Willowbrook's Aftermath: Can Lessons Learned Shape Current Policies?

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Abstract

In the 1970’s, Willowbrook School, a large group home on Long Island for individuals with developmental disabilities, slated for closure after political leaders and the public learned of its substandard conditions. Staff shortages and lack of training had led to deplorable living conditions where not only education and enrichment, but basic needs often were not met. When it finally closed in 1987, clients were placed in other situations, primarily in smaller group homes or with family. Willowbrook and similar schools were a major impetus for the disabilities rights and deinstitutionalization movements of the late twentieth century.

Almost forty years have passed, and clients, their families, and staff members are now elderly. While a comprehensive long-term study of survivors’ quality of life was never conducted. The information we have suggests that some survivors were able to develop happy, fulfilling lives.

Once again our society is at a crossroads in its treatment of individuals with developmental and intellectual disabilities. Deinstitutionalization is sometimes criticized, most notably by the current federal Administration, as having contributed to current rates of homelessness and crime. Individuals with disabilities are still sometimes a low priority for government funding. Nevertheless, deinstitutionalization and the disability rights movement, as well as studies of the potential for posttraumatic growth have changed public attitudes and treatment options. Ethics of care, which focuses on giving voice to individuals, has replaced older attitudes in the human services profession. Lessons of Willowbrook have implications from political, social, psychological, and ethical perspectives. The current study attempts to synthesize the available information about the survivors’ experiences can help to inform future decision making.

Keywords: Willowbrook School, survivors developmental disability, medical model, disability rights, deinstitutionalization movement, attachment disorders, positive psychology, posttraumatic growth, care ethics

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Introduction

Background

In the four decades since the Willowbrook School for individuals with developmental disabilities on Long Island closed its doors, a number of studies have explored the political, social, and psychological issues that led both to substandard conditions there and to its closure (see for example Goode et al., 2011; Rothman and Rothman, 2004). After the closure, clients were moved into various living situations, including group homes and families of origin. A few were able to live independently.

In ideal circumstances, at this point we would have rich longitudinal data on the former clients' quality of life; however, information on the survivors' experiences has substantial gaps, in part because some could not speak for themselves and others did not wish to relive their experiences, especially for public consumption. The Willowbrook survivors also constitute a protected group of subjects, with many having been under the age of 18 and most having had intellectual or physical vulnerabilities (Belmont Report, 1979).

Problem Statement

Despite these drawbacks, gathering information about the quality of life for Willowbrook School survivors can help to inform current policy and practice in treating individuals with developmental and intellectual disabilities. The present qualitative study reviews scholarly, journalistic, and archival literature about Willowbrook survivors, family members, and staff, to explore any gaps that still can be filled.

Important sources of information include The Willowbrook Project at CUNY's College of Staten Island and published information regarding the clients who resided at Willowbrook

School during its period of operation, from 1947 to 1987. Because of scarcity of survivor records, experiences of family members and Willowbrook staff are also considered. The goal of this study is to find evidence about the survivors' quality of life. The hypothesis is that they suffered from traumatic conditions, but that after they were moved to more humane, less constricting situations, at least some of them experienced post-traumatic growth. This information about survivors' experiences may be generalizable and relevant to current decisions about care, treatment and social policy for individuals with developmental disabilities.

A Qualitative, Phenomenological Approach

Creswell and Poth (2018) describe several approaches to research. Because of difficulties in gathering systematic statistical data on the Willowbrook survivors, and because little has been written from the residents' perspectives, a qualitative rather than a quantitative approach yields richer data. Creswell and Poth (2018) note that the choice of qualitative research is not an inferior one made due to lack of data, but one uniquely suited to the subject matter. It can provide a perspective lost in statistical and observational data. Exploring the perspectives of the residents, who often have been viewed as a nameless group or category rather than a collection of individuals of varying ages, genders, and disabilities and abilities, should enhance our understanding of their needs.

Literature Review

Willowbrook School: Historical and Policy Perspective

In *A History and Sociology of the Willowbrook State School,* Goode et al. (2013) describe conditions at the institution prior to their exposure to the public in Geraldo Rivera's 1976 documentary *Willowbrook: The last great disgrace*. Goode et al.'s book (2013) is based in part on the authors' own early-career experiences at Willowbrook. Much of the content is also credited to Maureen Fucillo's unpublished master's thesis (n.d.), which is available through archives of the Willowbrook Project at the College of Staten Island.

Goode et al. (2013) attribute the growth of large group homes in the mid-twentieth century to a medical model of disability, where children with intellectual and developmental disabilities were separated from their families and sent to specialized facilities ostensibly to be treated and educated. Today this model seems paternalistic and restrictive, but at the time, well-meaning physicians often convinced parents that their children would fare better with specialized medical care and education in group institutions (Goode et al., 2013). Willowbrook's construction was authorized in 1938, with plans to house 3,000 individuals with developmental disabilities, but after the U.S. entered World War II in 1942, the facility was repurposed to house and treat injured and disabled military personnel. After the war, it was returned to its original purpose, this time with a plan to hold 4,000 residents, mainly children but also some adults. Many clients were admitted to Willowbrook at young ages, during crucial developmental periods, and some stayed into adulthood. The school operated from 1947 to 1987, and in 1965 it housed over 6,000 residents, lacking adequate staff. The overcrowded conditions led to neglect and sometimes abuse of residents. After visiting Willowbrook in 1965, then-U.S. Senator from New York Robert F. Kennedy described it as a "snake pit" (Rivera, 1976; Tomasulo, 2018). Kennedy himself had a sister, Rose, who was institutionalized for most of her adult life, so his visit must have held personal as well as professional meaning.

