**Case Study**

**The Life and Death of the National Leprosarium**

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In 1894, the State of Louisiana established a leprosarium on an abandoned plantation on a remote peninsula of the Mississippi River just below the city of Baton Rouge. The site, near Carville, included a dilapidated plantation house and a few primitive slave houses. The first seven patients had suffered in so-called pesthouses in New Orleans before being secretly transported by raft and deposited to fend for themselves at the site. The staff was temporary and intermittent until 1896, when nuns from the Daughters of Charity of St. Vincent de Paul came to the facility. The order has provided nuns since that time (Silvers 1999, 96).

The federal government purchased the site in 1921 as a temporary place of forced exile for anyone in the United States who suffered from leprosy. Victims nationwide were transported to the primitive facility to join Louisiana’s exiles. The government, unable to find a permanent location that did not inspire powerful resistance, eventually established Carville as the permanent site. A barbed-wire-topped fence around the property assured that no one was exempted from the then-prescribed treatment for the disease—exile for life. The exiles were removed from their families, denied the vote, prohibited contact with the opposite sex, ordered to assume false identities, separated from children they bore, imprisoned in the Carville bastille without trial if they escaped, and humiliated by having their outgoing mail sterilized and any money they touched chemically treated. Civil service workers at the facility were paid hazardous duty wages. According to one former patient, “This place has seen many a tear, rivers of tears. It has robbed many of us of life’s joys” (Silvers 1996, 96).

There appeared to be no upside to this exile, as no effective treatment existed for the disease. Most of the patients came involuntarily, and since the disease is chronic, but rarely fatal, most lived there for decades until their natural deaths. Hidden in the language of the 1917 act (PL 64-298) that created the Center was an upside: That act required the U.S. Public Health Service (USPHS) to receive “any person afflicted with leprosy for . . . care, detention, and treatment.” The language assured that victims would be detained, but it also promised lifetime care for victims of the incurable disease. The promise was amended in 1985 (PL 99-117) to assure simply that the USPHS “shall provide care and treatment (including outpatient care) without charge . . . to any person suffering from Hansen’s Disease who needs and requests care and treatment for that disease.” This entitlement, made the same year the Center stopped accepting new residential patients, promised free care for those who “need” it for “treatment for that disease,” presumably excluding care for old age and other diseases.

Change came slowly to the leprosarium. In the 1930s and early 1940s, when the patient population reached nearly 500, a number of buildings were constructed on the property. In 1941, a doctor at the facility, Dr. Guy Faget, instituted sulfone treatments that, for the first time, gave hope to those who suffered from the disease. Faget’s discovery was one of many highly significant medical discoveries made at the Center.

In 1945, the American Public Health Association (APHA) advised against isolating people with leprosy. It was by then well established that 90 percent of the population had a natural immunity to leprosy, and that it was only mildly contagious to the other 10 percent. In response, the most onerous rules at Carville were repealed. In 1946, patients were granted the franchise, and in 1948 the infamous barbed wire came down. In the 1950s, patients were allowed to marry. By 1953, patients with arrested symptoms were encouraged to leave.

The USPHS decided in the 1950s to close the Center and sent in a terminator, Dr. Eddie Gordon, as director. The resistance to closure from the patients, staff, and community must have been shocking. Gordon was forced out in less than three years. Closing the Center would be harder than expected, largely because “patients at the leprosarium possessed a considerable degree of power . . . they exercised it both within the institution and outside of it” (Gussow 1989, 177). Having cavalierly entered into a termination battle and lost, the USPHS took only tiny steps toward closure in the 1960s and 1970s. The last involuntary admission came in 1960.

In 1981, the USPHS launched another assault. Armed with an alarming budget deficit and a *political* philosophy that questioned the need for many government programs, the congressional subcommittee charged with making appropriations for the nation’s health programs joined the USPHS as it targeted the nation’s nine public health hospitals including the Center at Carville. Eight hospitals were closed that year. The Center stayed open (Frantz 1997).

Additional closure steps were taken in 1981 including the opening of more ambulatory care centers. The closure battle was again fully engaged. In 1982, the Office of Management and Budget (OMB) attempted to contract out jobs at the Center. Contracting out would have reduced the number of civil service employees, one of the major constituencies opposing closure. A subcommittee of the House Committee on Energy and Commerce held a hearing in Carville that led directly to a change of mind for the OMB. (U.S. Congress 1982). The OMB was especially interested in contracting out at the Center, since the supplemental hazardous pay made the payroll particularly high, but it excluded the Center when reminded that 120 of the Center’s 360 patients were also on the Center payroll and unlikely to find other jobs (Peterson 1982).

The USPHS took the offensive again in 1983, when it did a formal review of the $15 million Center. By then the Center housed only 200 patients and included 98 buildings on 337 acres with “some of the amenities of a small town.” The staff included 317 civil service and Public Health Service workers and 125 part-time patient–employees (USPHS 1988, 5). The USPHS recommended that the Center continue its custodial care and research programs, but asked for more outpatient clinics and a study of the elimination of residential care (1988). In 1985, the infamous hazardous-duty salary supplements were discontinued for new hires only, and the Center stopped accepting residential patients.

