

Profiles in Medical Courage: Michael Wilkins and the Willowbrook School

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has. "

- Margaret Mead

With this article we begin an intermittent series on physicians who displayed courage in trying to help their patients. Although there are many examples, hopefully what will be illustrated are examples of the lesser known doctors who identified problems and stood up to address them. Few remember the controversy surrounding the now closed Willowbrook School and Dr. Michael Wilkins' involvement. However, Wilkins' courage in advocating for change not only resulted in substantial improvement in conditions at the school but also led to the Civil Rights of Institutionalized Persons Act (CRIPA) of 1980.

Wilkins was originally from Kansas City and graduated from the University of Missouri School of Medicine in 1967 (1). He left Missouri to do his pediatric internship and complete his military obligation in the United States Public Health Service on Staten Island. There he became familiar with the Willowbrook State School, which at the time was the largest institution for the mentally retarded in the world. After completing his time in the Public Health Service, Wilkins was persuaded by his friend, Dr. Bill Bronston, to join him at Willowbrook as a full time physician.

The Willowbrook School already had a bad reputation when Wilkins arrived (2). Built in the late 1930's, the campus was large with 38 buildings on 375 acres in the Willowbrook section of Staten Island. Designed to hold 4000 patients, it held 6000 when Wilkins arrived. As a result of the overcrowding and unsanitary conditions, virtually all children developed hepatitis, primarily hepatitis A. This led to a highly controversial medical study carried out from the mid-1950s through the 1970s by researchers Saul Krugman and Robert W. McCollum. Healthy children were intentionally inoculated, orally and by injection, with hepatitis virus, then monitored to gauge the effects of gamma globulin in combating the infection (2,3). Senator Robert Kennedy of New York, the younger brother of the slain President John Kennedy, had toured the institution in 1965 and proclaimed that individuals in the overcrowded facility were "living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo" and offered a series of recommendations for improving conditions (4). However, the result was a public relations effort with the creation of a few "model" buildings (5). Visitors were escorted through these "model" buildings and the controversy subsided.

Wilkins was not assigned to one of the model buildings but to building 6. There he cared for about 70 severely mentally retarded clients along with 2 or 3 attendants. In a 2008 interview Wilkins said, "The first thing that assaults you

when you walk in the building is the smell and that sets the tone for the whole experience. The smell is the smell of decay and a mixture of sweat and feces and lack of being cleansed ...it permeated the building" (1). The clients spent their days in the day room. Few went to school. For the incontinent the attendants would get 6-8 clients together in the shower room and hose them to keep them clean and clean up after them between showers. The severely retarded would be on the floor in straightjackets so as not to scratch themselves or assault other patients. Some would rock on the floor, while others sat motionless. Each building had a supervisor, sometimes with a nursing degree, but in Wilkins' building the supervisor had no nursing background. He was the person that would answer to the administration and carry out their orders.

Wilkins and Bronston began advocating for change especially in the wake of Governor Nelson Rockefeller's budget cuts which decreased the number of employees from 3000 to 2000. Parents and friends were not allowed in the buildings so they held Sunday weenie roasts for the clients and their parents. There they would advocate for improvement in the conditions. This eventually led to a conference for the parents. The keynote speaker, an expert on mental retardation, described conditions at Willowbrook as "primitive" and "outdated" (1). After trying to organize the parents to advocate change, Wilkins was fired by the School's administrator, Dr. Jack Hammond.

Now unemployed, and not having completed his residency, Wilkins fought back. He contacted his friend, a local WABC-TV New York newsman, Geraldo Rivera. Fortunately, when Wilkins was fired, Willowbrook had not asked for his key and he used it to let Rivera come to Willowbrook and document the conditions. The State of New York attempted to prevent the release of the resultant film citing patients' privacy, but Rivera, an attorney by education, persuaded his producer to make the film public. The exposé, entitled "Willowbrook: The Last Disgrace", garnered national attention and won a Peabody Award for Rivera. Rivera and Wilkins later appeared on the nationally televised Dick Cavett Show with the film.

As a result of the conditions, a class-action lawsuit was filed against the State of New York and a settlement in the case was reached mandating reforms. The publicity generated by the case was a major contributing factor to the passage of the Federal Civil Rights of Institutionalized Persons Act of 1980. This law enabled the US Department of Justice to protect the rights of those individuals who were in the care of state institutions, including jails and prisons, juvenile correctional facilities, public nursing homes, mental health facilities and institutions for individuals with intellectual disabilities. The law allows for the US Attorney General to intervene on behalf of institutionalized people whose rights may have been oppressed and ensure the safety of those individuals who may feel uncomfortable reporting issues of abuse in these government run institutions.

After leaving Willowbrook, Wilkins returned to Kansas City and completed his residency. For many years he ran a clinic in the inner city serving Kansas City's

poor. We should remember Dr. Michael Wilkins and how his act of courage led to improvement at Willowbrook and a law protecting all institutionalized individuals.

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