Halliwell and Jones (Introduction, 2022) discuss the relationships between medical care and public policy from the mid-twentieth century to the present. When Willowbrook was established, most parents did not have access to specialized school or medical programs. Most physicians were not well trained in diagnosing and treating children with developmental disabilities. Some of these parents found themselves unable to care for their special needs children, particularly those with severe physical or behavioral issues. Parents and caregivers were often advised that their children would be better served in an institution where their medical and psychological needs would be met. Some children were orphaned or abandoned (Kirst, 2025). As Goode et al. (2013) recount, Willowbrook became the world's largest institution for the intellectiually and developmentally disabled. Staffing did not increase at a proportional rate. Visitation was limited, and the residents were often cleaned and dressed for visitors' days so relatives did not see the children's daily living conditions. Although many of the medical professionals and care staff had good intentions, funding limitations meant that Willowbrook was severely understaffed, with one caregiver for every 50 students. Many students seldom or never received educational services.

Not only did the residents suffer from lack of interaction, affection, and education during their formative years but, as Rivera's documentary (1972) reveals, many had to sit for hours unclothed, sometimes in their own feces, and those who needed assistance in feeding were allotted very little support. Assistive equipment such as wheelchairs were in short supply. Residents were sometimes abused by staff or other residents, and supervision was inadequate to protect them.

Perhaps even worse, some residents were subjected to medical testing without their or their guardians' consent. Krugman (1986), who served as a consultant in infectious diseases at Willowbrook, defends the ethical foundations of a hepatitis study he was instrumental in conducting on the residents in 1955. He notes that when we worked on the project, almost all the residents and some staff already were infected with the hepatitis virus. Incidentally, he also describes a measles outbreak in 1960 that left 60 children dead.

Krugman (1986) explains that the original intentions were beneficent. The spread of contagious diseases in institutions needed to be studied, and researchers thought that they could acquire knowledge that would help to minimize the spread of illnesses that sometimes ravaged the populations. The institutions themselves were needed, Kruger argues. After World War II ended, the military hoped to keep at least part of the Willowbrook campus for its injured members. He quotes from a letter from then Governor Thomas Dewey to General Omar Bradley. Dewey argued that there were "eight hundred to nine hundred" children whose parents were waiting for an institutional placement, and that "hundreds" were sleeping on mattresses on floors in the existing institutions (Krugman 1986, p. 158). In the following excerpt, which reveals contemporary attitudes toward children with disabilities, Dewey describes the state's moral responsibility to care for them. (Note the language used to describe them):

> Thousands of children come into this world who are mentally and physically defective and feeble minded, who never can become members of society. They require constant care, both medically and physically, and in many cases, for social, psychological and economic reasons, few parents can afford to place them in private institutions. Even if such institutions existed in sufficient quantity, the result is that the state must take

> responsibility for the care of these children and do so with a high degree of tenderness and affection. (Dewey, qtd. In Krugman, 1986, p. 178)

This passage reveals a belief—here stated as fact--that these young people were incapable of becoming "members of society," and that the state has a "responsibility" to treat them with "tenderness and care." Krugman's statistics are also revealing; he states that about 77.7% of the residents were "severely or profoundly retarded," 60% could not toilet themselves, 39% were not ambulatory, 30% suffered from seizures, and 64% could not feed themselves (p. 178). As Krugman explains, this also made them an ideal, captive population for the study of transmissible diseases including hepatitis. The team of physicians believed that if a well-controlled study of hepatitis were conducted on some of the residents—new residents with parental consent—a protocol for controlling the spread of the virus could be developed. To acquire consent, parents were told that since hepatitis already was rampant at Willowbrook, their children in the controlled study actually would be better off than those in the general population. The deliberately infected children would be housed in a special unit and protected from other transmissible diseases. After a bout of hepatitis, these children would have immunity. Kruger describes how the hepatitis experiments were conducted and defends them against subsequent ethical criticisms; since most of the children would contract hepatitis at Willowbrook in any case, the controlled experiment on selected individuals was warranted with the hope of serving a greater good, mitigating the spread of hepatitis in institutions. His article is a fascinating window into the attitudes and language of the day, where good intentions paved a road to hellish outcomes.

As Goode et al. (2013) note, most visitors saw only a “cleaned up” version of the institutional conditions and did not know about this experiment. It was up to visitors like Kennedy and Rivera to show the world the true nature of Willowbrook.

Willowbrook’s Legacy: Civil Rights and Care Evolve

In 1972, Dr. Michael Wilkins, who had been fired after urging parents of Willowbrook residents in Building 6 to organize and protest the conditions, contacted local reporter Geraldo Rivera to film the actual conditions in Willowbrook and managed to bring him inside the facility. Years later, on Channel 50 (WABC-NY), where Rivera worked at the time of the expose, he reminisced about the shocking sights, sounds, and smells he encountered (2022). In this case, a (motion) picture was well worth a thousand words, as the public saw the conditions for the first time.

