

## Honoring 40 Years of Progress

### ANCOR Attends Pennhurst Marker Dedication

Once called the shame of the nation, Pennhurst State School and Hospital in Pennsylvania was the epicenter of a civil and human rights movement that changed the way the world saw people with intellectual and developmental disabilities. The atrocities of neglect at Pennhurst resulted in U.S. Supreme Court litigation that sounded the death knell for institutionalization worldwide.

More than 10,500 Pennsylvanians with developmental disabilities lived at Pennhurst from 1908 to 1987. Many Pennhurst employees struggled to provide the best life for residents they could in spite of a critically broken system and appalling underfunding by the state. Many considered the individuals they supported to be family and stayed in touch long after the institution closed.

On April 10th, the Public Interest Law Center of Philadelphia and the Pennhurst Memorial & Preservation Alliance marked the day under the theme “Tragedy Triumph: Telling the Pennhurst Story,” by concluding the day’s events with the dedication of a state historical marker. Hundreds of current and former state officials, family members, former residents, and advocates joined the many sponsors of the day to honor and remember the sacrifices and the humanity that changed the world for the better.

The event’s Dedication Planning Committee was emphatic in its desire to create a mechanism to recognize and honor the thousands of individuals who worked to make Pennhurst better, those who worked to end the kind of

institutionalization Pennhurst represented, and those who continue to serve at the vanguard of the struggle for true freedom for persons with disabilities.

The inscription on the marker reads:

*Between 1908 and 1987, more than 10,500 Pennsylvanians with developmental disabilities lived here. Public controversy over the inhumane treatment of residents and two decades of complex litigation, including three arguments before the US Supreme Court, led to the institution’s closure. Groundbreaking advocacy and new public policy, including transition to community-based living, made*

*Pennhurst a milestone in the disabilities civil rights movement.*

### *A Brief History of the Groundbreaking Court Rulings*

Pennhurst was the battleground in a monumental struggle to secure basic human rights for one of the last groups of Americans to attain privileges assumed to be the natural freedoms of all persons. According to the event’s planners: “Pennhurst’s historic and beautiful campus is, like Valley Forge and Independence Mall to the east, hallowed ground in the struggle for dignity and self-determination, a western anchor to a freedom corridor, that, though stretching but a few miles, reaches all the way around the world.”

In 1903, the Pennsylvania Legislature authorized the creation of the “Eastern State Institution for the Feeble-Minded and Epileptic”—the second such state-operated facility—in Chester County. The legislation stated that, “The buildings shall be in two groups, one for the educational industrial departments, and one for the custodial or asylum department....” Overcrowded from the outset, Pennhurst came under fire from within the institution as early as 1912. In the same year, the Superintendent reported to the Board of Trustees that, “It is without question absolutely wrong to place the feeble-minded and epileptic in the same institution. They are not the same; they are as different, one from the other, as day is from night.... and require entirely different treatment.” The Pennhurst Hospital was opened in 1921, essentially completing the development of the original campus. By 1955, the in-house population of Pennhurst peaked at 3,500 individuals. Conditions at Pennhurst were exposed in 1968 through a five-part NBC News television report, followed by numerous newspaper articles,

See *Pennhurst*, page 5.



*The Pennhurst Marker and Participants in the Dedication Ceremony*

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*Pennhurst, from page 1.*

legislative inquiries, and other investigations. A "right to education lawsuit" (*PARC v. Commonwealth of PA*) was filed in Federal District Court by the Pennsylvania ARC, the Public Interest Law Center of Philadelphia, and Thomas Gilhool, Esq. In 1975, the Pennhurst plaintiffs moved to intervene in the landmark civil rights case *Halderman v. Pennhurst State School*, originally filed by David Ferleger, Esq., on behalf of a mother of a Pennhurst resident in the District Court for the Eastern District of Pennsylvania. The 1977 ruling in favor of the Pennhurst residents declared that forced institutionalization of persons with disabilities as unconstitutional.

The District Court's orders remained in effect throughout multiple appeals and two trips to the United States Supreme Court. The Pennhurst Longitudinal Study from 1979 to 1985 found that Pennhurst residents who moved to the community were "better off in every way we know how to measure." By 1984, a final settlement was reached in *Halderman v. Pennhurst* that provided for the closure of Pennhurst.

In 1987, Pennhurst closed and, in 2008, it was sold to Pennhurst Associates for \$2 million.

## *The Struggle Continues*

Unveiling the Pennhurst State School and Hospital marker is not an end; it marks an important milestone in the continuing effort to assure that the struggle of individuals with disabilities to secure their human and civil rights is not forgotten, but continues.

ANCOR is joining with other national organizations in cosponsoring events this July marking the 20th anniversary of the passage in 1990 of the American's with Disabilities Act. The current administration has rededicated efforts to enforce the U.S. Supreme Court's 1999 decision in *Olmstead*. ANCOR has joined in many U.S. Supreme Court and federal court amicus curiae (friend of the court) briefs in support of the rights of individuals with disabilities in the areas of housing, community living, education, employment, and transportation.

ANCOR providers continue to rely on *Pennhurst, Halderman, ADA, Olmstead*, and other legal precedents in state and federal challenges to state budget cuts and adverse policy decisions. ●

*I don't think anybody anywhere can talk about the future of their people or of an organization without talking about education. Whoever controls the education of our children controls our future.*

*--Wilma Mankiller*

*CEO, from page 2.*

4. Shaping corporate identity. Shaping organizational identity, clearly communicating unique value-added, and aligning organizational with personal values is key to maximizing engagement and commitment.

5. Appreciating diversity. Emphasis must be on an appreciation of multiple points of view and knowing that the existence of differing points of views is vital to arriving at a full understanding of an issue and of possible outcomes.

Generation X is well suited for the leadership challenges ahead and is more prepared than any other modern generation to trade idealism for realism. Let's embrace the opportunity that nurturing this generation will bring to assuring a vital future. ●

*President, from page 3.*

and find. The second is to affect that information, both proactively and reactively.

I think we will always need training. We will always need to teach other how to lead and or manage or both. We as providers will always need clinical training so that our services are effective and reflect state of the art techniques. We need to expand and diversify our training and training market.

Historically, ANCOR has offered providers a forum to network and develop relationships with people and organizations that can teach them something or offer products, training, etc. ANCOR has not only served this function well in the past, it will excel at it into the future, as we add tools like ANCOR's Connected Community (ACC), the purchasing collaborative (SRPN) and other communities of specialties that will meet our members' needs. One need that I think will increase is the opportunity for face-to-face contact, in fact it might become quite novel. As I look at my past years in ANCOR, we have gone from virtually everything being a face-to-face contact to a flood of alternative and more efficient means of getting that needed information, networking and idea sharing. And not just ANCOR- it's everywhere. There was time when a good portion

of everyday was spent on the phone returning calls. Now its email, texts, writing on peoples walls (hell, we used to get in trouble for that as kids!) carrying on voice mail conversations etc., none of that time spent with a live person. The face-to-face contact is simply getting rarer. I think we should position ourselves for this; the rare has great value.

No doubt the future will come and will be different than how I see it now. In fact, I hope never to have to re-read this article in the future. So be it. I invite you all to celebrate our past and join in looking into the future. Send me your thoughts about what you see in ANCOR's future. Take part in those rare face-to-face encounters but join ANCOR's [Connected Community](#) as well. There is room for both and we need to make sure there is always room for both. Come join us in Washington in September to learn about your future in the health care reformed world. And while you're at it, enjoy today. ●

