

Pennsylvania Message

THE ARC OF PA'S BOLD AND COURAGEOUS HISTORY SHAPES OUR PRESENT & OUR FUTURE

This issue of The Arc's PA Message highlights two landmark pieces of our history!

<p>The Right to Education Lawsuit PARC v. Commonwealth of Pennsylvania</p>	<p>The Closure of Pennhurst Center Halderman v. Pennhurst</p>
<p><i>In the United States District Court for the Eastern District of Pennsylvania Filed January 7, 1971</i></p> <p><i>Plaintiffs: All other persons, residents of Pennsylvania aged six to twenty-one years, who are eligible for free public education except that defendants herein (1) have been excluded or (2) excused them from attendance at public schools or (3) have postponed their admission or (4) otherwise have refused to allow them free access to public education because they are "retarded".</i></p>	<p><i>In the United States District Court for the Eastern District of Pennsylvania Filed May 30, 1974</i></p> <p><i>Plaintiffs: Former and present residents of Pennhurst School & Hospital. The plaintiffs argued that the institutionalization of the residents 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. They sought damages and equitable relief, including the closing of Pennhurst, and provision of education, training, and care in community settings.</i></p>

“THROUGHOUT THIS ISSUE OF THE PA MESSAGE, THE EDITOR CHANGED THE WORDS ‘RETARDED’ TO ‘INTELLECTUAL AND DEVELOPMENTAL DISABILITY’. AT ONE TIME, THE WORD RETARDED WAS IN COMMON USAGE. IT IS NO LONGER USED IN PUBLIC DISCOURSE AND IS FOUND OFFENSIVE TO MANY. IN ADDITION, IN CERTAIN LOCATIONS, THE EDITOR CHANGED PARC, THE PENNSYLVANIA ASSOCIATION FOR RETARDED CHILDREN, TO OUR CURRENT ORGANIZATION NAME - THE ARC OF PA.

President's Message - Michael Marsh

A HISTORY WORTH REMEMBERING



Greetings! I am so grateful to have the opportunity to invite you to read this issue of the PA Message; it is about a history worth remembering. It is a great privilege to serve this organization and, in this issue, you will hear from many who have had an indescribable impact on our country, our Commonwealth, and our communities. In our most recent issue, we focused on the newest frontiers of The Arc's mission - competitive employment and the new era of ensuring civil rights for everyone - including those with intellectual and development disabilities (I/DD).

As I thought about this issue, a quote quickly flew into my mind that summarizes The Arc movement.

“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]”

More than any other state chapter, The Arc of Pennsylvania and our local chapters have had a place in the forefront of The Arc movement since the very beginning. This issue's focus is on two of the most important landmarks in our shared history. These are evidence of the impact that Pennsylvania has had across the country and the world. Having met several of the authors who generously share their insights in the following articles, it is humbling to volunteer for an organization with such impact on the lives of so many. People like Dr. Joe Angelo, Eleanor Elkin, Judy Gran, Janet Albert Herman, and our current Executive Director are examples in leadership. These folks, along with all the presidents, board members, executive directors, and volunteers at the state and local chapter levels, are courageous people who served when called, gave when asked, and built the foundation upon which we build today for so many to come. We, as an organization, are the beneficiaries of people who have walked the talk and left their mark on so many lives in such a way that we can never truly understand their impact.

It is my sincere hope that the writings contained in this newsletter will cause each of us to pause for a moment. To take time to think about where we have been. To celebrate the triumphs. All, as we plan ways in which we can take on the next challenge to have a world where fairness, compassion, patience, and the preservation of dignity are the measures of our success.

Our work on the closing of Pennhurst and The Right to Education lawsuit have been examples of The Arc's leadership. This work reflects our ability to collaborate and cooperate with other organizations, people, and government agencies. However, our work is far from done. Until we can truly say that every citizen of our Commonwealth can freely choose to work, play, and learn where, when, and how they want, we have not achieved our mission. To reach the goals we have set, we must stay committed to providing full access to education, employment, and community services. These must be provided freely, equitably, and with appropriate supports to enable meaningful engagement and fulfillment of each person's potential.

Please take the time to read about our history. Celebrate our achievements. Commit to doing the very best we can every day to reach our goals.

Sincerely, Michael J Marsh
President, Board of Directors



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Maureen Cronin

BOLD & COURAGEOUS HISTORY SHAPES TODAY'S WORK

This issue of the PA Message highlights the bold and courageous history of The Arc of Pennsylvania. I am so proud to be part of this organization. This parent movement started years ago and brought such important changes to the landscape of education, disability services, and informal supports for people with intellectual and developmental disabilities.

From twelve years of age through college, I worked at a camp for children with special needs in Chester County. Adults from Pennhurst Center also attended. Every day we would swim, ride horses, play games, and just enjoy being outside. We all loved being together and we knew how to have fun. I'd visit my friends living at Pennhurst in the winter and saw these same happy, energetic folks from summer camp, laying around on wooden benches with nothing to do. I was amazed at how their true personalities emerged during the summer - then became hidden. How they survived living in these conditions and their resiliency was amazing, but, sobering to me.



Also, my cousin lived at Pennhurst. I remember hearing the "stories" - how doctors and knowledgeable family members - told my aunt and uncle that Pennhurst "was best for their son and their whole family". My cousin was placed in Pennhurst at the age of seven. It broke my aunt's heart to leave her son, but I know she was very pressured to do so. He lived there till he was in his 30's, when he left to live in a group home in southeastern PA.

