

A Tribute to Thomas K. Gilhool
and an open letter to present day human rights activists

“Proof that a more just society can be shaped with a movement of fervent champions
partnering with an exceptionally gifted lawyer.”

November 12, 2020

More than any other person...

Thomas K. Gilhool died August 22, 2020. You might be thinking “Thomas who?” Few have heard his name. Fewer who worked alongside him are still alive to tell of his accomplishments, his wondrous impact. But those who care about people with disabilities today should get to know his name and be appreciative. Here’s why. Over the last five decades, *Tom Gilhool did more than any other person to improve the lives of Pennsylvanians with disabilities*. Millions of individuals and their families greatly benefited.

Life before Gilhool’s legal triumphs

To fully appreciate Tom Gilhool’s societal impact, consider life for people with disabilities before and after Gilhool’s monumental legal victories of the 1970s. Before these precedent-setting lawsuits, Pennsylvania both neglected and discarded children with intellectual disabilities: no public school, no training, no therapeutic services, no respite to give families a break from the 24/7 responsibilities, no place in society, no hope and often no alternative for families except to surrender their children to placement in state institutions. Parents of newborns with disabilities were regularly told by physicians to place their children in a state institution because there was no hope for a normal life for the child or family.

Pennsylvania institutions were shockingly cruel and inhumane

State institutions were irredeemable hellholes, understaffed, overcrowded, with residents ceaselessly being injured and dying from neglect and the absence of even basic care. Imagine the worst and it was happening – all in our name of the citizens of Pennsylvania. In fact, the entire nation had a shameful record of neglect and maltreatment of people with disabilities.

Why did people of “good conscience” allow the horrific conditions? This remains a perplexing question about humankind!

Families were appalled by the previously hidden horrors.

In the late 1960s, the leaders of the Pennsylvania Association for Retarded Children (PARC) were getting a glimpse behind the locked doors of the institutions. The institutions were far away from the population centers – “out of sight and out of mind.” Access to the residential wards was prohibited. The hideous conditions were hidden behind walls and locked doors.

But photos and videos leaked, and PARC leaders became aware and disturbed at what they saw. A consciousness arose. As a few advocates got more than a glimpse beyond the stately public lobbies, the inhumane conditions could not be justified nor ignored. Thinking of their own sons and daughters, as well as others, the parent leaders were distraught and heartbroken. Sadness erupted into anger. Anger became resolve.

Parent advocates joined with Tom Gilhool, who promised, “We will prevail. Our cause is just and right.”

All of these emotions led PARC’s parent leaders to Tom Gilhool, a 30-year-old lawyer at the Public Interest Law Center of Philadelphia (PILCOP). Neither PARC parent leaders nor Gilhool knew the exact remedies they would pursue but they were sure that asserting legal rights in the courts was crucial. No legislative nor executive branch reform was in sight or likely. People with mental retardation had forever been mistreated – an entrenched status quo. Although no elected leaders were promising to upend this injustice, attorney Gilhool vowed there would be change. In 1969 at the state PARC convention, Gilhool promised the parents “It will be a battle, but we will prevail. Our cause is just and right!” There it was his credo, his determination and his righteous call to arms.

This was the moment to vigorously fight for the civil rights of people with disabilities

Gilhool was the right champion at the right time. In the 1960s, raging civil rights battles and confrontational Vietnam War protests had stirred America to question what was right and what was wrong. PARC parent leaders drew some strength from the civil rights movement of the 1960s. The battle lines were now drawn between a society based on survival of the fittest or one that would respect each and every person. For people with intellectual challenges, the time had come to end their second-class citizenship and the concomitant punishment, harm, exclusion and deprivation.

The advocates fought for what was right despite withering criticism

The nascent PARC movement was constituted of a small cadre of untested and modestly resourced parent advocates who audaciously took it upon themselves to stand up against the wrongs and stand for the legal rights of people with disabilities. The parents were encouraged and bolstered by a few “change agent” staff leaders. They drew strength from each other in the face of daunting ethical questions, always landing on the primary question “what is right?” (Author’s note: I was one of those change agents.)

This small band of activists believed that the future could be better if they courageously stepped forward despite frequent opposition and withering criticism. The denouncements came from many sources including local media, politicians, clergy, administrators, workers, business and

labor leaders - and even some of the other PARC local chapters. The harshest dissents, and the ones most difficult to reconcile, came from other parents, especially those families who had a son or daughter in one of the institutions.

