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**WE WERE
MOTHER
BEARS”**

**THE WOMEN WHO SHAPED
WESTERN PENNSYLVANIA'S
DISABILITY RIGHTS MOVEMENT**

**BY TINA CALABRO
AND SIERRA GREEN**

Disability rights advocates demonstrating in downtown Pittsburgh to oppose a state government measure that would have charged parents for school and employment services received by their intellectually disabled children.

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On a cold January day in 1973, three women—Jean Isherwood, Barbara Sistik, and Ginny Thornburgh, all mothers of children with disabilities—gathered for what had become a singular mission: visit overcrowded and understaffed state-run institutions to investigate complaints from worried parents about the treatment of their sons and daughters with intellectual and developmental disabilities. They were active members of Arc Allegheny, a parent-led organization dedicated to the rights of people with intellectual and developmental disabilities.¹

On this day, the group was headed to Polk State Center in Venango County, a two-hour drive north from Pittsburgh. Polk Center opened in 1897 as a large-scale institution that housed thousands of children and adults with intellectual and developmental disabilities. Over decades it grew to be an indelible part of the economic and cultural life of the region.

Postcard of the Polk State Center campus, Venango County, PA, c. 1920.

Pennsylvania State Archives, MG 213 Postcard Collection, ca. 1880-1974.



Bob Nelkin, a young Arc Allegheny staffer, volunteered to drive. Behind the wheel of a family station wagon, Nelkin listened intently as the women discussed the overcrowding and poor conditions they saw on a scheduled visit to Polk Center a few months earlier and their intention to gain entry to areas that had previously been off limits to them. This time, the investigating team was arriving unannounced.

What the mother advocates saw and later wrote up in a report that day exceeded their worst imaginings. Residents tied to benches. Unbelievable stench. Overwhelming noise and confusion. A child lying in her own vomit.

Emotions ran high on the trip back to Pittsburgh. *What can we do? We can't just walk away.* Strategies to get people's attention and spur action begin taking shape: *Demand action. Call reporters. Appeal to the governor. Alert the Department of Public Welfare. Go*

back to investigate further as soon as possible. We likely have not seen the worst of it.

Four months later, that ominous prediction would prove to be true. In one of the wards of the institution, investigators saw a person in a cage. It was a breaking point. "We were mother bears," Ginny Thornburgh explained years later. "It was our job to explain why we were there to the superintendent, and what we expected to see.... We had no right to visit unless we in fact improved the quality of care for those children and adults. Just going in and interrupting program would be wrong, but if we in fact could make a difference, then we had a right to do that." She added that an important part of the work was not just "to guarantee safety and programs, but to guarantee dignity and respect."²

The mothers would meet with resistance at nearly every turn, seen by many as outsiders who had no professional training or

preparation to undertake this work. Despite this, they deployed the skills that they had for their cause. In addition to their first-hand experience raising children with disabilities, each of these women advocates brought unique personal strengths to the mission. By and large, they came from a social stratum that encouraged volunteerism and had sufficient support at home to take on a larger public role. "They were all middle-class or professional class, and mostly suburban," said Nelkin, adding that they brought resources from their memberships in women's organizations and other networks. These connections were important to the disability rights movement because, he explained, "When you got to the political persuasion, it brought a lot of credibility."³

PANELISTS:

Mrs. Virginia Thornburgh, Chairman
ACC-PARC State Schools & Interim Care Committee

"WHY WE CRY"



Mrs. Barbara Sistik
ACC-PARC Inspection Team & DPW Western Regional Review Committee

"WHAT WE LOOK FOR"



Mrs. Jean Isherwood, Chairman
Interim Care Facilities, PARC

"BEDS -- NOT PEOPLE"

Robert Nelkin, Director
Community & Chapter Affairs Division, ACC-PARC



"ARE THINGS CHANGING"

PATRICIA CLAPP

In their passion to challenge the degradation of people in institutions, the mother advocates stood on the shoulders of others who, just a few years earlier, first issued a call to action. One of these women was Wilkinsburg native Patricia "Pat" Clapp. Pat began her career as a disability rights advocate in the early 1950s, when, as a member of a women's club, she raised funds to establish one of the first preschools in the region for children with intellectual disabilities. This preschool opened in 1953 and was overseen by Arc Allegheny.⁴

Pat's advocacy became personal in 1955, when her son David was born with Down syndrome. When the Clapps reached out to the American Medical Association for information about the best services for David, they received a letter telling them that "the advice usually given is that such children should be placed in some institution, since there is no chance that the condition can be improved."⁵ "That was a dark letter," Pat said. "I just decided [institutionalization] was not

Pat Clapp (back row, center) with her children David, Jean, and Jeff on the occasion of David's fifth birthday in 1960. David was very fond of celebrating his birthday each year.

HHC Detre L&A, Patricia Clapp Papers and Photographs additions, 2023.0190.



going to happen to my child.”⁶ The Clapps charted a different course for their son that would include education, support services, and community inclusion. David’s educational journey began with a twist of fate: he would attend the preschool that his mother had founded.

By 1969, Pat had been active in Arc Allegheny and its parent organization, the Arc of PA, for more than a decade. She was present at its annual convention in 1969 when members discussed the gross lack of educational opportunities for disabled children. In conversation with legal counsel,

the Arc of PA decided to file a class action lawsuit that would envelope as many disabled children as possible in its assertion for the right to education.⁷ Similar to Pennsylvania, 80% of American children with disabilities were not being educated in public schools as late as 1970. This groundbreaking case brought by the Arc of PA and its legal team from the Public Interest Law Center sought to establish every child’s right to a “free appropriate public education.” As Pat rose in the ranks and became Arc of PA president in 1972, the lawsuit was settled. Pennsylvania’s *Right to Education* consent decree guaranteed a free public education to disabled children and influenced the Federal Government to pass the landmark Individuals with Disabilities Education Act (IDEA) in 1975.⁸ She and her colleagues launched an outreach campaign to let families know about the newly won rights for children.



— Press Photo by Robert J. Pavuchak

PAT CLAPP **DAVID CLAPP**
She was told he would never walk.

Pat Clapp with her son David on his *Pittsburgh Press* paper route, 1972. As early as 1966, the Clapp family shared their story with the public to reduce stigma around intellectually disabled people and to promote home- and community-based models of support.

The Pittsburgh Press, March 6, 1972, 9. Copyright ©, Pittsburgh Post-Gazette, 2024, all rights reserved. Reprinted with permission.



Pat Clapp used this briefcase, a gift from her husband Harry, in her disability advocacy work. As her daughter Jean fondly recalled, Pat would frequently take daytime flights to Harrisburg to meet with government leaders involved in the care for intellectually disabled people. Pat ensured that she was home from these trips before her children arrived home from school.

HHC Collections, gift of Jean Clapp Groome. Photo by Liz Simpson Romano.