After graduating from college, I went to work at Pennhurst. While my advocate friends were horrified at my decision, I felt compelled to work at Pennhurst... at least to see if I could help in some way. I was very attached to those who came to camp. By the time I started, it wasn't the horrors of the 60's and 70's, but it sure wasn't where I would want to live. Large dormitories were partitioned off to make smaller bedrooms, but, still 4 people slept in one bedroom. Attempts were made to make the living areas look less institutionalized. "Active treatment" was required yet challenging to deliver in congregate settings.

My first job, as an activity aide, was to take folks to various activities on campus - swimming, outside time, etc. Over the years, I held a variety of direct service and supervisory positions. In my final position as a Unit Manager, I had an active role in closing Pennhurst and helping individuals move to community programs. As staff, it was in some ways sad to see folks leave. There were many friendships established, yet, we all knew there were better things ahead for every single person living at Pennhurst. Everyone had the right to live in their community regardless of the severity of their medical or behavioral support needs.


This experience, as well as the experience of having a child with significant disabilities, has affected all that I think and do in my work. Our son Matthew died at the age of 4 and I hold him in my heart each day! In my job as The Arc of PA's Executive Director, these core beliefs drive me in the work I do:

Separate is Never Equal - The solution is never to remove people from their community. When the eyes of the community are gone, safety is jeopardized. There were so many reasons that the conditions at Pennhurst and other institutions came about - lack of training, lack of funding, lack of direction. But the biggest issue was the lack of family and public involvement. When people are not part of their community, we see them as less valued and treat them accordingly.

Don't ever BUILD something today, that you can't dismantle later - We must always be able to respond to the needs and desires of the next generation. We must be able to adapt to new information, new ways of doing things, and most importantly, to the way people choose to live their lives as part of their community.

Never underestimate the POWER of individuals, parents, and families - Before I was a mom, I saw parents through my lens as a professional -- as the person who knew the right way to support their loved one. I thought I was being emphatic and thoughtful, yet I was incredibly naïve to the actual experience of being a parent. I learned so much from my own experiences as a parent and from really listening to parents. We are all stronger with the support of our families and we, as a system, should do all that we can to strengthen family relationships.

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TEDDI LEIDEN, PARENT PRESIDENT, 1977-1979

The Arc of Pennsylvania is a leader in supporting people with disabilities to recognize and exercise their rights. We are engaged in a Civil Rights Movement and our struggle is NOT OVER. We must all work to ensure that people with disabilities have the same life experiences and opportunities as every other citizen in Pennsylvania.

The Arc's history is our firm foundation. We are a force for change. We stand on this history - the parents and the individuals with disabilities that fought for what we now consider basic human rights. And yes, our work continues. We must focus our work on assuring that students are educated alongside typical peers; that those who choose, have access to competitive, integrated employment and the supports necessary to make that happen. We believe that society is better when all its members, including people with disabilities, are full and contributing members of the community.

The history of The Arc of PA is the result of parents who were willing to speak out and work on behalf of not only their son or daughter, but every person with an intellectual and developmental disability. It is this strong, never ceasing advocacy that now includes consumers and self-advocates which will enable this wonderful, challenging, demanding, and exciting movement to go forward.

Parents devoted their lives promoting this movement...parents crisscrossed the state documenting the inhumane and dehumanizing conditions of institutions - conditions that we must never forget. These institution reports triggered the court cases that have made such a difference in the lives of people with intellectual and developmental disabilities.

For those of you who have been involved in the movement for any length of time, this history will bring back many bittersweet memories of battles lost and won. For those of you just entering the movement, whether family or friend, we hope it will inspire you to maintain the accomplishments of the past and to work diligently for an even brighter future - a future which can only happen with your personal commitment of time and talents.

Source: *Teddi Leiden, Blair County, Historical Overview 1949 to 1990 - Edited by Linda Drummond, 1990.*

“HIGH TIME TO STOP HOPING... TIME TO ACT!” (HEADLINE, PA MESSAGE, JULY 1969)

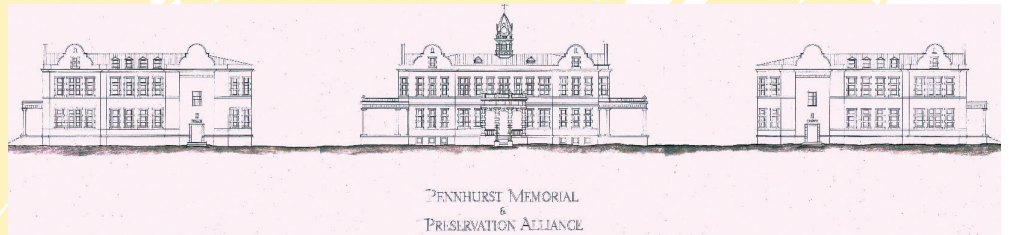


Exhibit 2-2, Population Trends at Pennhurst Center (1966-1984), Excerpts

Date	Clients on Books	Admissions	To Normalized Environments	Transfers
1966	3071	51	57	22
1969	2653	94	184	158
1972 Right to Education Consent Decree	2217	90	63	79
1975 Halderman v. Pennhurst	1619	81	49	85
1984 Pennhurst, Final Order	576	1	180	5

Source: *The Pennhurst Longitudinal Study, U.S. Department of Health and Human Services, Washington D.C. & Temple University, Philadelphia, 1985*

BOLD ACTION CREATED WIDESPREAD CHANGE

**James R. Wilson, Jr.,
President, 1969 - 1971**

The historic discrimination of Pennsylvania's children with intellectual and developmental disabilities, regarding education opportunities, was not the result of actions by any one person or state government administration. It was the result of the accidental occurrence of many factors over many years. Among these factors was the erroneous concept that people with disabilities were unable to benefit from education as do others.