Tom Gilhool's incredible personal gifts and legal talents were mighty in the fight for rights

As determined as they were, the advocates lacked the legal prowess to convert their pursuit of justice into the laws governing all of Pennsylvania. They needed someone who could take their complaints, fashion effective legal remedies and convince the courts to make sweeping changes. Tom Gilhool was that person. Gilhool brought his character and talents: his close partnership with the families he represented, an unquenchable thirst to learn about the problems to be remedied, a deep and religious sense of right and wrong, a world-class brilliant legal mind, a capability to influence and persuade, a perseverance amid immense and never-ending obstacles, a bright and hopeful vision for the future and the requisite audacity (some might say arrogance) to be the first, to create the breakthrough, to make the lasting change.

Gilhool and PARC initially battled against the mass exclusion of children from public education

On January 7, 1971, Gilhool on behalf of children and families, sued the Commonwealth of Pennsylvania and its 501 school districts decrying as unconstitutional the public schools' exclusion of children designated as mentally retarded. The class action civil rights lawsuit in federal court sought a free, individually appropriate public education for all children. Among other virtuous propositions, Gilhool claimed, "No child may reasonably be expected to succeed in life if he is denied the opportunity of an education ... The opportunity of education, where the state has undertaken to provide it, is a right which must be made available to all on equal terms."

Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania was a momentous legal victory

Gilhool pleaded and persuaded both the Pennsylvania Governor Milton Shapp and the U.S. District Court. The resulting consent agreement with the Commonwealth of Pennsylvania forever changed public education in Pennsylvania and the lives of children with disabilities and their loving families. The Court approved settlement included this conclusion, "Plaintiff retarded children who heretofore had been excluded from a public program of education and training will no longer be so excluded after September 1, 1972. This is a noble and humanitarian end in which the Commonwealth of Pennsylvania has chosen to join. Today, with the following Order, this group of citizens will have new hope in their quest for a life of dignity and self-sufficiency." Advocates were excited. With the PARC case, ideals had become dreams and dreams were becoming "noble and humanitarian" reality.

The Right to Education consent decree dramatically improved the lives of millions of children across Pennsylvania and beyond

So how big was this victory? The landmark case was the precursor to current day special education in Pennsylvania that did not exist before the lawsuit. In the 48 years since that 1972 Right to Education Consent Agreement, millions of Pennsylvania children have been educated

and educated better as a result of the lawsuit. Further, the impact went way beyond Pennsylvania's borders as the PARC consent decree became a model for a federal law Public Law 94-142 of 1975 the Education of All Children Act. Education was now a right for children with many different disabilities. Across America for the last forty-five years, children have been included and not excluded and have had education and supports tailored to meet their individual needs. Gilhool and PARC had achieved a civil rights victory both monumental and lasting!

The movement fought persistent opposition to implementation of the legal mandate

Even after the settled Right to Education lawsuit enumerated clear mandates, the struggles continued. School districts, educators and bureaucrats balked. Parents and PARC advocates again turned to the lawyers including Tom Gilhool to battle for individual students and school district changes. In the end, this band of activists prevailed fueled by righteous outrage and steely determination. Social change always entails great struggle and sacrifices. That was also true in this instance. The advocates believed as Gilhool had advised them years before, "It will be a battle, but we will prevail. Our cause is just and right!"

The Right to Education agreement sparked changes for both family and community life

To truly calculate the impact of the Right to Education victory, one has to also look outside of the school settings. Life changed for families as many could now keep their child at home given the practical help of not being caregivers 24/7/365. Now there were individual educational plans and at least some hope for the future. Life also changed in communities as children were visible in schools, shops and streets helping all citizens to experience, think about, appreciate and respect the value of all persons no matter our differences. Public norms were changing in a good way.

The PARC movement next attacked the atrocities in Pennsylvania's institutions

PARC advocates next attacked the state-sanctioned horrendous abuses of institution residents. In Allegheny County, several parent advocates and I embarked on unannounced visits to state institutions and state-funded private residential facilities, boldly demanding to see the previously hidden wards of these institutions. Appalled and sickened by what was witnessed; advocates made the public aware through many dozens of news stories over several years. More than 20 state and private institutions were investigated, and many were closed or forced to drastically downsize. During the visits, all kinds of mistreatment were uncovered including the caging of people and dozens and dozens of tragic deaths. The issues were not limited to any one facility but rather a systemic failure of our society and government to protect and provide needed services to our most vulnerable citizens. (See <https://www.youtube.com/watch?v=SHSZRxjBOcA> for a nine-minute video story of this advocacy.)

This seemed true: "Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has." – Margaret Mead

Gilhool and the PARC movement asserted the civil rights of institutionalized citizens

Although the public shaming and advocacy with the state executive and legislative branches yielded some improvements, progress was modest, and a complete reform and creation of a new and better system was desperately needed. Again, the PARC advocates joined with Tom Gilhool to assert state and constitutional rights and remedies in the federal courts. Allegheny County advocates met with Tom Gilhool and sought a federal lawsuit in Western Pennsylvania to remedy the unconscionable conditions uncovered by their inspections.

