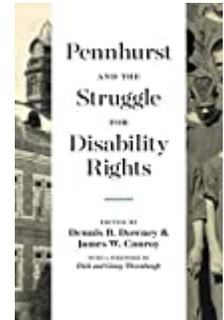


**Dennis B. Downey.** *Pennhurst and the Struggle for Disability Rights* (Keystone Books). University Park: Pennsylvania State University Press, 2020. xviii + 269 pp. \$35.00, cloth, ISBN 978-0-271-08603-3.



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Dennis Downey and James Conroy have produced a volume that traces the rise and fall of Pennhurst State School and Hospital (1908-87) as a residential institution for individuals who were developmentally disabled. In eleven essays, plus an introduction and conclusion, this book provides a detailed examination of the rise of institutionalization for individuals classified as feeble-minded and epileptic in the early twentieth century and the conditions and changing conceptions of treatment that closed Pennhurst some seventy years later. Pennhurst, a state institution near Philadelphia, Pennsylvania, is particularly significant because the court cases that forced its closure in the 1970s and 1980s proved to be important support for the rise of disability rights.

In their introduction, Downey and Conroy argue that the establishment of Pennhurst as a residential institution in 1908 was part of a Progressive reform growing out of the eugenics movement to protect society from the perceived danger of the feeble-minded and epileptic reproducing and weakening the nation. If they could not be eliminated,

at least they could be removed from society, supposedly for their own good and the improvement of the nation. Over the next seventy years, over 10,000 individuals were institutionalized at Pennhurst, many of whom spent most if not all of their lives behind its walls. Whatever the initial promise of institutions like Pennhurst, the reality was quite different and appalling. Pennhurst was always underfunded and understaffed, less impaired residents were forced to work for no wages to maintain the institution and care for custodial residents, and physical and sexual abuse was common. However wretched the conditions, Pennhurst continued to expand so that at its height it had over 3,500 residents with only 600 caretakers. The walls of secrecy were breached in 1968 when Bill Baldini, a young reporter with a Philadelphia television station, was able to film and broadcast a five-part expose from inside Pennhurst. This series helped initiate numerous inquiries into conditions at Pennhurst that led to families and other advocates on behalf of the residents filing lawsuits that ultimately forced the closure of Pennhurst and the

transfer of all of its residents to community living situations. These federal lawsuits, along with legislative initiatives such as Section 504 and the Americans with Disabilities Act, put legal support under the growing disability rights movement.

The essays are arranged in three sections: “Pennhurst in Time and Place,” “The Power of Advocacy,” and “A View Toward the Future.” In “The Idea of Pennhurst: Eugenics and the Abandonment of Hope,” Dennis Downey sketches the intellectual, medical, and political background to the establishment of residential institutions like Pennhurst in the early twentieth century. Social reformers, doctors, scientists, and university-based experts “forged a new consensus, a new descriptive terminology that redefined the purpose of institutionalization as a permanent preventive measure aimed at protecting society from those who threatened biological and social progress” (p. 18). Many of the advocates of institutionalization considered themselves, and were considered by others, to be Progressive reformers. As Downey puts it, “this convergence of modern science, eugenics, and public health reform ... was one of the most striking developments in public policy in the Progressive era (1890-1915)” (p. 22). These experts advocated three approaches to preventing the eugenic threat to American progress: “elimination through sterilization, segregation through institutionalization, and regulating the right to marry” (p. 27). Although Pennsylvania saw some of the earliest forced sterilizations, public support for the procedure was never strong and institutionalization emerged as “politically the most palatable solution to the perceived rising tide of feeble-mindedness” (p. 29). The freedom and liberty of individuals with developmental disabilities were sacrificed in pursuit of a public policy of permanent institutionalization. It was a policy that lasted until the exposures of the 1960s and 1970s and the rise of disability rights. The other two essays in this section, “Living in a World Apart” and “The Veil of Secrecy: A Legacy of Exploitation and Abuse,” present vivid examples of the inhuman conditions

under which the residents were forced to live and work and the abuses to which they were so frequently subjected.

The five essays in the second section, “The Power of Advocacy”, describe how family and organizational advocates and, eventually, disabled self-advocates successfully challenged the residential model and secured the closure of Pennhurst and the movement of its residents to community living arrangements. Bill Baldini, in an oral history, recalls how his 1968 television series, “Suffer the Little Children,” produced for a Philadelphia station, shocked viewers who witnessed the appalling conditions at Pennhurst. Other essays detail the rise of family and organizational advocacy as family members and social organizations collaborated to speak on behalf of Pennhurst’s residents and to advocate for improved conditions and ultimately closure of the institution. Families were particularly important, beginning in the late 1940s and 1950s, in pushing for improvements and in creating vehicles such as the Association for Retarded Children to advocate for change. The all-volunteer Pennsylvania Association for Retarded and Handicapped Children, later known as PARC, became an effective advocacy and lobbying group on behalf of the residents of Pennhurst and other other state institutions. Tying into the emerging disability rights movement in the 1960s, PARC eventually moved from advocacy to legal actions to force changes in how their children were treated.