In the 1960's, the leadership of PARC, (Pennsylvania Association for Retarded Children, now known as The Arc of PA) had noticed the huge changes sweeping the country. Previously ignored minorities including African Americans, gays, women, and others began to emerge, speak out, and fight for their individual rights. It was a time of institutional change as James Gardner, then former Health, Education & Welfare Secretary called it, "the tension between released human aspirations and sluggish institutions."

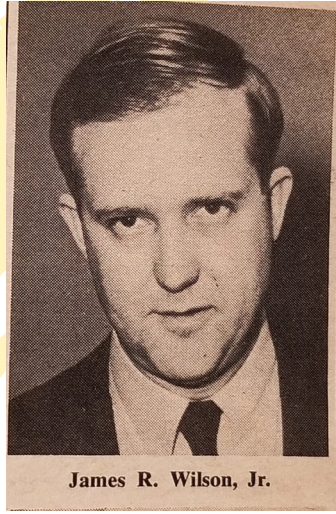
Where were people with disabilities? For years they were neglected and ignored. Many were forced to live in state institutions like Pennhurst, which our board member and chair of the Legal Action Committee, Stu Brown said "was a place where many are sitting around aimlessly without motivation, hope, incentive, or programs." Others lived at home, often in dark back rooms or just were left to roam the streets at their own risk. Of course, there were a few who were fortunate to live in loving homes where they received many advantages.

"NOW WITH FAITH AND COURAGE WE MUST GO FORWARD AND FIGHT." JIM WILSON

For many years, there were investigations, TV and newspaper reports, visits to Pennhurst by legislators, as well as The Arc of PA advocates, and other efforts to effect change. But these initiatives faced huge stumbling blocks of resistance.

And there were other obstacles. We tried to negotiate with Pennsylvania state government to bring about change. Another stumbling block... parents' fears of possible retaliation against their love ones if they spoke too loudly and advocated for change. Additionally, we faced the widespread belief in the necessity of mass care for people at state institutions far from their families and communities.

The Arc of PA leaders realized that we had to be bold and have faith -- to take action in order to create change. The time was propitious to do so. We had noticed the 1954 Brown ruling of the U.S. Supreme Court which recognized the constitutional right of black students to receive a public school education.



Then there were other signs. Executive leadership, on the part of President John F. Kennedy, established the President's Panel on Mental Retardation. This panel made a big contribution to the discourse over the rights of people with disabilities. An outgrowth of the President's Panel was comprehensive planning in over 50 states proposing recommendations for community services. And then there were the courts, beginning with California and Alabama, asserting the rights of those with disabilities.

At the 1969 PARC Convention in Buck Hills, the delegates were very frustrated, but there was hope for change. I expressed these feelings in my address to the delegates, as the newly elected president. I strongly urged the delegates, as did other leaders, to have courage. I said in my opening address to the Convention that, "It was high time to stop hoping...time to act!" I noted that we had gone the route of the executive branch, the legislature, and bureaucracy with little or no results. "Now with faith and courage we must go forward and fight."

The rest is history. At the Convention, the delegates resolved to file a lawsuit to close Pennhurst or

explain why not. Subsequently, we retained Tom Gilhool, Esq. as Counsel. Even though there were other leaders who played significant roles, without Tom this story would not have the ending that it did. Tom went to work and recommended several courses of action but settled on a right to education approach. He said that this would impact the program at Pennhurst and further advance beyond the residential context there.

In November of 1969, PARC took the audacious forward step and accepted Tom's recommendation. The Board gave him the approval to sue the Commonwealth. In May 1972, the Federal Court in Philadelphia issued its final order approval of the consent decree in PARC v. Commonwealth of Pennsylvania. This decree provided access to a free public program of education and training for school age children with disabilities. This was a game changer with huge national implications. Later Chief Justice Rehnquist of the U.S. Supreme Court said that the PARC decision was the source of two Federal statues, (1) the first civil rights act for people with disabilities - Section 504 of the Rehab Act of 1973, and, (2) the Education for All Handicapped Children Act of 1975 (now the Individuals With Disabilities Education Act, or IDEA).

In summary, this landmark initiative was the result of our leaders taking the bold initiative to get out of our comfort zone and step up and fight. Again, without Tom's brilliant work and passion, we could not have accomplished this. There were so many truly amazing folks who were there on the ramparts, too. They deserve the real credit.

Source: James R. Wilson, Jr. served as President from 1969-71. Mr. Wilson is the brother of Lowell. Lowell had special needs - "of course, this is relative" he says. Lowell was his only sibling and a fabulous brother. They were always great pals and buds. Lowell was himself very successful. He won many Special Olympics medals, was an accomplished pianist, had season tickets to the Philadelphia Orchestra, was an important member of the family and was a charmer. "Lowell changed the direction of my life for the better," says Mr. Wilson.

A PENNHURST SURVIVOR

Gerry Wheaton, Former Resident of Pennhurst Center

Interviewed by Jodi Dill, The Arc of Chester County



Gerry Wheaton and his sister were placed at Pennhurst by their parents. Gerry was 3 and his sister Theresa, was 4 at the time. Gerry would occasionally go for weekend visits back to his home, but trips were rare. His parents lived in upstate Pennsylvania - that was a long car ride home. Gerry lived at Pennhurst until he was 21. At age 21, he was “sent out” into the community.