Pat Clapp used this Dictaphone in the early 1970s to record conversations during unannounced site visits to state-run institutions for people with intellectual disabilities. Pat and Department of Public Welfare Secretary Helene Wohlgemuth investigated alarming reports concerning the use of cages to confine disabled individuals at Polk State Center. After Wohlgemuth fired Polk's superintendent, the women received both backlash and support.

HHC Collections, gift of Jean Groome, 2024.1.1. Photo by Liz Simpson Romano.



While knee-deep in the logistics of locating disabled children who had been turned away from public schools, Pat did not lose sight of the large-scale, state-run institutions for intellectually disabled individuals. These institutions were a source of grave concern for her and other Arc members. Reports of human rights violations at these facilities had loomed large for years, and Arc leadership decided to place a renewed emphasis on investigating conditions at these facilities. As Arc of PA president, Pat maintained close contact with her peers at the local Arc Allegheny chapter. Recalling this early era of the Disability Rights Movement in Pennsylvania, Bob Nelkin reflected that Pat “was one of the first to show leadership in advocacy” and that she was “a force within the movement.”¹⁰

GINNY THORNBURGH

GINNY THORNBURGH was one of three mothers who took up the mantle of advocacy from Pat Clapp at Arc Allegheny in the 1970s. Ginny became committed to disability rights when she married Richard (Dick) Thornburgh in 1963 and became the stepmother of his three sons. The youngest, Peter, had acquired a brain injury in a car accident that killed the boys' mother in 1960. Four-month-old Peter and his two older brothers had been passengers in the car. As Peter's stepmother, Ginny became involved in the world of disability services. She and Dick—at that time federal district attorney for Western Pennsylvania—came to understand that community services for most children and adults with disabilities were severely limited. Like the Clapps and most

parents of intellectually disabled children in that era, the Thornburghs were advised to place Peter in a residential institution. They rejected that option out of hand. The couple found high-quality education and therapy for Peter at The Children's Institute in Pittsburgh, then known as the Home for Crippled Children.

Ginny was hit again with low societal expectations of Peter when she was advised to explore public schooling for him. On her orientation visit, Ginny was led down to the basement classroom of a Pittsburgh Public Schools elementary building. The stark reality shocked her. The students were making potholders next to the school's furnace. A screen was the only barrier between the children and the furnace. Water oozed from the basement's windows. It was clear to her



that “the whole environment said low expectations.”¹¹ Ginny recounted what came next:

I stormed up the stairs and stormed into the principal’s office and announced that I was probably going to be one of his new parents, and that I found that classroom totally inaccessible, and I said not just for my son, but for the other boys and girls in that room. He said words that are burned in my heart. He said [referring to the disabled students in the school], ‘they don’t care. They don’t care.’ ... That was the begin-

ning—one of the beginnings—of my transformation from being a concerned mother to being an activist. ‘They don’t care.’ Of course they do, and of course that means we have to care triple.¹²

At the time, services for families with disabled children were severely lacking. If care in the home became challenging, parents were presented with a single option for support: state-run residential institutions. Through the early 1970s, over 10,000 people were institutionalized at these chronically

overcrowded and understaffed facilities in Pennsylvania.¹³ Several factors contributed to this bleak reality, including a lack of community-based supports, societal limitations placed on intellectually disabled people, rural settings of institutions, limited oversight by government employees and elected officials, and unsuccessful pleas for help from institutional administration.

Outraged by these deficiencies, Ginny committed herself to building an effective and respectful system of support for disabled children and adults. She found like-minded colleagues at Arc Allegheny: “We had a very strong chapter, and the minute I got involved with the Arc, that changed my life.”¹⁴ By the early 1970s, Ginny was leading her fellow mother advocates at Arc Allegheny. There was “never any question that she was in command,” recalled the late Chuck Peters (executive director of Arc Allegheny from 1969–1973). “She led, and it was inclusive and it was consensus.”¹⁵

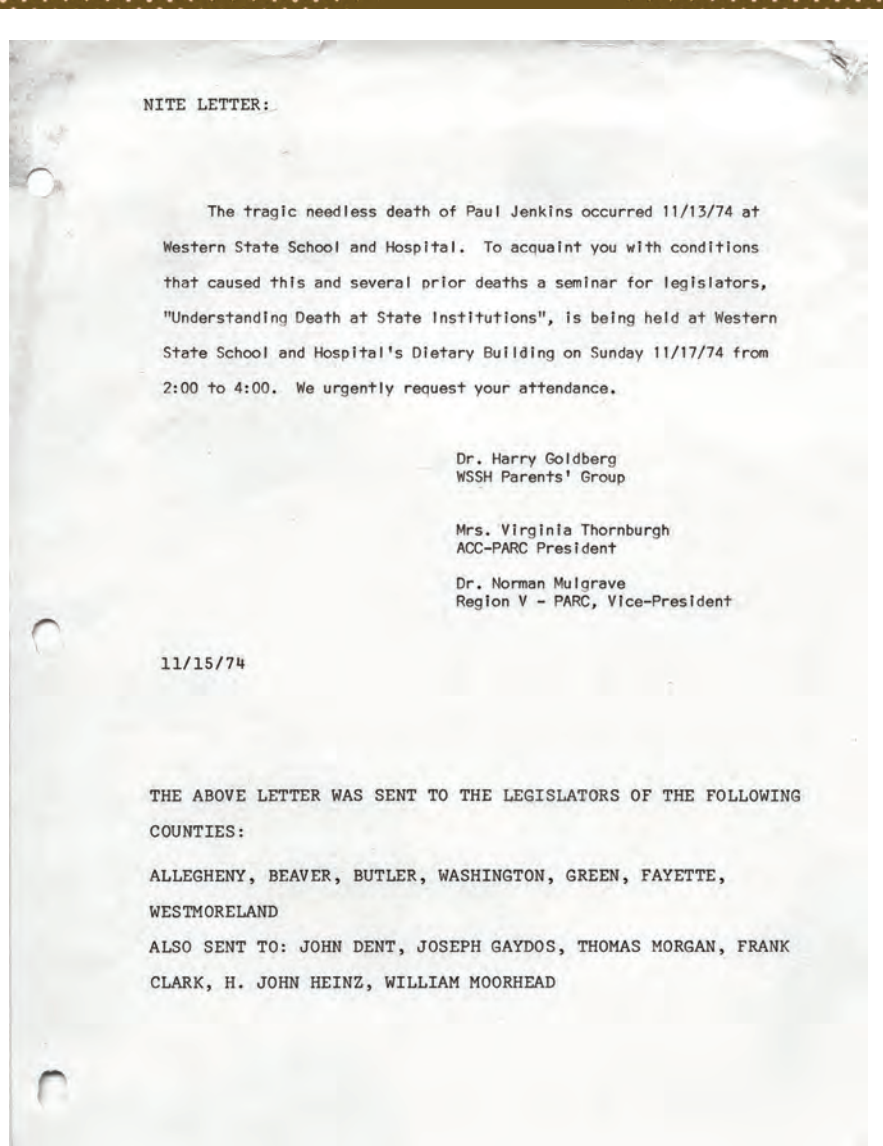
Beginning in summer 1972, Ginny and a core group of Arc Allegheny mother advocates began to investigate reports of human rights violations at PA’s state-run institutions for people with intellectual and developmental disabilities. Working closely with Arc Allegheny staff members Bob Nelkin and Chuck Peters, Ginny and fellow mother advocates made both announced and unannounced visits to care facilities across the state.