Staff, who Rivera says were “trying to do their best,” spoke about not having enough clean clothing for residents or time to feed and clean their wards. At the time, the way the children were deprived of basic care held the most obvious shock value; however, the residents were also deprived of the attention that Governor Dewey assumed would be given to them. In the latter half of the twentieth century, the field of developmental psychology made great strides, as researchers learned the importance of establishing attachment bonds. In 1958, Harlow and Zimmerman had published a groundbreaking study of infant rhesus monkeys deprived of their mothers, the results of which demonstrated that the infants preferred clinging to cloth “mother” dolls over wire dolls that dispensed milk. Their work influenced Bowlby (1969) and others in developing attachment theory. Insecure attachment in early childhood can lead to lifelong difficulties in relationships. Therefore, although we have few records, it can be assumed that lack of affection and attention the Willowbrook residents, especially the youngest ones, received from staff likely led some to attachment disorders later in life.

After Rivera's expose (1972), Willowbrook became a symbol of deprivation of civil liberties and a keystone of the disability rights movement. A class-action lawsuit was filed in federal court against the State of New York in March1972. The settlement with the State Department of Mental Hygiene in 1975 included an agreement to close Willowbrook, but although steps were begun, the facility remained open for over a decade. The success of this suit led to others being filed across the country to give individuals with developmental disabilities due process and "freedom from cruel and unusual punishment" (ADA Legacy Project, 2013). One might well ask what crimes these residents had committed that would warrant any punishment.

Rothman and Rothman (2004), who were involved in ensuring the transition of residents into safe housing, explore the role of the court system in three years of litigation for clients' rights. Their study recounts the challenges involved in expanding the rights of people with disabilities, and the impact of advocacy and intervention on securing the state's commitment to providing community services. They characterize the judges who heard and ruled on the cases as conservative but concerned about the conditions the residents had endured.

Life After Willowbrook: Survivors' and Caregivers' Perspectives

As Goode et al. (2013) state, Willowbrook has become "famously both a scarlet letter and a beacon—a symbol of shame and pride…. It is symbolic of public indifference to people with disabilities that has characterized their treatment throughout history and of the power of citizens to confront and defeat socially organized evil" (5). One could argue whether Willowbrook is a testament to “socially organized evil,” or to ignorance as in Dewey’s and the parents’ cases, or to a Utilitarian ethical principle of causing suffering for a few in service of the greater good (Kruger, 1986). It would be comforting to think that, once freed from this large institution, the many residents led happier, more fulfilling lives, but evidence is scant. After Willowbrook’s closure, many residents disappeared into anonymity.

Several survivors and staff have kept the memory alive. Perhaps the best-known former resident is Bernard Carabello, who as a child with cerebral palsy was placed at Willowbrook. In *Remembering Willowbrook* (2022), Carabello reminisces with Rivera, who has become a lifelong friend, about the deplorable conditions and the lack of formal education he received. He describes being “scared” there many times. Since his release into the community, Carabello has devoted his life and career to advocating for individuals with developmental and intellectual disabilities. He states that he has found fulfillment and meaning in his post-Willowbrook life. Rivera characterizes Carabello as “focusing on the humanity” of those for whom he advocates. Carabello received an honorary doctoral degree from the City University of New York at Staten Island, which now encompasses the former Willowbrook grounds. One wonders how many other children were, like Carabello, placed in Willowbrook despite not having intellectual disability.

Padnani interviewed Willowbrook survivors for *Staten Island Live* in 2010, when three of them awarded a plaque to Geraldo Rivera for his work in exposing conditions at the school. Barbara Meyer, who lived at Willowbrook from age 17 onward for a period of 23 years, states that she still has vivid memories of “pests that scuttled about” and residents’ screams.

According to Padnani, however, “Ms. Meyer exudes a sense of resilience she likely gained while living at Willowbrook.” Deemed to be one of the “bright girls,” she was moved from infamous Building 5 to an all-girl dormitory, where she learned to advocate for others as well as herself. After being released in 1972, she spent many years in the workforce. At the time of the article, she reported living in a supportive YAI group home.

Another survivor featured in the article, David Clark, also lived in a YAI group home. He told Padnani that his eyesight deteriorated in the 10 years he spent at Willowbrook, which he describes as “like a jail scene, a prison.” Padnani reports that David’s counselors find his behavior “guarded,” although he socializes with others through a day program. In Pandani’s view, the third survivor, Franklin Davis, has “perhaps healed the most of the three,” as evidenced by his frequent smiling. (Of course, smiling can also be a defense mechanism of the powerless.) He lives with two roommates and seems to appreciate small accomplishments like “paying his own bills.” Padnani also interviewed Joan Leinwand, the Medicaid services coordinator at YAI, who marveled at the survivors’ resilience and strength.

While these three survivors, seen from Padnani’s perspective (2013), seem to represent a spectrum of adjustments, unfortunately, we do not have statistical data on their nearly 6,000 peers. We do not know the extent of trauma, the disruption of attachment, or the achievement of posttraumatic growth for them. We can only speculate based on the data we do have.

We also have narratives of survivors’ relatives. Goldstein (2021) in his memoir *Fred and Me* writes about his relationship with his brother, Fred. Goldstein recalls visiting Fred in Willowbrook every two weeks during their childhoods, then moving away, and finally reconnecting with his intellectually disabled brother, who now resides in a group home, after their mother dies and he assumes Fred’s guardianship. Goldstein is surprised at Fred’s ability to reason, plan, and communicate at a higher level than he had expected. He notices that unlike in their childhood, when people would stare at his family because Fred seemed different, public attitudes have changed and people now seem more protective than dismissive. By the end of the memoir, Fred has bonded with his brother, who also has met a girlfriend. Goldstein believes that reconnecting with Fred has led to his own growth as well—a common theme among the stories of survivors’ lives after Willowbrook. Fred was fortunate in that family members remained in touch and provided emotional support. His family remained in supportive contact through his Willowbrook years and beyond and seems relatively well adjusted, able to cope with many daily living activities and experience connections with loved ones.