What was your life like at Pennhurst?

While at Pennhurst, Gerry described doing many jobs. “Each job was based on each person’s intellectual ability”, says Gerry. He worked in the kitchen - moving food to and from the walk-in freezer. He helped prepare food for meals. He remembers seeing people coming in from outside to throw grass clippings and mud in the soup pots. The same soup was served to the individuals who lived there. He would not eat soup when he saw that.

Other times, Gerry would bathe the babies. Sometimes he saw that they would get burned in the bathtub because the caretakers wouldn’t check the water temperature first. He didn’t like that the babies were always strapped down in their cribs. Gerry says, “That was not right.”

In addition, Gerry worked on the farm where the livestock was raised. Gerry remembers, “The farmer didn’t like me because I named the animals. Then they would come to me when I called them.”

How did you manage the hard times?

Gerry said that Pennhurst was not a nice place. He remembers, “They were very strict and when one person got in trouble, everyone got beaten and abused.” Gerry currently lives in Spring City to this day. Jodi was a case manager from 1982-1985 and supported many individuals, including Gerry, who were discharged from Pennhurst to live in the community. Jodi asked Gerry, “How did you survive when so many became bitter from their experience at Pennhurst?” Gerry said, “I prayed to the good Lord every day to get me out of there.”

What happened when you left Pennhurst?

When Gerry was discharged at age 21, he was NOT a protected Pennhurst class member. The folks at Pennhurst sent him to an apartment in nearby Royersford. This apartment had no bathroom and he had to use two buckets when he needed to relieve himself. He later got a job at the Johnson Home which is a place for those who were elderly. He worked there for 7 and a half years. Later he got a job at the Valley Forge Military Hospital as a short order cook. He also worked at the post office as a janitor. He worked both jobs for 25 years.

What is your life like now? Now Gerry is retired. He has a nice apartment in Spring City and he says his life is much better. He has learned a lot since leaving Pennhurst. He learned to read using the basics. He has friends. “Everyone likes him!” says Jodi. He likes to walk. He goes out to lunch and he likes bowling.

Gerry receives supports from The Arc of Chester County. These supports help him live independently. Gerry wants to share a special recognition - this past winter he won the Dickie Geiger award at the Self Determination luncheon in Chester County. This is a self-advocate award for those who display remarkable self-advocacy skills. His sister died 3 years ago, and he misses her a lot. He plans to be buried next to her in Downingtown, Pa.

TIMELINE OF LEGISLATIVE & LEGAL ACTIONS 1954-1987

- **1954...** Legislation passed permitting public schools to provide classes for children with IQ scores under 50.
- **1955...** PARC and PA government officials tour state institutions, discovering severe overcrowding and long waiting lists. Legislation is passed to establish state-supported interim care facilities.
- **Late 1960’s...** Two major Philadelphia newspapers and a TV station began a series of exposes on Pennhurst following The Arc’s complaints about “deplorable” conditions.
- **PARC Consent Decree**
- **1969...** PARC files Right to Education Lawsuit against the Commonwealth of Pennsylvania.
- **1972...** The final Right to Education stipulation, a consent decree between PARC and the Commonwealth of Pennsylvania, is signed. This decree guarantees a free public education to all school-age children.
- **Pennhurst Litigation**
- **1974...** Winifred Halderman, the mother of 21-year-old Terri Halderman, a Pennhurst resident, filed a 1.25-million-dollar damage suit in U.S. District Court alleging that her daughter suffered more than 40 incidents of abuse ranging from a fractured jaw to a drug overdose.
- **1975...** PARC, alleging adverse and dangerous conditions at Pennhurst State School and Hospital, joins the Halderman v. Pennhurst suit as a plaintiff-intervenor.
- **1977...** U.S. District Court Judge Raymond J. Broderick agrees with PARC that Pennhurst Center is not a suitable environment for its residents. In a landmark decision, he finds the institution to be in violation of the civil rights of the people living there. The Commonwealth is ordered to replace Pennhurst with appropriate programs in the community.
- **1987...** Pennhurst Center is officially closed after an 11-year battle between PARC, advocates, and the Commonwealth.

THE ARC'S LEGAL REVOLUTION

Judith A. Gran, Esq. Halderman v. Pennhurst Counsel

In Halderman v. Pennhurst, The Arc of Pennsylvania revolutionized not only Pennsylvania's service system for persons with intellectual disabilities, but also the state of the courts' understanding of the rights of persons with disabilities. Before The Arc became a party in Halderman v. Pennhurst, the federal courts had tried to remedy institutional conditions by applying legal theories premised on a "right to treatment" - the concept that in giving up their liberty by entering an institution, persons with disabilities were entitled to receive treatment or habilitation in return. This theory treated persons with disabilities as passive recipients of care and treatment and failed to challenge the institutional model. In contrast, the district court's approach in Halderman v. Pennhurst was grounded in the Equal Protection Clause and viewed persons with disabilities as active citizens and persons who are created equal with their fellow citizens without disabilities.