The advocates defined their scope to encompass any public- or privately-run facility that included an Allegheny County resident in its population. They investigated living conditions, educational programming, sanitary conditions, staff-to-individual ratios, disciplinary practices, nutrition, medical care, and treatment strategies. Following each visit, they compiled notes and reports that documented their observations to ensure that government officials and the public were informed. As the team honed this strategy,

they began to understand the levers available to them to effect change.¹⁶

When Arc Allegheny began regular site visits to Western State Center in July 1972, they immediately witnessed the direct impact of systemic overcrowding and understaffing at this Canonsburg, PA, facility. They noted inadequate ratios of 45 individuals to 2-3 care aides.¹⁷ These ratios had critical implications for residents at Western Center, a bleak fact confirmed by the facility's superintendent. In response to the advocates witnessing a woman tied to a chair on a ward, the facility's superintendent remarked, "Obviously there are better ways of handling her behavior than restraints; however, with the limited staff on Cedar I [building] and the fact that the majority of the residents in Cedar I are [disabled], the staff of the unit felt it necessary to resort to restraints."¹⁸ Isolation rooms were also in use, and a gross lack of educational programming pervaded the facility. The mothers alerted reporters and officials about these conditions, raising moral questions about the treatment of intellectually disabled people that were difficult to refute.¹⁹

Ginny and her fellow mother advocates pulled on numerous levers to expose and improve conditions for the individuals at Western Center. They also supported efforts to bring in outside experts to assess conditions at the institution. In 1973, a team of specialists led by Dr. Irene Jakob, professor of clinical psychiatry at the University of Pittsburgh's School of Medicine, was commissioned by the Department of Public Welfare's Western Region to assess the facility. The experts were shocked by the extent to which Western Center was understaffed. Dr. Edward Nuffield lamented, "It is inconceivable that a complement of 3 childcare workers per shift for 38-44 residents" could provide proper supportive care. Nuffield continued, reporting that "the ratio of one registered nurse per 120 residents is mind-boggling, and such staffing belongs to the dark ages of care."²⁰



Telegram to Pennsylvania legislators about the Arc Allegheny-organized "Death at State Institutions" seminar, November 15, 1974.

HHC Detre L&A, Nelkin Collection, MSS 1002, B3.F61.

Most horrific were the deaths of individuals at state-administered institutions. The death of Paul Jenkins at Western Center in November 1974 was an inflection point for the investigative team. Jenkins choked to death following dinner. This tragedy was particularly distressing given that the advocates had specifically questioned why food was not cut into bite-sized pieces during a visit six months prior to Jenkins's death.²¹ In an Arc Allegheny press release, Thornburgh posed the question, "When will the deaths end? The Department of Public Welfare has failed, again, in its legal and moral responsibilities for the safety of the residents."²² Jenkins marked the third death in five months that was later attributed to overcrowded and understaffed conditions at Western Center.²³

Following Jenkins's death, the Arc Allegheny advocates joined with allies to

convene a seminar titled "Understanding Death at State Institutions," squarely directed at both state and federal legislators representing Southwestern PA districts.²⁴ Ginny was a central speaker at the seminar. Legislators were stunned by her raw accounting of the untimely deaths and living conditions at Western Center.²⁵ Moved by her appeals and the efforts of Arc of PA, they passed an emergency multimillion-dollar appropriation to hire dozens more additional staff at Western Center, quite a significant feat.²⁶

Continuing to advocate, Arc Allegheny engaged in legal battles to stymie any court attempts to admit new residents to the already overcrowded institution. They also pushed for the transfer of institutionalized individuals back into communities. From 1974 to 1975, 80 individuals from Western Center transitioned into community homes or supported living in

apartments. With admissions closed—in part due to Arc Allegheny advocacy—staff-to-individual ratios fell by 50 percent.²⁷

The degradation that Ginny saw spoke to her moral core, said Nelkin. "We would be looking at [situations] that obviously would be ambiguous. Even if they were wrong, they had existed for a long time. It took moral courage to say, 'No, that's wrong.' Ginny would listen politely to rationalizations and justifications, Nelkin said, but not accept them "because of the bright lines about what is moral and what is not, what is right and what is wrong."²⁸

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The Western State School and Hospital was built on the campus of the Pennsylvania Training School (later known as the Canonsburg Youth Development Center) and opened in 1962.

HHC Detre L&A, General Postcard Collection, B16.101.



BRINGING DIGNITY TO THE POLK CENTER CEMETERY

BY TINA CALABRO
AND SIERRA GREEN

As First Lady of Pennsylvania from 1979 to 1987, Ginny Thornburgh led the effort to address an indignity in the graveyard at Polk Center. For decades, the graves of people who died at the institution were identified only with numbers, not names.

The degradation implied in the nameless graves struck a deep chord in Mrs. Thornburgh from the first time she visited the cemetery as an Arc Allegheny advocate. “Every one of us is known by god and named by god, and for us not to be remembered by name and the date of our birth and death was unthinkable,” she said.²⁹

Through her leadership as First Lady, markers with the names of former residents were placed on some 1,450 headstones, and the cemetery was rededicated in 1985. 🌻

Gravestone 573 of Margaret
A. DeMarko from Polk State
Center, 1928.

HHC Collections, gift of Polk State Center, 2016.29.11.



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JEAN ISHERWOOD

Among the members of the advocacy team, Jean Isherwood brought a sobering dose of personal reality to the movement of challenging the institutional system. Unlike fellow advocates whose children with disabilities lived at home, Jean and her husband Jack's daughter Janet, born in 1961, was institutionalized at Polk State Center from ages 4 to 16. Jean's connection with Polk Center and her belief that there could be a better life for her daughter and others led her to become one of Arc Allegheny's most fervent leaders. She served as president from 1968–70.