Kirst (2025), who like Padnini reports for a local news outlet, wrote a retrospective article after the passing of Willowbrook survivor Henry Wesley. Unlike Fred, as children Henry and Jean Jeffers Wesley, who would later become his wife, had no contact with family while living at Willowbrook. Henry recalled being beaten, put into a straitjacket and into solitary confinement, as well as being taunted for being Black. He crawled on the floors until age 13, when he received his first wheelchair. After being released into the community, Henry began advocating for the rights of others with disabilities. Using a Dynavox, he was able to communicate. He and fellow Willowbrook survivor Jean Jeffers married. With help from friends, they researched their ancestry. Henry found that his mother had died, but he was welcomed by surviving relatives he discovered. Jean, who believed she had been abandoned, learned that her mother had died a year after Jean’s birth, and as an infant with cerebral palsy, she had been placed at Willowbrook. Learning about their families, including some caring relatives, gave them closure. Kirst (2025) reports comments from those who knew the Wesleys, who said that the couple's "love for each other" was central to their success and the "joyful" presence they exuded. Their pastor, Reggie Smith, comments about Henry, "His mind was one of the strongest minds I have ever experienced"--yet Henry recalled being treated at Willowbrook as if he had an intellectual disability. Andrew Marcum, Academic Director of Disability Studies at the City University of New York, discusses the couple as an example of how attitudes have changed, empowering those with disabilities. Nevertheless, Marcum, who himself has cerebral palsy, expresses concern that in the current fiscal climate, funding and services that have enabled individuals with disabilities to lead happy, productive lives may be cut.

While in graduate school, Dan Tomasulo took a job rehoming and supervising some of the residents who were leaving Willowbrook for a group home that Tomasulo describes as innovative for its time. He has gone on to research positive psychology and therapies for individuals with intellectual disabilities, and to advocate for the rights of people with intellectual disabilities. In his forward to *American Snake Pit: Hope, grit, and resilience in the wake of WIllowbrook* (2018), he writes about how the survivors' experiences have remained in his mind all his life.

While fictionalized, his stories about them depict issues that Willowbrook survivors no doubt faced, some dealing with co-occurring mental and physical issues, a history of being raped, assaulted, or otherwise abused. As a psychologist and academic, Tomasulo (1999b) has developed the Interactive Behavioral Therapy Model for individuals with intellectual disabilities. This enables them to act/interact to express what they cannot verbalize. Clients can set and evaluate their own goals.

Mental Health Sequelae: Attachment Disorders, Post-traumatic Growth

As stated in the introduction, one roadblock to learning from the experiences of Willowbrook survivors is the difficulty of measuring both lingering mental health damage and posttraumatic growth by empirical measures. Other factors include the passage of time and the desire for privacy of these individuals in a protected class of subjects. Furthermore, many of the survivors who might wish to communicate their experiences could find it difficult to answer survey questions that ask them to draw abstract conclusions. The widely used measure of posttraumatic growth, Tedeschi and Calhoun's Posttraumatic Growth Inventory (1996), is not suitable for individuals with intellectual disabilities.

In a personal correspondence email (January 2026), Tomasulo suggested that if a version of the Posttraumatic Growth Survey or another instrument could be developed for individuals with intellectual disabilities, this would open the path for richer empirical data to be gathered. Presently, however, such a survey does not exist. Creation of such a survey would be a worthwhile project for further research.

Nevertheless, promising research into the diagnosis and treatment of intellectual and developmental disabilities is occurring, and scholars recently received funding for a center devoted to study of individuals with intellectual and developmental disabilities. In its 2026 budget, New York State has allocated $75 million to establish a Center for Learning to modernize the New York State Office for People with Developmental Disabilities Institute for Basic Research on the former Willowbrook campus. A Genomics Core Facility will also be created to conduct customized research into disabilities (Bascome, 2026). Founded in 1968, The Institute for Basic Research provides specialized research, treatment, and preventative services, as well as educational services for individuals with developmental disabilities and their families.

At a ceremony announcing the funding, New York Governor Kathy Hochul stated, “This proposal aims to modernize a community space into a nationally recognized Center for Learning, fostering innovative treatments and educational opportunities while preserving history.”

Another promising development is that ethics of care, first proposed by Gilligan (1962), has become an important thread of medical ethics. It involves several principles. The first is respect for the rights and dignity of individuals, including their right to autonomy. The second is a person-centered approach that considers the individual’s strengths, needs, and goals. The third is advocacy and support, as carers are expected to advocate for rights and autonomy, considering their unique individual challenges. The fourth is ethical sensitivity, with protection of privacy and informed consent. Finally, an ethics of care takes into account the disparities the individuals may face in accessing health and human services resources. Rather than seeing these individuals as a homogeneous groups, ethics of care supports the dignity of each person (Evidence-Based Care Sheet, 2022).