The legal revolution that Pennhurst represented began in PARC v. Commonwealth, the landmark right to education case brought by The Arc of Pennsylvania. In the wake of the exposure of horrific conditions at Pennhurst in the late 1960s, the Pennsylvania Association for Retarded Children (PARC), hired an attorney, Thomas K. Gilhool, to analyze the various legal options and make a recommendation to the board. Tom suggested that the most effective approach to challenging Pennhurst would be to stop children from being sent there -- to "Close the Front Door." Tom recommended that PARC file a lawsuit challenging the interpretation of the Pennsylvania School Code of 1949, Section 1304, that allowed local school boards to refuse to educate children of school age who did not display a "mental age" of five years. Tom pointed out that these provisions of the School Code were much like the de jure segregation of African-American children that the NAACP Legal Defense Fund challenged successfully in the systematically planned and executed

series of lawsuits that culminated in Brown v. Board of Education, 347 U.S. 483, 495 (U.S. 1954).

The Arc of PA decided to file a lawsuit in Federal court based on the Equal Protection Clause to obtain the right to the free, appropriate public education enjoyed by every other child in Pennsylvania. PARC v. Commonwealth was filed in 1971 and settled in a consent decree in 1972, 343 F. Supp. 279 (E.D. Pa. 1972). The PARC decree was based solidly on the Equal Protection principle that all children, including those whose disabilities are most severe, are created equal, and that the exclusion of children with intellectual disabilities from school violated this legal guarantee. The court found that these children had been excluded, not because they were "uneducable and untrainable," but because of the stigma attached to the label of "mental retardation," stigma with its roots in the eugenics movement that began in the second decade of the twentieth century. 343 F. Supp. at 284.

After resolving PARC v. Commonwealth, The Arc of PA made plans for a follow-up suit on behalf of institutional residents and chose Pennhurst State School and Hospital as the target of the proposed litigation. Halderman v. Pennhurst was filed in 1974 by David Ferleger, a Philadelphia disability rights attorney, seeking damages for the egregious harm and abuse experienced by Pennhurst residents. In 1975, The Arc of Pennsylvania filed a motion to intervene in the case, seeking community placement of Pennhurst residents; the United States also intervened in the case. All plaintiffs quickly came to consensus that the goal of the litigation should be the creation of a network of Community Living Arrangements where all residents of Pennhurst could receive services in typical homes, communities, and neighborhoods. In 1976, the attorneys drafted and filed an amended complaint that reflected this goal.

By the time Halderman v. Pennhurst went to trial, legal scholars had already analyzed the implications of PARC for

confinement of persons with intellectual disabilities in segregated institutions. Professor Robert Burt, in "Beyond the Right to Habilitation" in THE MENTALLY RETARDED CITIZEN AND THE LAW 425-32 (1976), wrote that the PARC theory as applied to state institutions should mean that "any state program that segregates mentally retarded citizens as such from others is highly suspect because "large-scale geographically remote institutions cannot by their nature provide adequate programs to remedy the intellectual and emotional shortcomings and the galling social stigma that led the retarded residents to these institutions." Professor Burt concluded that "[i]f this evidence is fully marshaled in litigation, courts can . . . require alternative programs for mentally retarded persons which treat them as indistinguishably as possible from other persons."

The Arc's attorneys in Pennhurst, led by Tom Gilhool, made this argument to the district court, and the court adopted it, citing Professor Burt's article approvingly. In his opinion following the

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Tom Gilhool, Counsel for PARC, told the court "there is no reason for any person to be at Pennhurst, and that the record shows of the 1,264 residents, 76% have been there for 10 years or more, and the median age of the residents is 36." Gilhool said everyone went there as children, because no alternative care existed in the community.

Source: Pennsylvania Message, April 1977. Halderman v. Pennhurst Litigation opened on Monday, April 18th, 1977. Comments before Judge Raymond J. Broderick in his chambers before the proceedings began. At the time, Mr. Gilhool Esq. was an attorney at the Public Interest Law Center of Philadelphia. Thomas K. Gilhool, Esq. Special Counsel to PARC

trial, Judge Raymond J. Broderick held that segregation at Pennhurst violated the Equal Protection Clause because it was both separate and unequal.

In this record, the evidence has been “fully marshaled” and we find that the confinement and isolation of the retarded in the institution called Pennhurst is segregation in a facility that clearly is separate and not equal. We are convinced that the same equal protection principles enunciated by the court in Pennsylvania Association

of Retarded Children v. Commonwealth of Pennsylvania, 343 F. Supp. 279 (E.D. Pa. 1972), prohibit the segregation of the retarded in an isolated institution such as Pennhurst where habilitation does not measure up to minimally adequate standards. ... on the basis of this record we find that the retarded at Pennhurst have been and presently are being denied their Equal Protection Rights as guaranteed by the Fourteenth Amendment to the Constitution.

In all the appeals to the Court of Appeals for the Third Circuit and the United States Supreme Court, Judge Broderick's holding

that confinement of class members at Pennhurst violated the Equal Protection Clause was never reversed or vacated. Throughout those appeals, the District Court's orders remained in effect and implementation proceeded until the case was settled in 1984.

Judith A. Gran is a partner in Reisman Carolla Gran LLP and formerly served as Director of Disability Projects at the Public Interest Law Center of Philadelphia (PILCOP). She represented the plaintiff class in Halderman v. Pennhurst throughout the enforcement phase of the litigation, from 1984 to 1998.

THE ARC OF PA'S BATTLE CHANGED OUR SON'S LIFE

Dr. Joe Angelo, President, 1991-1993, Parent



The epic battle for the rights of people with intellectual and developmental disabilities really took hold with a decision by The Arc of Pennsylvania. The Arc of PA decided to file the lawsuit which resulted in the Right to Education and the closing of Pennhurst.

