State School & Hospital et al.*, 446 F. Supp. 1295.

²²⁴ Bradley, Valerie J. and James W. Conroy, *The Pennhurst Longitudinal Study: Combined Report of Five Years of Research and Analysis* (Washington D.C.: United States Department of Health and Human Services, 1985), <https://aspe.hhs.gov/basic-report/pennhurst-longitudinal-study-combined-report-five-years-research-and-analysis>.

²²⁵ Bradley and Conroy, *The Pennhurst Longitudinal Study*.

In institutions, many disabled people experienced physical abuse, medical abuse, sexual abuse, controlling staff, racism, and neglect. They also experienced negative outcomes from institutionalization, including physical harm, regression, feelings of dehumanization, and had difficulty adjusting to life outside of institutions. Disabled people were opposed to institutionalization and helped to bring about deinstitutionalization. Their actions contributed to the destigmatization of disability which helped garner support for deinstitutionalization. They advocated for independent living and community services, which became alternatives to institutionalization. They also advocated for the abolition of harmful treatments and the closure of institutions. Disabled people brought lawsuits against institutions which caused their eventual closure. All of these actions contributed to deinstitutionalization.

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