Analysis/Theories

This literature review presents only a fraction of the available information, much of it unpublished, and the available information leaves significant gaps. The survivors interviewed and described are higher-functioning, able to communicate verbally. They have managed to achieve at least a level of recovery and growth. What of the ones who have not told their stories? And what is the situation today for individuals with disabilities? Has the movement toward deinstitutionalization been successful, or does our society need reform and perhaps a partial return to institutionalization? This study is informed by a qualitative, phenomenological approach, as well as by a disability rights and empowerment perspective, as well as an ethics of care. The psychological contributions of research into positive psychology and posttraumatic growth are also foundational to understanding and applying the lessons of past experience such as Willowbrook to achieve a better quality of life for those with intellectual and developmental disabilities.

Three distinct perspectives, Willowbrook School's place in the replacement of the medical model of disability with a civil rights model, biopsychosocial wellbeing of the clients, and fiscal and policy implications, are considered. Informing the analysis are four theories common in humans services and helping professions: Social Ecology, Social Learning Theory, Strengths-Based Learning Theory, and Disability Civil Rights/Empowerment Theory.

Social Ecology Theory

Social ecology theory exposes the flaws of both the medical model of disability and the argument that education designed specifically for intellectually and developmentally delayed children could best be provided at Willowbrook and similar institutions. Bronfenbrenner, who developed social ecology theory, describes child development as taking place over time in an ever-widening environment, from immediate family and friends to neighborhood, community, school, and the broader culture (Bronfenbrenner, 2009). Bronfenbrenner stressed the importance of community and environment, countering the widely held belief at the time that biological factors have the greater influence on individual development. Although his research focused on children outside institutional settings, his work has influenced the thinking of those striving to provide a rich environment for individuals with disabilities. DeConstanza Eagle et al. (2026)

apply the social ecology concept to study barriers individuals with intellectual disabilities face in self-advocacy. Sox et al. (2026) studied the role of social supports for youth with disrupted attachment and trauma, finding positive outcomes. While not all children with profound intellectual disability can be supported in a nuclear family, providing social and emotional supports has an overall beneficial effect on mental and physical wellbeing. This positive effect of community is reflected in some of the survivors' stories of "fitting in" either through advocacy work or through establishing emotional bonds with others.

0Social Learning Theory

Bandura developed his Social Learning Theory at about the same time Bronfenbrenner was crafting his Social Ecology theory. Bandura (1965) emphasized the importance of learning by observing and copying the behavior of others. Both theorists found that children in enriched environments were much more likely to learn as well as to gain self-efficacy. Even nonverbal individuals can benefit from interacting with others. It was as if several factors were converging to move society away from the practice of segregating individuals with disabilities in a harsh, unstimulating environment.

Strength-Based Learning Theory

The Strength-Based Learning Theory advocated by Seligman et al. (2006) and others encourages educators to focus on children's strengths to enhance their self-esteem and c0onfidence and help them to reach their potential. For some of the higher functioning Willowbrook survivors such as Cabello and the Wesleys, this approach resulted in their successful advocacy for others. For many survivors, capitalizing on strengths may mean simply practicing skills of daily living and prosocial behaviors. Tomasulo and others (1999; 2018) have advocated for a more comprehensive approach, Positive Psychology, to enhance quality of life.

Both Strength-Based Learning and Positive Psychology have moved beyond labeling and educating around perceived deficits to a growth model. As Goldstein (2021) notes, social norms have moved from hiding away individuals like his brother, Fred, or staring at them in public places, to accepting them as part of the American social ecology.

Positive Psychology and Posttraumatic Growth

Positive psychology, as developed by Seligman and others, offers a path away from the medical model of disability toward a strength-based one (Seligman, et al., 2006). Seligman's PERMA model consists of five elements of wellbeing: "positive emotions, engagement, relationships, meaning, and accomplishment" (Madeson, 2017). Tomasulo (1999b) has developed an Interactive Behavioral Therapy model drawing from positive psychology concepts, encouraging groupwork and psychodrama to help clients with limited verbal communication abilities express their feelings. It is hoped that the theory of strengths-based positive psychology is part of current in-service training.

Unsurprisingly, survivors of abusive institutional settings are likely to experience trauma. In the past quarter-century, much research has been done on psychology of trauma. Van der Kolk (2015) and others have increased our understanding of the neurological and psychological sequelae of trauma. Trauma victims may experience posttraumatic growth as well as suffering. McCormack et al. (2022) analyzed 141 studies of posttraumatic growth after complex trauma, which involves "horrific events that have the potential to impact the individual with severe psychological or emotional distress" (p. 253). Such events may be cumulative and/or interpersonal. The Willowbrook survivors' experiences qualifies as inducing complex trauma over time.

In their results, McCormack et al. (2022) expressed a need for more cross-cultural studies with different populations. In the studies they reviewed, no mention was made of subjects with intellectual or developmental disabilities. They conclude that despite current interest in posttraumatic growth, more research needs to be done in this field, as the results are somewhat skewed toward the experiences of certain groups but may exclude others.

While there are few or no studies of posttraumatic growth among institutionalized survivors with disabilities, the post-institutionalization experiences of Romanian children orphaned or abandoned in the late twentieth century have been more thoroughly documented. Chugani et al. (2011) found neurological changes in a group of survivors who experienced attentional and behavioral difficulties. Some of them suffered from attachment disorders that in turn caused many to have behavioral issues. Furthermore, Rus et al. (2016) report that 28.4% of children who had experienced institutionalization reported having been abused by peers. When they were adopted, many of these children had attachment issues that prevented them from easily adjusting and forming relationships with their new families. Tomasulo (2018) describes distrust and violent behavior in some of the adult Willowbrook survivors he was resettling into a group home setting, which is unsurprising given the deprivations they had faced. Staff at the group home treated the clients calmly and rationally, as they understood that this type of behavior could occur. Thanks to the disabilities rights movement and to an adoption of positive psychology and an ethics of care, more personalized, strength-based care is given to many intellectually and developmentally disabled individuals now.