Nothing other than a lawsuit could have freed people with disabilities from the incarceration they endured. That

service care model was so large and so segregated from the rest of society. I say this because I was and still am a member of The Arc of PA. I had a role in subsequent lawsuits leading to the closing of institutions in Embreeville and in Canonsburg, more than 20 years after the Pennhurst case.

Arc members made unannounced visits

Conditions were bad in most institutions. The Arc members made unannounced visits to gain information first hand. That information was brought to the Pennsylvania Departments that administered the services, to the Governor's office, to the Budget Office, to legislators of both the House and the Senate. We got mostly lip service. Some Governors proposed 5-year plans to move all residents out of institutions and into their communities. Their plans died on the vine. That was a shame. It gave us hope, and then let that hope die.

Maybe the Administration didn't push hard enough. Maybe the Legislature was unwilling to find the revenue to do the right thing. Maybe it was the lobbying of unions that realized that most of the jobs of people who worked in institutions

would be lost. Maybe it was the prejudice of communities who were afraid that if people who lived in institutions moved into their neighborhoods, their property values would go down. No one seemed to realize that to keep the status quo, tens of thousands of people were being incarcerated just because they had a disability.

Grateful to The Arc for courageous action

While the Pennhurst case was before my time in The Arc, I felt the same frustrations the families of people living in Pennhurst must have felt. I am so grateful to them and The Arc for the courageous efforts in bringing that landmark lawsuit to trial. They demonstrated that when the other two branches won't move on such an important issue, we can use the judicial branch as a last resort and win!! Judge Broderick, who presided over the settlement of the Pennhurst case, did a marvelous job in the face of some severe opposition, including that of many parents of children who lived in Pennhurst. His order, that I think was amazing for its time, was that the people who were most severely handicapped would be the first to move into community living.

I had a significant role in the closing of the institution called Western Center in Canonsburg, PA which stopped taking admissions in 1992. It closed completely in the year 2000. Charlotte Twaddel, president of The Arc of Pennsylvania, asked me to serve on a Task Force to determine what the conditions were at Western Center and to make recommendations as to how The ARC should proceed.

Vivid memories of institutional life

The task force consisted of advocates from The Arc and from Pennsylvania Protection & Advocacy, now called the Disability Rights Pennsylvania, and there may have been some others. We numbered about 15 to 20 advocates who formed several small groups. We made an unscheduled visit to the Western Center campus and quickly went to several buildings simultaneously.

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We saw many things that day that were inhuman and certainly inhumane. I visited a day room in one of the buildings and found everyone in the room, residents and staff, all “watching” the NCAA Basketball Tournament. More correctly, the staff was watching while the residents were just there. Some of them were lying on pallets in their own feces.

We saw people being fed in shifts, each shift taking about 20 to 30 minutes. Most people were eating pureed food because they had no teeth. There seemed to be very little programming. After we were there awhile, we found some of the residents bowling with plastic pins and balls in the hallways.

We had an informant working undercover at the time. He reported that many of the staff wore keyrings that looked like paper clips, but were about 12 to 18 inches long. They were used to move people along; kind of like herding cattle. He also reported that they sometimes used them for corporal punishment. We saw the keyrings but saw no abuse while we were there.

The Task Force recommended the lawsuit, and at a press conference a few weeks later, I announced our decision to sue the Commonwealth. Our plan was to seek improvement of the conditions at Western Center and the return to community living for all of those deemed capable of living in an integrated environment.

What we learned compelled us to raise our son in the community

When my own son, John, was born with Down syndrome in 1972, my wife Shirley and I accepted his care as a ministry. We had six other children to help us in the task and all of them helped John to develop his gifts. He became and still is a prominent member of our community in Indiana, PA. He became his own advocate and advocates for others with disabilities. The year after he was born, Shirley and I joined a group of 25 people who wanted to form a chapter of The Arc. Just about that time, The Arc of PA was celebrating the court victory that resulted in education for all children with disabilities in Pennsylvania. I went to the Annual Convention of The Arc of PA in 1973 and was so impressed that I became active at

both the state and local Arc chapter and remain active today.

Because of what I was able to learn through The Arc, Shirley and I made critical decisions when John was just an infant. We decided to engage him in as many activities as we could. He had early intervention before it was ever started anywhere. Between the ages of 1 and 3, John had swimming lessons, speech therapy, and he participated in an infant stimulation program offered by The Arc of Armstrong County. Through that program, we were encouraged to enroll John in a regular nursery school, and then enrolled him in a regular kindergarten class at the Indiana University of Pennsylvania's Laboratory School. Then the local Intermediate Unit and the University received a grant to begin an inclusive education program for children in grades K-6. He had a marvelous start and was reading at near the 6th grade level when he graduated to secondary school.

I eventually became the president of The Arc of PA at a time when The Arc was still battling for institution closures and for inclusive education. Our goals were 1) to assure that students with disabilities would be educated alongside students without disabilities, as much as possible; 2) to expand opportunities for employment in the community in real jobs; 3) to assure that students would have a meaningful transition from school to work. John had all those things and as a result had a regular job in a community pharmacy for 24 years. He held this job until his abilities began to decline. Aging occurs earlier for most people with Down syndrome. So, he retired, but has decided to remain active in the community through his many volunteer opportunities. He tells people that he retired so he could become his parents' caregiver!