As something of a local celebrity, Isherwood brought a certain cachet to the Arc Allegheny movement. A former fashion model and the original "weather girl" for KDKA-TV, her polished demeanor undoubtedly impressed the often-powerful people she encountered. Behind her dignified speech and appearance, however, "there was real strength and moral conviction."³⁰

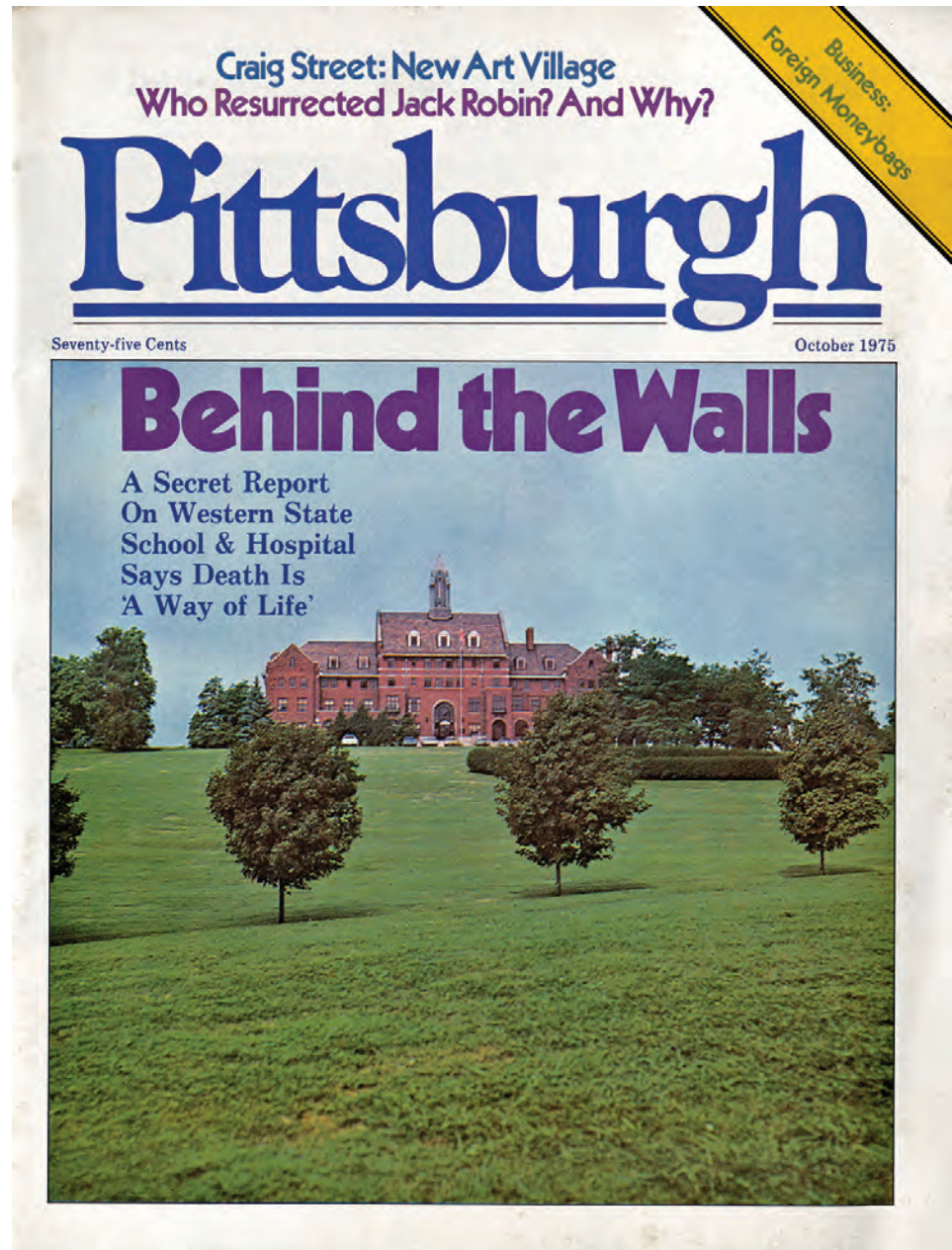
Isherwood was also "a character," said Marsha Blanco (retired CEO and president of Arc Allegheny), recalling how she would entertain her fellow advocates on overnight trips with songs from her Appalachian upbringing, accompanying herself on ukulele.³¹ "Her gift to the movement," explained Bob Nelkin, "was that it wasn't just self-interest, but for the common good." When she spoke about her daughter's experience, including instances of harsh treatment, "it wasn't ideological."³²

To Jean and the rest of the team, the overcrowding and understaffing at Polk State Center were devastating. The state entrusted the care of 3,000 people to this facility, despite its bed capacity of only 1,800.³³ The January 1973 visit to Polk was particularly alarming. Viewing a women's residential building, the advocates reported:

Residents were tied to their benches. The stench (a combination of urine, feces, and body odor) was unbelievable. There were no attendants actively

Pittsburgh Magazine featured an article in 1975 on the deplorable living conditions at Western State School and Hospital and the human rights violations endured by people with disabilities residing there.

HHC Detre L&A, MSS 1002, B03.103.



engaged in program for these residents. The noise level and confusion was overwhelming.... Our institutional system has done it again: the most unbearable working conditions surround the individuals who need attention and care the most.³⁴

Walking around the grounds of the facility where her daughter lived, Jean witnessed barrack-style sleeping quarters with 100 individuals sharing a single room. Equally troubling to her was the lack of education for

children. Jean and the other mothers observed "no impact of the PARC Right to Education suit."³⁵

Jean, as Secretary of the Arc of PA, was integral in alerting Pat Clapp about dire conditions at Polk Center during the January 1973 visit.³⁶ Pat convened a small group of colleagues, including Jean and renowned mother advocate Eleanor Elkin, to visit Polk for a February 1973 visit.³⁷ The group was particularly disturbed by the use of five-foot-

Mother advocates Jean Isherwood and Ginny Thornburgh, c. 1973.

HHC Detre L&A, Bob Nelkin Collection Additions, 2021.0212.



tall wooden, cage-like enclosures to confine individuals. In her notes from this visit, Eleanor Elkin wrote:

In the first day room we visited there was a large wooden enclosure of wooden slats placed close together and about 5' high. (High enough that I could not see the man huddled, apparently asleep, on the floor near the wooden side – and I'm 5' 3").... "Why is he there?" "He fights"... The man was lying on his face so I could not tell if he was asleep, leering, unconscious, weeping or bruised. His defeat was clear to all.

The report from these women about the dehumanizing use of these cages moved DPW Secretary Helene Wohlgemuth to schedule a

surprise visit to Polk Center in April 1973, accompanied by Pat Clapp. Closely inspecting the cages, Wohlgemuth observed that the vertical wooden slats were so closely spaced together that she could not put her hand in the space between each slat.³⁸ In the same day room, approximately 16 to 25 other individuals were tied to long benches or chairs.

Wohlgemuth's visit led to action. Wohlgemuth confronted Polk Center's superintendent, Dr. James McClelland, and insisted that the institution stop the use of wooden enclosures to confine individuals. McClelland complied yet defended their use,

citing the lack of staff and the behavioral challenges of institutionalized individuals that necessitated their use.³⁹ Wohlgemuth then terminated McClelland on the grounds that "the cruel, degrading, and inhumane conditions which I personally observed during my visit ... specifically to the locked 'cages' and pens in which you authorized the confinement of patients."⁴⁰

Both public support and outrage followed. Wohlgemuth received many letters from individuals, parents, and professional and community organizations who either emphatically supported or vehemently

Dorm rooms at Polk Center depicting multiple beds in a common sleeping area, c. 1970. The scale of the institution's overcrowded conditions led to barrack-style sleeping quarters for the individuals with intellectual and developmental disabilities who lived there. The advocates frequently noted this stark reality, devoid of privacy and personalization.