Civil Rights for Individuals with Disabilities

While sociologists and psychologists were developing new theories to promote biopsychosocial wellness and inclusion, a number of civil rights movements intersected and came to the foreground during the 1960's and 1970's. The affirmation of basic human rights extended to all individuals thus has a firm if fairly recent basis in law. The Disabilities Rights

Movement is grounded in foundational documents and laws. Both the United States Declaration of Independence (1776) and the United Nations Universal Declaration of Human Rights (UDHR, 1948) provide a general premise for granting human rights to individuals with intellectual and developmental disability. Furthermore, the United Nations Convention on the Rights of Persons with Disabilities (1966) explicitly extends those rights to that class. In the United States, The Americans with Disabilities Act was signed on July 26, 1990. The affirmation of basic human rights extended to all individuals thus has a firm if fairly recent basis in law. A dominant perspective in medical ethics argues that a "common morality" should apply in medical and policy issues (Childress and Beauchamp, 2022).

For higher functioning individuals, the Disabilities Rights Movement has borne fruit as gaining autonomy, humane treatment, and supportive housing has made positive differences. Although the current situation indicates progress, however, it is likely that many individuals are not receiving adequate services. If supportive housing is not available, how will individuals like the Willowbrook residents survive? According to Thurman et al. (2023), almost half of the homeless population have an intellectual or developmental disability. In a qualitative study consisting of interviews with 18 service providers, Thurman et al. found concerns about locating enough services for intellectually and developmentally disabled clients. The service providers cited inadequate funding sources as well as their own lack of training in finding appropriate housing and treatment. They also noted that one contributing factor may be that clients how are already involved in the social services system may lose autonomy to follow their own preferences. Thurman et al. recommend changes that would allow service providers access to data-driven decisions and collaboration in placing individuals in care.

Brown and McCann (2021) conducted an international review of studies on homelessness, including among the developmentally disabled. Their analysis of nine peer-reviewed studies on homelessness among persons with intellectual disabilities reveals that death of a family member, family disagreements and estrangement are the most common reasons these individuals lose stable housing, and that being diagnosed with an intellectual disablity is a predictor of greater likelihood of homelessness. Other characteristics that correlate with this population being unhoused include male gender, African American ethnicity, and low educational attainment. Some homeless individuals may not know how to access services. Since today many developmentally and intellectually disabled children live with family members, they are likely to need housing, not as youth but as adults. In a sense, then, the problem has shifted from one of warehoused children to one of unhoused adults. 000

Ethical Implications

Questions of society's responsibility for civil rights and humane treatment of individuals with intellectual and developmental disabilities raise ethical issues. It can be argued that there is a Kantian categorical imperative to treat all human beings fairly, justly, and humanely (Flanigan, 2018); nevertheless, Kruger (1986) in his explanation of the motives behind conducting the hepatitis experiments, makes the utilitarian argument that knowledge gained from infecting a group of Willowbrook children with the hepatitis virus could ultimately yield information that could be generalized to benefit institutionalized residents. Similarly, a practical, utilitarian benefit for parents can be assumed in the attitudes of mid-twentieth-century doctors who suggested to parents that their special needs children be institutionalized, for their own good as well as for that of the family. Since Kruger's time, with civil rights movements for individuals with disabilities and of different races and ethnicities, society has shifted toward an argument for universal rights.

Beauchamp and Childress (2015) maintain that there are four basic principles of medical ethics: respect for autonomy, beneficence, nonmaleficence, and justice. They argue that these four principles form the basis of a common morality; however, although these principles are widely accepted, Childress and Beauchamp (2022) are engaged in a debate with ethicists who have other perspectives.

Smith (2005) argues that there is a fundamental paradox or conflict within the Disabilities Rights Movement (DRM), which seeks to have universal rights and common morality applied to individuals with disabilities, yet recognizes special circumstances or privileges. Disabilities rights activists often critique societal laws and conventions that omit or exclude disabled people, but at the same time identify as an "other" and excluded identity within these societal norms and laws (p. 566). If people with disabilities were to be accepted within societal norms, would they still be eligible for special status and privileges? According to Beauchamp and Childress (2022; 2015) they would be.

Nevertheless, some individuals with disabilities find themselves in the criminal justice system. Disabled Youth who violate societal laws or conventions are often excluded and segregated into institutions, argues Bihani (2024). Once a disabled youth breaks the law, the criminal justice system often abrogates their rights. She states that the criminal justice system has become a "new Willowbrook" in that minors with intellectual disabilities, attention deficit, and other neurological disorders are sent far too often into the criminal justice system, where they languish without proper diagnosis and care.

Ethics of Care, first proposed by Carol Gilligan (1962), offers the possibility of navigating a path between the dichotomies of universal principles versus individual rights and needs. Gilligan suggests that traditional ethics focuses on general principles and premises, whereas ideally ethics should be grounded more on inductive psychological, and contextual factors. Power differentials are a part of life, but the heart of ethical decision-making is in human relationships which can empower those with less power and give them a voice in their own destinies.