A 1988 USPHS report examined “whether it would be cost effective and feasible to contract out the patient care activities of the Center and transfer the research activities elsewhere” (p. 1). The report recommended: expanding the Center’s mission to include other nerve-desensitizing diseases including diabetes, contracting out long-term patient care, and moving the Center’s research facilities to Baton Rouge. While the Center would continue to meet “the federal government’s promise of lifetime care to the current patient population,” there “would be no further additions to the population, however, and over time the population would dwindle until the entire remaining facility could be closed” (p. 32). That same year, Surgeon General C. Everett Koop sent a second terminator, Dr. John Duffy, who within a year of his appointment began to loudly advocate closure. Although he favored allowing healthy residents to stay, he announced plans to move “the center’s acute care, research and education functions to Baton Rouge.” His recommendation was spiced with the comment that “Certainly, if given a choice between staying in this rather safe, protected world and the real world of hard knocks, most people would choose to stay, but we can’t continue to create paradise forever on the backs of the American taxpayer” (Applebome 1989). His calls for change were insistent and repeated the theme “. . . a colony like this is a disgrace” (Struck 1989).

But the patients, who were organized into a Patient’s Rights Federation (PRF) that dated back to the 1940s, did not want to leave and worked to keep the facility open. In 1990, the patients did agree to a plan that would gradually transform the facility into a geriatric prison. The Bureau of Prisons (BOP) rented half of the space and half of the health care services at Carville to support a small number of inmates. The prison would expand to absorb all the space and services as the Center’s patient population decreased. After more than four decades, the government was finally in a position to phase out the Center as the elderly patients died. Death was imminent. The government, it seemed, had placated antitermination forces, and the Center would close (Frantz 1992).

Alas, there was considerable fight left. The geriatric prisoners arrived in 1990, and in 1992 the research branch, including 50 scientists, 150 armadillos, and 7,000 mice, was relocated to a location at Louisiana State University in Baton Rouge (Atlanta Constitution 1992). The patients, professional and nonprofessional staff, and the community fought back. In 1994, the BOP withdrew from the site claiming concern over its ability to renovate the facilities due to the designation of the site as a National Historic District (1992) and concerns about hazardous waste deposits (United States Department of Health and Human Services 1995, 34). Some of the patients took credit, claiming to have run “the Bureau of Prisons out of here” (Frink 1996). The patients called for and eventually won the resignation of Dr. John Duffy, the second terminator.

To nearly everyone’s astonishment, the Center became a centenarian. A 100th birthday celebration was held in November 1994. The celebration featured a keynote speech by James Carville, a high-profile *political* supporter of then President Bill Clinton and a native of the community that housed the Center and carried his family’s name (Frink 1994).

Once the celebrating was over, the USPHS and congressional budget-makers began a new assault. The staff at the Center was reduced from 344 to 216 through a 1994 government wide buy out plan (U.S. Congress, PL103-226) designed to reduce costs. Early in 1996, Congressman Richard Baker, who represented the district prior to 1992, and other government officials visited the Center to “discuss the idea of closing the center with patients and staff members” (McKinney & Frink 1996). Baker then proposed to Congress that the site be used for a job training school and that patients be given an annual living subsidy if they departed. The idea was quashed immediately when Congressman Cleo Fields, who represented the district from 1992 to 1996, objected (Carville Center Staying 1996).

Following the 1996 elections, which returned the Center to his district, Baker proposed that the site be transferred to the State of Louisiana. This time his plan was adopted. PL 105-78 provided for “relocation of the Federal facility, . . . including the relocation of the patients of the Center.” There were conditions: The Carville site had to be used for health or educational purposes for thirty years, the State had to maintain the cemetery and permit burials and visitations there, and the State had to agree to permit a museum to be maintained at the site.

PL 105-78 also authorized an annual stipend of $33,000 to each patient who left the facility. The remaining patients were to be relocated within three years unless such relocation was “not feasible.” The legislation offered transfer options, disability coverage, and unprecedented retirement incentives to civil service employees. It also accepted responsibility for hazardous waste problems and provided nearly $2.5 million for renovations to the property (U.S. Congress, “Report to Accompany H.R. 4272,” 1999, 1). Weeks later, the U.S. Department of Labor selected the site for an $18.4 million Job Corps center for at-risk youth. In 1999, a second program operated by the Louisiana National Guard, Youth Challenge, placed its first class at the facility (Times-Picayune 1999).

The property was deeded to the State of Louisiana in August 1999. By then, some 50 patients had taken the $33,000 stipend and departed, leaving only 69. By June 2000, 37 patients remained at the site where they continued to live in their own apartments, received care from a 24-hour clinic, and shared “their own separate section in the cafeteria,” which was also used by the Youth Challenge program (Frink, 2000). Roughly 24 other patients resided in a special wing at a hospital in Baton Rouge