Our whole family has been blessed to have John in our lives, and The Arc, through its advocacy for people with intellectual disabilities, has been able to help many other families to have the same experience. John has written a book about his life called *My Wonderful Life*, a fitting title for someone living in Indiana, PA, the home of Jimmy Stewart. And that's what it has been, for him and for many others, thanks to The Arc of PA and its many chapters.

THE PENNHURST LONGITUDINAL STUDY - PEOPLE ARE “BETTER OFF” IN THE COMMUNITY

The Pennhurst Longitudinal Study was a five-year, in-depth review of the effects of the court-ordered deinstitutionalization of Pennhurst residents. Its aim was to provide federal and state officials and others with information to make better policy decisions regarding the processes related to the deinstitutionalization which is underway in many parts of the country. Federal planners, recognizing the significance for clients, families, communities, and states of Judge Broderick's and other similar actions, decided in 1979 to launch this five-year study.

The Pennhurst Longitudinal Study tracked all the people who left Pennhurst and moved into small community homes from 1978 onward. More than 1100 people were visited every year for over 15 years, measuring their qualities of life, comfort, health, and safety. The study showed conclusively that the people were better off in almost every way we knew how to measure. It has been repeated in 12 states and several other nations with the same results. The Pennhurst Study and its replications are still shown all over the world as evidence in favor of the United Nations Convention on the Rights of Persons with Disabilities - Article 19 of which states that no one should grow up in, or live their life in, a big segregated institution apart from society.

Source: Dr. James Conroy,
James W. Conroy, PhD, Pennhurst
Memorial & Preservation Alliance
www.preservepennhurst.org
Center for Outcome Analysis
www.eoutcome.org

Dr. Conroy was a Principal Investigator
of the Pennhurst Longitudinal Study.

PENNHURST CLASS MEMBER

Jerome Iannuzzi, Jr. was only 13 years old when he and his brother were placed in Pennhurst State School and Hospital in 1951. During his stay he would see and experience much abuse and terror. He was forced to work for no pay on the farm raising food for the institution during the day. At night he fed, washed and cleaned residents who were referred to as 'low functioning.' While at Pennhurst, a caring staff person taught him the basics of reading and writing.

Jerome was released in 1966 at age 28. By 1985, he had become one of the early leaders in the self-advocacy movement and an officer of Speaking For Ourselves. He worked tirelessly for his friends and colleagues still living in institutions. Jerome made presentations to governmental officials, college students, and professional groups. When we first started doing work to close institutions, he was worried about the folks with the most severe disabilities. He would say, "Where are they going to go?" He knew firsthand how much help some people needed, and it was hard for him to fully embrace community life for everyone. He had to go visit several homes in the community and see some of the people he had provided care for at the institution, now living successfully in the community. After that, he became a fierce advocate for everyone to live in the community.

In 1990, Jerome was appointed by Governor Dick Thornburgh to serve on the Pennsylvania Developmental Disabilities Council. This gave him a platform to speak out against the institutions and promote their closure. He was one of the first self-advocates in the country to be appointed in his own right to serve on a Developmental Disabilities Council. He was also interviewed on radio and television. He spoke at public forums of his experience as "a frightened child locked in a room" and about "seeing the unmarked graves of people who had lived almost their whole lives at Pennhurst."

Jerome shocked us all when in 1993 he announced his engagement to a woman who was also a member of Speaking For Ourselves. None of us had known that they had been long time sweethearts at Pennhurst. At that time, few former residents of institutions had gotten married.

When Jerome passed away at the end of the year in 2003 from a heart condition, we were all deeply saddened. The advocacy movement had lost a powerful voice for freedom and justice. What a journey he lived, from being "put away" as a teenager to major advocacy and a happy marriage.

Source: Conroy, J. (2018, personal communication). Pennhurst Survivors Vignettes 2018-04-26a. Pennhurst Memorial & Preservation Alliance. Havertown, PA.

VISIONARY VOICES

A Project of the Institute on Disabilities, Temple University

Pennsylvania played an important and historically significant role in the creation of public policy (both through legislation and litigation) changing the way people with intellectual disabilities live in our community. From the right to education, to the closing of institutions and the movement toward self-determination, Pennsylvanians with disabilities, family members, and advocates paved the way for national policies that led to widespread reform. The Institute on Disabilities is working to preserve this largely untold history through its Visionary Voices project. Featuring oral history interviews with the Movement's leaders and archival documents significant to the Movement, Visionary Voices tells the ongoing story of the struggle for equity and inclusion. Watch a short documentary on Visionary Voices or BROWSE THE INTERVIEWS. <https://disabilities.temple.edu/voices/>

REMEMBERING MOMENTS THAT CHANGED YOUR LIFE'S WORK

Eleanor Elkin, President, 1957-1959, Parent



Pictured: Ken Oakes, President, 2015-2017; Eleanor Elkin (seated), President, 1957-1959; Maureen Cronin, Executive Director; & James R. Wilson, President, 1969-1971.

Eleanor and her husband adopted a son and they grew to love him deeply. The adoption agency later came back to them saying "We gave you a defected one. You can turn him back." The professionals explained how he needed extra care and extra treatment and that the best possible place to receive that care was at a large facility for children with disabilities. "And, we now have a little girl for you."

Believing the experts, Eleanor agreed to let him live at the facility. Wanting to stay connected, she visited him there. What she saw was striking. She saw him playing by himself, no friends, no adults around, very lonely. The fight was on! She and her husband were determined to get him back home.

This story has a happy ending. Her son came back to live with his family, but, the Elkins were never allowed to officially adopt him. He remained a "ward of the state" till his death.