"Dorms," c. 1970, Carton 14, Folder 51, Photographs, RG 23.419, Records of the Department of Human Services (DHS): Polk Center, Pennsylvania State Archives.



opposed her decision to fire Dr. McClelland. Individuals and groups that supported Wohlgemuth's decision cited outrage concerning the conditions described in the advocates' reports. Those who supported McClelland shared observations about his positive treatment of staff, individuals, and families. Among the most ardent supporters of McClelland were Polk Center staff and board members, and the doctor successfully appealed his dismissal. Rather than accept reinstatement, he retired.⁴¹ In the aftermath of McClelland's firing, new superintendent Joseph Colombatto set out to update policies on staff-to-individual interaction, desiring that the emphasis be placed on treatment and education rather than physical care. Employees countered by saying that the institution did not employ enough staff to roll out this level of engagement and care.

To many Polk Center staff members and administrators, the advocates came from the outside, making brief visits and describing conditions without their input. The reports downplayed the immense challenge of providing care for nearly 3,000 individuals daily. Those who did this work daily had the support of many parents whose children lived at the facility and felt they were adequately supported. Largely, the administrators and staff felt that additional funding and staff were the keys to improving care. The advocates' position that the system itself needed to change was met with resistance from administration, staff, and many parents. Another aspect of the resistance was that Polk Center had been a primary employer in the region for decades and that a shift away from institutionalization would impact the local economy.

Polk Center was a complex place, with different kinds of care happening throughout the campus, including some educational and therapeutic practices. While largely an isolated campus, the facility did facilitate some community engagement. Critics of the advocates' questioning of the institutional system could agree with the need for

improvement but disagreed on the ideal care model. At first, even the advocates did not have that answer about alternatives to institutional care, although they felt that answer should be based in family or smaller community-based homes. It would be the better part of a decade (and a lot of trial and error) before a significant number of formerly institutionalized people with intellectual and developmental disabilities were living in their home communities—and the new paradigm came into focus.⁴²

Prior to these events, Jean characterized her visits as a parent to Polk as “the good tour,” scheduled in advance and highly controlled by the institution. Later, when she made surprise visits with fellow advocates, she was heartbroken to find her daughter abused. In a 1981 *Pittsburgh Post-Gazette* article, she recounted seeing an attendant holding Janet’s head up by her hair. On another visit, she learned that Janet’s eye had been hurt when someone stepped on her face when she was lying on the floor.

Isherwood’s outspoken stance against conditions at Polk put her at odds with other Polk Center parents. Nelkin explained, “There was tremendous defensiveness [among parents] and ‘why are you stirring this up?’” Isherwood understood their position but chose to look critically at the reality within the institutions rather than defend them. “She wanted something better for Janet and for others like her.”⁴³

BARBARA SISTIK

For many administrators of Pennsylvania’s institutions, the scheduled and unannounced visits from Arc Allegheny advocates were unsettling. As the women named their concerns and asked pointed questions, administrators often went on the defensive.

Despite their genteel appearance, the Arc Allegheny advocates pulled no verbal punches, especially Barbara Sistik, who was described by Arc’s Chuck Peters as a “formidable woman, an



Superintendent Joseph Colombatto (second from left) and others removing the door from a seclusion room used at Polk Center, c. 1974. Colombatto was appointed superintendent following the firing of Dr. James McClelland. Among the major changes he instituted was the closure of the facility’s discipline cottage. Recalling his early days as superintendent, Colombatto said, “I was in an absolute trauma almost daily.”

“Quiet Restraints,” c. 1974, Carton 15, Folder 29, Photographs, RG 23.419, Records of the Department of Human Services (DHS); Polk Center, Pennsylvania State Archives.

in-your-face advocate” who was to the local de-institutionalization movement “what Mother Jones was to the labor movement.”⁴⁴ Barbara, he recalled, was involved in one of the most memorable instances of verbal jousting. Told by a PA Department of Public Welfare official that the advocates were “not playing fair,” she replied, “We’re not playing at all.”⁴⁵

Barbara served as vice chair of Arc Allegheny and was a leader on the team that inspected institutions. She and her husband, Vendel, lived with their family in Mount Lebanon. Their son, John, had a disability. “Barbara was fierce,” said Bob Nelkin, recalling her confrontational style. “She not only had

strong opinions but she wasn’t afraid to voice them in a fierce way.”⁴⁶ There was a toughness in Barbara and all the women advocates, he said. On the return trips from visits to the institutions, Barbara stood out with her decisiveness. “When you were dealing with Barbara, there was some quietness, but then once she spoke, she was pretty sure about how the change had to happen.”⁴⁷

Barbara and the mothers faced some of the harshest conditions and the longest drives during visits to deficient interim care facilities across the state. Interim care facilities received funding from Pennsylvania’s Department of Public Welfare to oversee care for small

populations of intellectually disabled individuals. The department was responsible for monitoring the operations of these facilities and ensuring that they were meeting the regulations for care. The mother advocates heard reports of punitive practices such as forced use of outdoor outhouses, extended periods outdoors in winter, and confinement to bed. Like most institutions at the time, these interim care facilities were grossly understaffed, with staff-to-individual ratios as high as 1 staff

person per 43 individuals.⁴⁸ The advocates also reported grave concerns about nutrition and medical care.

Particularly disturbing to the mothers was the August 1972 drowning of Louis Novak, a 15-year-old Sharpsburg native, at Ridgeview Center, an interim care facility in the northeastern Pennsylvania borough of Hawley. The advocates visited the facility three times in advance of Novak's death in failed attempts to raise the alarm about the conditions that they

witnessed.⁴⁹ Horrified by their son's untimely death, Novak's parents asked Barbara to investigate.⁵⁰ Barbara and her fellow advocates quickly called for the closure of Ridgeview Center, which had long violated state regulations.⁵¹ Arc Allegheny appealed to the governor, the Department of Public Welfare, state legislators, and the public to act.⁵² According to Wayne County Coroner Robert Jennings, Ridgeview Center was "not fit for cattle."⁵³ Facing pressure from advocates, the state revoked Ridgeview's license, and the facility closed. Arc Allegheny, the county coroner, the Novak family, and reporters successfully pressured police and government officials to investigate the case and hold authorities accountable. Throughout summer and fall 1972, Arc Allegheny played a role in closing at least two other interim care facilities across Pennsylvania.⁵⁴

FROM INSTITUTIONS TO COMMUNITY INCLUSION

Sadly, concerns about the quality of life of intellectually disabled people at large state-run institutions persisted throughout the 1970s. While Arc Allegheny advocates continued to push for improvements at state institutions, they simultaneously advocated for the right of intellectually disabled people to leave such places and pursue life in broader society. They pushed for reform by engaging state employees, partner advocates, legislators, and the general public in conversations about the benefits of community living.⁵⁵

The mothers' efforts fit within a broader evolution in care for intellectually disabled people that was just starting to take hold across the state and country. By the 1970s, DPW had begun to slowly transition thousands of intellectually disabled individuals back to their

Barbara Sistik and her husband supervise their son, Johnny, and foster child Jay, playing at their home in Mount Lebanon.