While the legal arguments for disability rights are founded on general premises and housed in legal and quasi-legal documents, Jacobs et al. (2020) suggest that, at least in direct client care, an ethics of care should be central to decision-making. Through interviews and observations, they used an ethnographic approach to study six adults with “severe” intellectual disability and interviewed family members and staff as these individuals made the transition from school and family settings to adult services. They concluded that the six adults were able to communicate through their families and caregivers; through trusting relationships, the clients were able to show agency and make their preferences known.

One conclusion to be drawn from Jacobs et al. (220) is that adult clients were more likely to make a successful transition from “school” to adult care when staff and family members took time to learn their preferences and needs. This was not the case at Willowbrook, despite the caring attitudes of some overextended staff. Jacobs et al.’s study clearly reflects post-Willowbrook era values.

Despite the movement to offer clients as much autonomy and decision-making as they are capable of, however, much of the funding has to come from governmental agencies and private charities. It may be necessary to legislate morality through movements such as disability rights, which can argue from general premises that funding and rights must be made available to all regardless of “ability” to ensure that it is possible to provide an ethics of care. Perhaps our current situation as a society provides the best of both approaches.

Policy Implications

The current federal administration has proposed a return to institutionalization as a solution to the homelessness problem. In July 2025, President Trump signed an executive order making it easier to institutionalize homeless individuals who refuse treatment. Thompson, (2025), writing for the National Alliance to End Homelessness, expresses concern; without mentioning Willowbrook she references the time before the deinstitutionalization movement, arguing that housing people *en masse* in large facilities failed to provide a suitable answer. Unfortunately, although today fewer large institutions exist and staff are better trained, some abuse still occurs. For example, recently four care staff were charged with abusing a patient at the Sunmount Developmental Center in Upstate New York (State Police Charge Four, 2026). While the proposed government facilities to house the homeless have not yet been built, this proposal represents a potential removal from society and threat to the freedom of choice of those with intellectual and developmental disabilities.

It is difficult to know whether a social or behavioral theory or a simple desire to beautify our cities is behind the current administrative directive, which appears to erode the disabilities rights concept that individuals should have as much autonomy as possible. As yet unanswered is whether under the directive, homeless individuals with disabilities would be classified under the same umbrella as those with criminal histories, addictions, or severe mental illnesses.

Yet, as the United States' current housing dilemma illustrates, the processes of ensuring human rights to individuals with disabilities has been challenging. Tøssebro and Gustavsson (2025) provide insights from the deinstitutionalization movement in the Nordic countries. They find that individuals with milder forms of disability and knowledge of financial and daily living skills are more likely to participate successfully in self-advocacy, while children and those with more difficulty functioning are more likely to spend most of their time with other disabled individuals and their caregivers rather than enjoying freedom in the broader community. Thus, “mainstreaming” has been achieved only to a limited extent. It is likely that the same conclusions could be drawn in the United States.

Burch (2017) suggests that some inequality is inevitable and hence so called “mental capacity” laws exist to provide a mechanism to make decisions for those who cannot do so themselves. While some would argue for individuals with disabilities to be able to follow their “will and preferences,” Burch disagrees. Yet if the individual lacks the mental capacity to make the decisions, who can be entrusted to make them by proxy? While our society has made great progress in self-determination and advocacy by individuals with disabilities, there will always be some persons whose fate is determined by families, private agencies, or various levels of government. Although the 2026 Presidential Executive Action is brief and has not yet been implemented, it suggests that representatives of the federal government will have jurisdiction to make that decision. Thus, the disabilities rights movement has opened the windows and doors to freedom, but society must be aware of those who are not free to leave the building without assistance; in this case it is hoped that trained, caring staff working from an ethics of care perspective will prevent the recurrence of Willowbrook-like situations.

If our society has actually reached the point where equal rights, as well as a universal right to humane, ethical care for all, are acknowledged, we are in a far better place than in 1947, when Dewey argued that the best practice to care for “feeble minded” individuals was through large-scale institutionalization. Our attitudes—and our vocabulary—have changed. As Tomasulo argues (2018), group homes with staff who provide individualized attention as well as targeted therapies (1999b), even to those clients with behavioral issues, can offer clients posttraumatic growth. Diagnosis has also become more targeted; today, individuals with cerebral palsy such as Cabello and the Wesleys would not be labeled intellectually disabled and would be given appropriate education. We also understand that children, regardless of intellect or ability, need stable attachment figures for their social and psychological wellbeing.

Yet with all the progress, much remains to be done. Developmental Centers still exist, although under closer supervision. Sunmount Developmental Center, discussed above as the site of a recent charge that staff had abused a client, now houses only “high need” clients; the person whom staff allegedly abused had been exhibiting unruly behavior in a cafeteria. As Bihati (2024) notes, young offenders with behavioral issues are often incarcerated instead of receiving mental health care. While staff today are trained in crisis intervention and direct care, and institutionalized clients are taught daily living skills, these environments sometimes fall short of being models of care ethics.

Perhaps the greatest obstacle to ensuring no more Willowbrooks is funding. Indeed, fluctuations in New York State appropriations led to the 50-to-one patient to staff ratio at Willowbrook (Goode et al., 2013; Willowbrook Project Archives, College of Staten Island, n.d.). Among many priorities in the state budget, legislators need to weigh the needs and demands of their constituents.