Judith Gran, in “From PARC to Pennhurst: The Legal Argument for Equality,” examines the significant legal cases emerging from PARC’s advocacy that articulated and embodied the development of the rights of the men, women, and children confined in places like Pennhurst. The 1972 consent decree in *PARC v. Commonwealth* took the position that “*de jure* exclusion of children with intellectual disabilities from public school violated the Equal Protection Clause” of the Constitution (p. 107). This established the right to education and

would lead in 1975 to the congressional passage of the Education of all Handicapped Children Act, later changed to the Individuals with Disabilities Education Act. In 1974, David Ferleger, an attorney in Philadelphia, filed *Halderman v. Pennhurst* “as an action seeking damages for the egregious harm and abuse experienced by Pennhurst residents, with PARC seeking community placement” (p. 117). In his decision, Judge Raymond J. Broderick ruled that the confinement of residents in Pennhurst violated the Equal Protection Clause of the Constitution and Section 504 of the Rehabilitation Act of 1973. He required Pennsylvania to move residents to the least restrictive community settings and his decision led to similar rulings in other states.

The final two essays in this section reveal the positive consequences of deinstitutionalization. “The Rise of Self-Advocacy: A Personal Remembrance” tells the story of the creation of Speaking for Ourselves in 1982 and its subsequent history. Speaking for Ourselves was organized by former residents of Pennhurst with the assistance of disability advocates and soon became an effective forum to advocate for the rights of individuals with developmental disabilities. The essay focuses on former residents Jerome Iannuzzi Jr., Betty Potts, and Roland Johnson. James Conroy, in “The Pennhurst Longitudinal Study and Public Policy: How We Learned that People Were Better Off,” describes the long-term statistical study based at Temple University that, by regularly interviewing 1,154 former residents of Pennhurst, demonstrated that by every measure they were better off living in the community than they had been institutionalized. The study provided convincing evidence that Judge Broderick had been right in his decision in *Halderman v. Pennhurst*, not only on constitutional grounds, but on the direct benefits to those freed from lifetime confinement at Pennhurst. As Conroy points out, studies in other states replicated the Pennhurst results, and individuals with developmental disabilities benefited from living in the least restrictive community settings.

The three essays in part 3, “A View to the Future,” take up the historical and material legacy of Pennhurst. They describe what happened to the physical plant when the state closed Pennhurst and largely abandoned it to the elements. They also raise the question of how what happened at Pennhurst and the emergence of disability rights in the struggle to close the institution should be remembered and memorialized. Once closed, parts of Pennhurst were repurposed as a nursing home for veterans and as a National Guard Armory. Other parts became a playground for urban explorers who wandered the empty halls in search of adventure, photographs, and sometimes artifacts and scrap metal. Parts of the buildings were eventually demolished and some that remain are transformed every Halloween into a commercially operated and very profitable haunted asylum. The haunted asylum is particularly problematic since it plays on outmoded stereotypes of the disabled and insane to scare the thousands who flock to the remains of Pennhurst to be safely frightened. Though a state historical marker was established on the site, and plans exist to turn the superintendent’s house into a museum, lack of funding and other obstacles have hindered the development of an effective and respectful historical memorial.

This volume provides a fine introduction to the history of Pennhurst and the disability rights movement that emerged out of the effort of disability advocates and eventually the former residents of the institution to assert their constitutional rights to live as freely as possible in the community. It is striking to see how in one state attitudes and policies toward men and women with developmental disabilities evolved in less than a century from seeing them as mortal threats to the reproductive health of the nation and deserving lifelong incarceration to recognizing their constitutional rights as individuals to determine how and where they would live under the least restrictive constraints. The essays also remind us how small groups of determined individuals aided by crucial judicial decisions can expand constitution-

al rights to populations once considered not fully human. Freeing the residents of Pennhurst took the strenuous efforts of parents, social scientists, lawyers, judges, physicians, politicians, and eventually the self-advocacy of former residents. While this book celebrates and remembers the success of freeing the residents of Pennhurst, we need to remember that the struggle to ensure the rights of the disabled does not end with this or any other particular success. The essays in this volume represent a good beginning in the historical recovery of the story of Pennhurst and its residents. For most of the essays, I felt that much more could be said on every topic addressed. I hope *Pennhurst and the Struggle for Disability Rights* spurs further scholarship, not only on Pennhurst but on other, similar institutions in the United States and other nations. Both the appalling conditions present in institutions like Pennhurst and the successes of advocates and residents in liberating those confined behind asylum walls need to be more widely studied and known.

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