The Pittsburgh Press, March 24, 1974, 109. Copyright ©, Pittsburgh Post-Gazette, 2024, all rights reserved. Reprinted with permission.



— Press Photos by Robert J. Pavuchak

Cheering Johnny on the trampoline are Jay and his parents.



Open house in Avalon for the first community home opened by Arc Allegheny in 1991.

HHC Detre L&A, NeilKin Collection, MSS 1002, B5.F22.

families and communities. From 1971 to 1975, the number of intellectually disabled people transitioning out of Pennsylvania institutions increased by more than 1,000%, from 148 to 1,605.⁵⁶ By 1981, that number had topped 3,000.⁵⁷

Arc Allegheny pursued several other means to promote inclusion in the community, such as challenging court commitments and supporting the expansion of community homes in residential neighborhoods. Eventually, Arc Allegheny would itself become a provider of home- and community-based services for individuals with intellectual and developmental disabilities.

Remarkably, this small group of mothers witnessed a number of tangible results from their efforts, including treatment reform, a multimillion-dollar emergency legislative appropriation, the closure of deficient interim-care facilities, and the growth of home- and community-based living. By appealing to the public, civil servants, the press, and all three branches of government, they helped dismantle a dehumanized institutional system and propel

the transition to home- and community-based services for people with intellectual and developmental disabilities.

More broadly and most significantly, the advocates contributed to normalizing the inclusion of people with intellectual and developmental disabilities in broader society as an alternative to institutionalization. They and other compatriots leveraged the energy that people of the period were feeling about civil rights and used it to push people to work in a similar way for people with disabilities.

Today, the institutions that the women persistently inspected are closed. Support services for people with intellectual and developmental disabilities are now overwhelmingly based in schools, homes, and community organizations. Conversations about supportive services now include and prioritize the preferences of the person served. Self-determination is now a central tenet of disability rights. This all amounts to an astounding level of progress in just over 50 years.

Yet, disability rights advocacy will likely never be considered complete. Challenges to

the fully funded educational, therapeutic, housing, and employment supports persist. So do concerns about instances of exclusion, abuse, and neglect, despite a strong system of safeguards. Although the climb continues, it is worth looking back and recognizing the progress made as a direct result of women working on a grassroots level to improve the lives of their children.

For the parents involved in Arc Allegheny advocacy of the 1970s, the work “helped us heal,” Ginny Thornburgh reflected: “Instead of just concentrating on our son or daughter or brother, we were able to see other people, and that was a very strong healing process. I see people advocating today in just as strenuous ways.”⁵⁸

The timelessness of this work is profound. In the words of Ginny, “As a mother, as a parent, as an advocate, you never rest. You never rest.”⁵⁹



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The authors wish to acknowledge that this is the first publication of ongoing research into Western Pennsylvania’s Deinstitutionalization Movement, with the intent of further scholarship on this subject matter to come.

- ¹ Arc was founded in the 1950s as the Association for Retarded Children, but in 1992, as its website explains, “Over time, as the words ‘retardation’ and ‘retarded’ became pejorative, derogatory, and demeaning in usage, the organization evolved its terminology to reflect the desires of people with disabilities, and changed its name to ‘The Arc,’” accessed at <https://thearc.org/about-us/history/>.
- ² Ginny Thornburgh interview with Lisa Sonneborn, “Visionary Voices,” Temple University Institute on Disabilities, November 16, 2011, <https://disabilities.temple.edu/voices/interviews/thornburgh-chapter-3>.
- ³ Bob Nelkin interview with Tina Calabro, October 4, 2019.
- ⁴ Arc Allegheny is today known as The Arc of Greater Pittsburgh/Achieva.
- ⁵ “Today’s Health Letter,” 4 Oct 1955, Pat Clapp Papers and Photographs, MSS 1196 B1.F5, HHC Detre L&A.
- ⁶ Patricia Clapp interview with Tina Calabro, October 8, 2013.
- ⁷ Patricia Clapp Memo to PARC Chapter Presidents and Executives, 23 Apr 1973, Bob Nelkin Collection of ACC-PARC Records, MSS 1002, B4F45, HHC Detre L&A.
- ⁸ “A History of the Individuals with Disabilities Education Act,” United States Department of Education, accessed October 13, 2023, <https://sites.ed.gov/idea/IDEA-History>. For an in-depth history into this case and its impact on the Deinstitutionalization Movement, see Dennis B. Downey and James W. Conroy, eds., *Pennhurst and the Struggle for Disability Rights* (University Park: Pennsylvania State University Press, 2020).

- ⁹ In addition to the right to education, Clapp is also remembered for her advocacy for intellectually disabled people’s right to marriage, informed consent for medical testing, and community living.
- ¹⁰ Bob Nelkin interview with Lisa Sonneborn, unpublished.
- ¹¹ Ginny Thornburgh interview with Lisa Sonneborn, “Visionary Voices,” Temple University Institute on Disabilities (November 16, 2011).
- ¹² Ibid.
- ¹³ *An Analysis of Pennsylvania’s Program for the Mentally Retarded* (Harrisburg: Arthur Bolton Associates, 1973), J-6.
- ¹⁴ Ibid.
- ¹⁵ Chuck Peters interview with Tina Calabro, 2013.
- ¹⁶ “Draft of letter to Helene Wohlgemuth,” 20 Nov 1972, MSS 1002, B1.F66, HHC Detre L&A.
- ¹⁷ “Report on Visit to Western State School and Hospital,” 5 July 1972, MSS 1002, B3.F18, HHC Detre L&A.
- ¹⁸ Nancy Jean report, 6 Jul 1973, MSS 1002, B3.F15, HHC Detre L&A.
- ¹⁹ “Visit to WSSH (Unannounced),” 20 Nov 1972, MSS 1002, B3.F18, HHC Detre L&A. For example of mother advocates’ appeal, see “Night letter called into Western Union 12/6/72,” 6 Dec 1972, MSS 1002, B3.F18, HHC Detre L&A.
- ²⁰ Dr. Edward Nuffield, “Further Supplementary Report,” 16-20 July 1973, MSS 1002, B3.F17, HHC Detre L&A.
- ²¹ Press release following Paul Jenkins death, 14 Nov 1972, MSS 1002, B3.F61, HHC Detre L&A.