Source: As told by Eleanor Elkin to Maureen Cronin, Executive Director, The Arc of PA, May 2018.

THE PENNSYLVANIA STATE TASK FORCE ON THE RIGHT TO EDUCATION

Janet Albert-Herman, President 1999-2001, Parent

State Task Force member, representing The Arc of Pennsylvania 1993-2004

Exciting changes began to take place in Pennsylvania in the later 1960s and early 1970s with a dynamic and bold group of volunteer leaders within PARC (Pennsylvania Association for Retarded Children). This was an era of “civil rights” for all. It is often stated that “timing is everything” and this was our time for advancing the rights and freedoms for persons with intellectual disabilities. In January 1971, PARC filed PARC vs. The Commonwealth of Pennsylvania.

By October of 1971, a Consent Order was approved and adopted by the Commonwealth, the Department of Education, and the Department of Public Welfare. The agreement mandated the development of a Commonwealth Plan for the Identification, Location and Evaluation of Mentally Retarded Children (COMPILE), and a Commonwealth Plan for the Education and Training of Mentally Retarded Children (COMPET). Due process procedures were also established. Within weeks, COMPILE was drafted and established a state task force and 29 local task forces (one in each intermediate unit). Their primary purpose was to ensure that the intent and spirit of the Right to Education Consent Agreement was carried out throughout the Commonwealth.

To identify, locate, evaluate, and then to educate new children in the current system proved to be a daunting task for the Commonwealth. There were guesses of 40,000-50,000 unserved children in the Commonwealth. To find these children a massive campaign, both in and out of the disability field was created. On Friday, May 12, 1972 at the Zembo Mosque in Harrisburg, 1,300 educators, school psychologists, and other intermediate unit personnel, as well as PARC chapter representatives, listened to Governor Shapp kickoff the search for those, “retarded children who have not been able to be afforded an education - The CHILDHUNT”.

All 29 Local Right to Education Task Forces were asked to organize and assist with

This desk is empty!
A Retarded Child can fill it!

50,000 retarded children in Pennsylvania can be in school because: a recent Federal court order guarantees the right to a free public education to every retarded child, age 6-21.

Join the Pennsylvania **CHILDHUNT**

If you are the parent of a retarded child, or know a retarded child who is not in school **Let us Know!**

contact: The Pennsylvania Association for Retarded Children, Inc. 2 North Second Street - Harrisburg, Pa. 17101 phone 717-238-4767

Contact your Local P.A.R.C. Chapter

Childhunt Activities

finding children in their own local areas. PARC’s own “CHILDHUNT” campaign and Government’s “Child Search” marketing tools were used for locating children. The campaign included television and radio spot announcements, envelope stuffers, local newspaper features, large posters in food stores, requests to state senators and representatives to include “child search” in their letters to constituents, even the Liquor Control Board enclosed announcements in their consumer packages.

By the start of the school year in September 1972, over 8,000 children in the community and 3,000 living in institutions were found, identified, evaluated, and were ready for school in less than four months. Teachers, therapists, psychologists, nurses, and aids were quickly hired and trained. The efforts among the Department of

Education, the Department of Welfare, the Governor’s Office, and PARC was proving to be a successful partnership and a strong beginning for the newly formed State Task Force on The Right to Education.

I was fortunate to sit at the State Task Force table with the Governor’s Office, The Department of Welfare, and The Department of Education for eleven years. I supported annual statewide trainings for Local Task Force parent leaders. We established video conferencing at the three regional PATTAN offices to connect with more Local Task Forces. We forged ahead on the never-ending quest for additional monitoring of classrooms. It took great leadership almost fifty years ago when the lawsuit was filed, and the agreement was implemented. It takes great leadership today to continue its responsibilities, still relevant in today’s world, as we continue our quest for an appropriate education for all.

“Have you ever had the experience of asking for a service and be refused on the grounds that “she is totally incapable of learning what I have to teach - she belongs with her own kind - in an institution.” Can one ever put down in order, pain, love, frustration? Can one ask unemotionally, “Why are some people expendable”? “Why is one life less valuable than another?” “Why are people less important than potholes?”

Source: Pennsylvania Message, December 1974, Teddi Leiden’s Letter to Special Assistant to the Governor, Teddi Leiden was President, Blair County PARC at the time. Teddi was the parent of a child with disabilities. Ms. Leiden also served as President of The Arc of PA, 1977 - 1979.



The Arc[™]

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PENNHURST NOW? PENNHURST FUTURE? THE PENNHURST PRESERVATION WORK

For the past decade, The Pennhurst Preservation Work (PMPA) has been working to find a way to memorialize what happened at, and because of, the Pennhurst institution. The Superintendent's Mansion is one possible avenue. Under consideration is setting up "pop-up" museums to inform the public during the Halloween season. Roughly 50,000 people pass by that property each season as they attend the Pennhurst Asylum. The Pennhurst Asylum has historically contained imagery that is degrading and demeaning to the memory of folks with disabilities - but which is gradually decreasing to focus instead on traditional horror images of vampires, mummies, and monsters. The real long-term goal of all the PMPA efforts is to contribute to the creation of a national place of dignified memory and learning about American's least known great civil right movement - disability rights.

For more information about PMPA and its work, contact: Pennhurst Memorial & Preservation Alliance, www.preservepennhurst.org/ 610.246.5961. 426-B Darby Road, Havertown, PA 19083.

MISSION STATEMENT

The Arc Pennsylvania promotes the human rights of people with intellectual and development disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.