As discussed above, deinstitutionalization, group homes and supportive housing have given people with intellectual and developmental disabilities overall more autonomy and care. Nevertheless, some individuals may drift into homelessness due to deaths or estrangement in their family, or their distrust or ignorance of resources offered by government and private organizations. (Fear is a major reason that some unhoused people do not take advantage of homeless shelters, and a history of abuse and insecure attachment certainly can lead to fear and distrust.) the current federal administration has issued a Presidential Degree called “Ending Crime and Homelessness on America's Streets” (July 24, 2025). While the National Alliance to End Homelessness (2026) advocates for safe housing, it is possible that longstanding policies may change and some individuals may be returned to institutional care.

Based on our literature review, there appear to be better diagnostic, educational, therapeutic, and care standards available today. Public understanding has also evolved. Legal and ethical views are consistent with providing individuals with intellectual and developmental disabilities with a high standard of care. It is important to continue to advocate for their rights, and to fund both research and human services approaches to their care. Families and caregivers need to continue to receive education and support from schools and agencies. The fields of positive psychology and posttraumatic growth hold promise for improving the quality of life for these clients. As a democratic society, we are on a path of progress. It is hoped that current priorities and funding sources will remain focused on this population's needs and wellbeing.

Summary

In the half-century since Rivera’s documentary exposed conditions at the Willowbrook State School, much progress has been made, both in policies and in ethical perspectives. Most persons with intellectual and physical disabilities now live in small group homes or with their families, where they receive individualized care and attention. Guidelines for research with human subjects now prohibit the kind of research that Krugman justified, when he infected

Willowbrook residents with hepatitis, ostensibly for the greater good. The disability rights movement, the rise of positive, strength-based therapies, and the growth of an ethics of care have no doubt improved the lives of individuals with developmental disabilities.

In summary, multiple strands of information can be used to inform care for individuals with intellectual and developmental disabilities. As time passes, however, bad memories fade. Therefore, it is important to keep alive the stories of survivors, their caregiver and families, as a reminder of how the best of intentions can go astray due to overcrowding, lack of appropriate funding and staffing, and a perspective that individuals with disabilities are unfit to participate in society and need to be kept hidden (segregated) from the public.

Today, the remaining Willowbrook survivors are elderly. After being released from the state school, many led quiet lives out of public awareness, unwilling or unable to communicate about the quality of their lives after experiencing at best insufficient care, and at worst, physical and mental abuse. How many were able to achieve posttraumatic growth? The survivors discussed above did, to varying degrees, achieve such growth. How much more could they have achieved had they not been warehoused at Willowbrook during their formative years?

Although the deinstitutionalization movement has succeeded in that most individuals with intellectual and developmental disabilities now live in supportive housing, small group homes, or with their families, problems still exist. Institutions, including prisons as well as large facilities such as Sunmount, are still home to many clients with behavioral issues. Homelessness among the intellectually and developmentally disabled is an increasing problem that often occurs after individuals have reached adulthood and family are no longer able or willing to care for them. They and their caseworkers may lack knowledge or resources for their care.

Democracy has worked in favor of disabled persons' rights. Yet in our democracy, not everyone shares the same priorities for spending limited public funds. Since the United States is still recovering from the fiscally destabilizing results of the COVID pandemic, and since funding for other pograms has been increased, will there continue to be sufficient funding to provide individualized care for the intellectually and developmentally disabled in a least restrictive environments? It appears that the current administration views homelessness as a serious problem; however, the Executive Order of 2925 removed some barriers to forcing individuals off the streets and into institutions. Since past experiences with institutionalization have not been ideal, oversight will need to be maintained.

Recommendations for Future Research and Action

As with survivors of other mass tragedies, such as the Holocaust, some survivors' tales have not been published. The City College of Staten Island has a large archive of records relating to Willowbrook, many of them unpublished. This researcher plans to study them to seek more survivors' stories, as well as any other documents that pertain to the residents' experiences and quality of life. If possible, the stories of surviving residents should be gathered while there is still time.

There is also a continuing need for public advocacy and education about individuals with intellectual or developmental disabilities and their families. These people are not hidden away; we see them in our schools, shopping centers, and medical facilities, but we often view them from outside. Although public attitudes are0 more positive, many non-disabled observers have likely not communicated directly with a disabled individual. Prejudice, fear, and sympathy—all unproductive attitudes, are still common, particularly toward individuals who look "different" or are unhoused. Returning some of these individuals to large institutions, out of the public eye, with the belief that this would make our cities 000000more beautiful and safe, is a return to an unsavory past. Instead, funding for care, education for care providers including families, and supportive, subsidized housing can provide many individuals with intellectual or developmental disabilities with a good quality of life. An ethics of care rather than a return to viewing these clients ae a group to be hidden away can provide progress. Therapies designed to help them communicate and express their needs and opinions can also improve their quality of life. The Willowbrook survivors have been able to tell their stories of recovery, resilience, and posttraumatic growth. We cannot remove their traumatic memories, but we can assist them in making their futures better.

To recognize the Willowbrook survivors and their contributions to progress in the care of those who have come after them, three areas can be addressed. First, when possible, statistical data should be kept on their lives; alternatives to institutionalization can be studied. Second, qualitative phenomenological research can be used to gather information on the survivors' experiences, from the clients themselves as well as from caregivers and family. An alternative to Tedeschi and Calhoun's Survey of Posttraumatic Growth, modified for individuals with intellectual and developmental disabilities, is worthy of research and development, as Tomasuli notes (personal email, January 2026). Finally, it remains crucial to advocate for funding and training so that these individuals can experience not just freedom from abuse, but positive, enriching experiences and relationships that will make growth possible. Our society will be the better for improving their lives.

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