- ²² Ibid.
- ²³ Jonathan Williams, “Retardeds’ Hospitals Still Lack Manpower,” 23 Jan 1975, *Pittsburgh Post-Gazette*, 4.
- ²⁴ “Understanding Death at State Institutions” letter, MSS 1002, B3.F61, HHC Detre L&A.
- ²⁵ Jonathan Williams, “Report on Retarded Spurs Call for Aid,” *Pittsburgh Post-Gazette*, 18 Nov 1974.
- ²⁶ Jonathan Williams, “Retardeds’ Hospitals Still Lack Manpower,” 4.
- ²⁷ Pattak, “Behind the Walls,” 29.
- ²⁸ Bob Nelkin interview with Tina Calabro, October 4, 2019.
- ²⁹ Ginny Thornburgh interview with Lisa Sonneborn, “Visionary Voices,” Temple University Institute on Disabilities (November 16, 2011).
- ³⁰ Bob Nelkin interview with Tina Calabro, October 4, 2019.
- ³¹ Marsha Blanco interview with Tina Calabro, [date].
- ³² Bob Nelkin interview with Tina Calabro, October 4, 2019.
- ³³ “ACC-PARC Meeting with Dr. James McClelland Minutes,” 2 Apr 1973, MSS 1002, B4F9, HHC Detre L&A; “Polk Improving But Patient Load Problems Persist,” *Pittsburgh Post Gazette*, 8 Feb 1974; Dr. James McClelland Appeal, Patricia Clapp Papers and Photographs, MSS 1196, B1F14, HHC Detre L&A.
- ³⁴ “Polk State School and Hospital Visit Report,” 24 Jan 1973, MSS 1002, B4.F45, HHC Detre L&A.
- ³⁵ Ibid.

- ³⁶ See Letter from Barbara Sistik to Governor Milton Shapp, 7 Mar 1973, MSS 1002, B4.F11, HHC Detre L&A.
- ³⁷ Clapp Memo to PARC Chapter Presidents and Executives, 23 Apr 1973, MSS 1002, B4 F45, HHC Detre L&A.
- ³⁸ Dr. James McClelland Appeal, MSS 1196, B1F14.
- ³⁹ Dr. James McClelland Appeal, MSS 1196, B1F14.
- ⁴⁰ Dr. James McClelland Removal Letter, 16 Apr 1973, MSS 1002, B4 F14, HHC Detre L&A.
- ⁴¹ Dr. James McClelland Appeal, 1973, Patricia Clapp Papers and Photographs, MSS 1196, B1 F14, HHC Detre L&A.
- ⁴² Clara Herron, "3 Mothers Battle," 9.
- ⁴³ Bob Nelkin interview with Tina Calabro, October 4, 2019.
- ⁴⁴ Chuck Peters interview with Tina Calabro, 2013.
- ⁴⁵ Chuck Peters interview with Lisa Sonneborn, "Visionary Voices," Temple University Institute on Disabilities (July 25, 2013).
- ⁴⁶ Bob Nelkin interview with Tina Calabro, October 4, 2019.
- ⁴⁷ Ibid.
- ⁴⁸ "Findings of ACC-PARC Review Team at Mountaintop School," 20 Oct 1972, Nelkin Collection, MSS 1002 B4.F58, HHC Detre L&A.
- ⁴⁹ "ACC-PARC News Conference regarding Louis Novak," August 28, 1972, Nelkin Collection, MSS 1002, B4.F26, HHC Detre L&A.
- ⁵⁰ "Louis Novak investigation note," Nelkin Collection, MSS 1002, B4.F26, HHC Detre L&A.
- ⁵¹ "PARC, State to Conduct Probe," *The Daily News*, 6 Sep 1972, 10; "ACC-PARC News Conference Regarding Louis Novak Death," MSS 1002, Box 4 Folder 26, HHC Detre L&A.
- ⁵² "ACC-PARC News Conference regarding Louis Novak," August 28, 1972, Nelkin Collection, MSS 1002, B4.F26, HHC Detre L&A.
- ⁵³ Dolores Frederick, "4th Death Closes Retarded Center," *Pittsburgh Press*, 23 Aug 1972, 6.
- ⁵⁴ These facilities include Ridgeview Center and Mountaintop Interim Care Facility.
- ⁵⁵ For a visual introduction to these advocacy and impact, see the *From Wrongs to Rights* film at <https://wayback.archive-it.org/11546/20211021140152/https://uwac.omeka.net/items/show/883>.
- ⁵⁶ *Challenge*, Department of Public Welfare, Nov-Dec 1975, MSS 1002, B1.F30, HHC Detre L&A.
- ⁵⁷ Herron, "3 Mothers Battle," 9.
- ⁵⁸ Ginny Thornburgh interview with Lisa Sonneborn, "Visionary Voices," Temple University Institute on Disabilities (November 16, 2011).
- ⁵⁹ Ibid.

HORIZON HOME

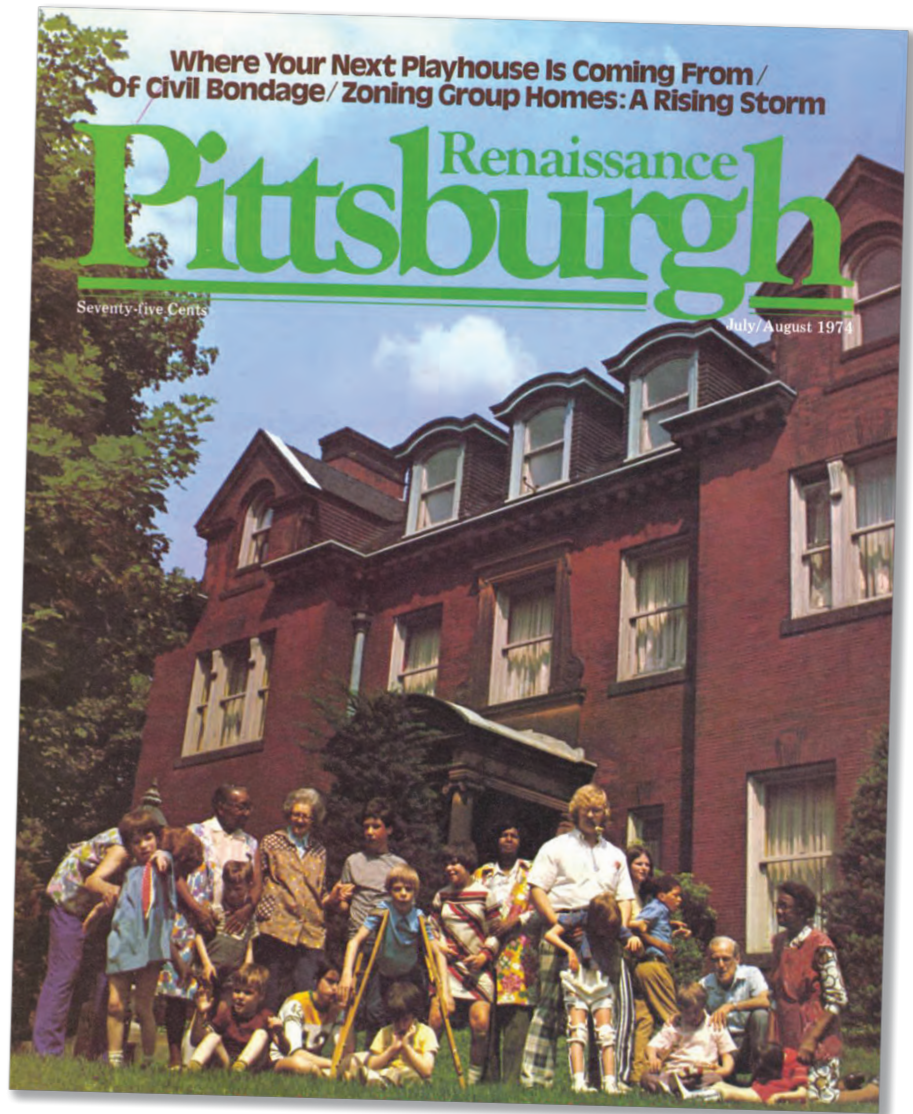
BY TINA CALABRO AND SIERRA GREEN


Cropped cover of *Renaissance Pittsburgh* featured Horizon Home on the cover of its July/August 1974 issue.