The Pennhurst lawsuit was filed to stop the inhumane treatment of people with disabilities

The Public Interest Law Center of Philadelphia (PILCOP) joined the Pennhurst class action lawsuit that alleged conditions at Pennhurst (a state institution in Chester County) violated constitutional and state statutory rights for the residents. Tom Gilhool, Frank Laski and Michael Churchill, all brilliant and extraordinary lawyers, represented the Pennsylvania Association for Retarded children. Although the case was brought in Federal Court in Philadelphia, the Allegheny County advocates were thrilled that there would finally be an assertion of rights and the chance for systemic remedies.

The Federal Court ruled that rights were violated and ordered breathtaking remedies

In 1977, Federal Judge Raymond J. Broderick ruled that "Conditions at Pennhurst are not only dangerous, with the residents often physically abused or drugged by staff members, but also inadequate for the 'habilitation' of the retarded. Indeed, the court found that the physical, intellectual, and emotional skills of some residents have deteriorated at Pennhurst." The District Court held that these conditions violated each resident's right to "minimally adequate habilitation," "freedom from harm" and "nondiscrimination," abridging their constitutional, federal and state law rights." Judge Broderick ordered "immediate steps be taken to remove the retarded residents from Pennhurst" and "to provide suitable community living arrangements" for the class members. The rulings were breathtaking and promised a new enlightened era for people with intellectual disabilities. The outcome was phenomenal. PARC advocates were ecstatic.

Lawyers Gilhool and Laski and PARC advocates now clashed with the state government as it appealed the landmark Pennhurst ruling

The advocates pleaded with the state administration to not appeal the Pennhurst ruling. Gilhool implored the state "to not frustrate the present opportunity which ten years work has created for us and for retarded people in Pennsylvania and across the land". He sought a consent agreement as he did eight years earlier in the Right to Education case rather than continued combative litigation. However, the state appealed all the way to the United States Supreme Court contending that the Pennhurst ruling was just too sweeping. The state argued against the legal rights of people with disabilities. During these contentious years of legal battling, Judge Broderick held a state administrator in contempt of court for violating his orders. Ultimately, the Supreme Court ruled in the state's favor. Though the rights were not enumerated and enshrined in a Supreme Court ruling, the remedies were still achieved - Pennhurst closed and residents were provided individually appropriate community services. Throughout, lawyers Gilhool and

Laski were resolute and formidable – knowing full well that their cause was just and their remedies brilliant.

The lawyers and advocates achieved lasting reform benefitting many through the years

Judge Raymond Broderick's ruling decreed the right to live in the community with appropriate services – a significant societal advancement. Today, almost all of the institutions and the inherent neglect and abuses are gone. In their place are community services. In 1972, at the peak of the state institution system there were 40,000 people incarcerated in institutions. Today there are less than 1,000 residents. The Pennhurst lawsuit became a model for other lawsuits throughout the country generating like reforms. Since the March 17, 1978 Court order (see note above), hundreds of thousands of Pennsylvania citizens who would have been subjected to extreme and inhumane institutions were instead provided services in the community.

Over the past 50 years, Tom Gilhool's legal advocacy established the rights of people with disabilities

When I think of positive social change that has happened in society over the past 50 years, I rank the recognition of the rights and justice for people with disabilities as one of the most significant improvements. We may wrongly take for granted the right to education and the right to live in the community. Those rights did not exist until they were fought for and won. Many people were part of this grand social movement. However, Tom Gilhool and his PILCOP partners were the ones who understood how to realize legal rights and enforce laws to protect and help people. Without his extraordinarily profound and singular legal advocacy we probably would not have achieved the same results. When the executive and legislative branches falter and fail, judicial remedies are essential. Many people who could attest to these wondrous legal achievements have now passed. They were the parents and the advocates and the legal partners and the judges and the legislators who joined in this heroic fight. But one individual - Tom Gilhool - stands out among all of these heroes as the champion who did more than any other person to improve the lives of Pennsylvania's people with disabilities. Millions of individuals and their families greatly benefited.

My personal gratitude

During most of my 50-year career, in an unusual variety of capacities – for the plaintiffs, for the defendants and for the federal court, I had the privilege to work with Tom Gilhool. I witnessed and do attest to the grand advances in our society attributable to Tom Gilhool's brilliant legal work.

My life was surely enriched by our partnership and friendship.

With great admiration for the life and work of Tom Gilhool,

Bob Nelkin
Advocate for people with disabilities