HHC Detre L&A.

The first shift from institutional to community care arose in Western Pennsylvania thanks largely to the efforts of Irene Jacob and her husband, Rabbi Walter Jacob, of Rodef Shalom Congregation in Pittsburgh's Shadyside neighborhood. Rabbi Jacob and Irene had an intellectually disabled daughter who lived and attended school at D.T. Watson Home (today the Watson Institute). They were alarmed by what her life as an adult might be like in a state-run facility if she did not have residential alternatives. The two convened leaders from the local religious and advocacy communities to create a viable alternative to institutions. Pat Clapp served as vice-chairwoman of the group in its early days. They also organized a trip out of state to visit and study leading community homes that provided support services for individuals with intellectual disabilities.

Thanks to the Jacobs's efforts and the support of Pittsburgh leaders and community members, they raised more than \$250,000 to start the venture, including the purchase of a residence in Pittsburgh's Highland Park neighborhood that would become Horizon Home. The Jacobs encountered obstacles to opening the community home, including difficulty obtaining state funding. They also met with resistance from Highland Park residents who opposed the home's location in their neighborhood. In response, young Bob Nelkin worked with the Jacobs to launch a campaign in which young people canvassed the neighborhood to dispel preconceived notions of intellectually disabled people. This combined with other advocacy efforts successfully overcame opposition and Horizon



Home opened in 1972 as the first community home in Allegheny County.¹ “The best work we’ve really done in Pittsburgh I would say is to establish Horizon Home,” reflected Irene Jacob.² Today Horizon Home operates as Mainstay Life Services, providing support services for more than 350 people with intellectual disabilities and autism. 

¹ Rabbi Walter Jacob Papers, Rodef Shalom Archives.

² Irene Jacob Oral History, 16 Nov. 1999, National Council of Jewish Women (NCJW), Pittsburgh Section Records, AIS.1964.40, Archives and Special Collections, University of Pittsburgh, available at <https://digital.library.pitt.edu/islandora/object/pitt:ais196440.206/>.

SISTERS IN ADVOCACY

BY TINA CALABRO
AND SIERRA GREEN

In addition to Pat Clapp, Jean Isherwood, Barbara Sistik, and Ginny Thornburgh, other women advocates associated with Arc Allegheny in the 1960s and '70s played essential roles in the effort to chart a new course for children and adults with intellectual and developmental disabilities. Here are a few of them:

MARLENE BURDA

A former corporate public relations professional, Marlene understood the power of the media to increase public awareness and influence policymakers. She became a board member and communications director at Arc Allegheny, and later was on staff at the state Department of Public Welfare. Marlene's son, Matthew, born in 1965, had intellectual disabilities. When she and her husband were advised to institutionalize him, they refused. At Arc Allegheny, Marlene played a role in the changes resulting from Pennsylvania's "Right to Education" consent decree of 1972. She helped develop the "ChildHunt" kit used throughout the state to locate children who had previously been excluded from school. She also wrote the script for *Cry Sorrow, Cry Hope*, a film produced by WQED-TV about raising a child with an intellectual disability. It aired in 1972 on local and national television.

SARAH ANN [SALLY] HOLLYFIELD

Sally, the mother of a child with disabilities (Catherine, born in 1968), also refused doctors' advice to institutionalize her daughter. Instead, Catherine grew up with her three older sisters at home, and Sally joined the pioneering advocates at Arc Allegheny. When former Polk Center residents left by the hundreds to live in their communities, Sally was part of the Arc Allegheny team who visited smaller facilities to make sure they functioned better than the institutions. When the team found problems—such as discovering the use of a cattle prod at the Highland Park Center—they took action.

JOAN MURDOCH


Unlike most of the women advocates at Arc Allegheny in the 1960s and '70s, Joan was not the parent of a child with a disability. In 1976, she became the first president of Arc Allegheny who was not a parent (although she became a parent later on). She developed educational programs for parents, staff, and students with disabilities at Community College of Allegheny County, North Campus. She was also actively involved in advocacy efforts regarding incidents at Polk Center. "Joan showed really strong community connections at a time of upheaval in the entire system," said Marsha Blanco, retired CEO and president of Arc Allegheny. Later, Joan continued her efforts as a member of the

Allegheny County Mental Health/Mental Retardation Board and served on the Quaker Valley School Board for 10 years.

SARAH SATTLER

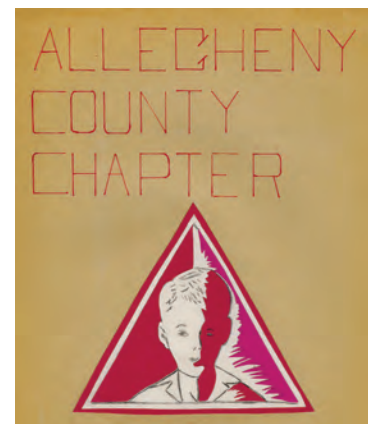
Sarah was a founding member of Arc Allegheny in the early 1950s. Her son Michael lived at Polk Center when advocacy to expose abuses began in the early 1970s. Sarah represented the "older demographic" who struggled to understand alternatives to institutions, said Bob Nelkin, a staff member from that period.¹ Although Sattler did not participate in visits to institutions, she was a voice for the practical concerns of family members. Later on, her son Michael was among the hundreds who moved out of Polk and into the community.

MILDRED [MIDGE] SCANNELL

Midge, whose son Eddie had an intellectual disability, became active in Arc Allegheny when she and her family returned to Allegheny County in 1974 from Westchester County, New York. Although Midge had been active in the Westchester Arc, she was surprised to discover a local chapter like Arc Allegheny doing "so much and such meaningful advocacy."² She participated in many institutional visits. 

The ACC-PARC logo is found on one of the organization's scrapbooks from 1966.

HHC Detre L&A, MSS 1002, B03.104.



¹ Bob Nelkin interview with Tina Calabro, October 4, 2019.

² Midge Scannell email to Tina Calabro, November 10, 2013.