

Nellie's Last Act

Act 1.

Nell Claraty was born in 1918 in San Francisco. In 1918 Woodrow Wilson is president, World War I is coming to an end, women's suffrage passes the House, less than 5% of American households own a car, the airplane has yet to carry a commercial passenger, and Nelson Mandela is born. 1918 is also the year Nell is diagnosed with Cerebral Palsy and mental retardation, conditions that will shape most of her life for the next 79 years. Despite her diagnosis, Nell required little care the first few years of her life beyond that needed by other children her age. Unlike other children, as she grew her needs didn't diminish, and so the difficulty in caring for her grew as well.

Like the families of most developmentally disabled children, Nell's parents were urged to "let her go". Almost from the day she was born, they were told she would become a burden too great for her family to bear, endangering her brothers and sisters, the children who most needed, and were most capable of returning, the love and attention of their parents.

Nell's parents were not alone in their struggle. Throughout the 20th century, many thousands of parents were lambasted with these same cautions and forceful advice, eventually leading to 80% of people with developmental disabilities being confined to state institutions.

In 1927, Nell's family, exhausted from the strain of her care, and realizing the limitations of their ability to provide for their daughter, finally succumb to the pressure of the doctors and professionals, feeling foolishly arrogant in their admittance that they should have listened to the experts and relinquished care for their child years earlier. They packed a few clothes and family photos, and sent their daughter to live with others like her, at the age of nine.

The Sonoma State Home opened in 1891 as The California Home for the Care and Training of the Feeble Minded. In its 120 years, Sonoma Developmental Center, as it's now called, has been many things to many people, but it wasn't at all, like a home.

The first generations of institutions began in the mid 1900's, modeled after small family farms. They collected residents from jails, almshouses, or families hoping to improve the utility of their disabled family members, offering training in farm and domestic labor in the hope of returning residents to "normal society" as useful contributors. These training farms, as with all models before and after, were seen as *the solution* to people with disabilities. This model, as with all models before and after, were eventually seen as obsolete or insufficient, perhaps because they were created with a fatal flaw; the assumption that people with disabilities are something that require a solution. 100 years later, this assumption is still at the heart of many service models.

By the turn of the century, the agricultural economy of the United States began to give way to a powerful new economy based on innovation and manufacturing, in which

industry saw no profitable place for disabled workers. A new “solution” arose modeled after sanatoriums, hospitals, boarding schools and factories, but eventually were perverted into something that most closely resembled human warehouses.

In 1918, when Nell was born, 38% of American adults and children with developmental disabilities resided in state institutions. By her 30th birthday, this number had more than doubled; a surge that utterly destroyed any past pretense of training and education, as well as any delusions of wards returning to their families and communities. All that remained of a once thoughtful and progressive undertaking was the well-intentioned arcane terminology that referred to a handful of places on the grounds: the campus, cottages, the canteen - hidden by walls and fences from the public eye and collective conscious.

The hope and promise of the institution, seen by the 19th century progressive reformers who engineered them, was a professional and centralized system of care, security, education, and training for society’s most vulnerable and destitute members. This salvation decayed into damnation for those made invisible by this new generation of institutions. A structure built on a faulty foundation of good intentions collapsed beneath the multitudes condemned by American shame and ignorance, and was finally buried by the weight of American apathy and dismissal.

Those who entered institutions during this period experienced the doomed reality that their new home was a prison, characterized by intolerable overcrowding, pervasive neglect, and the grinding routine dehumanization of all involved – wardens, watchmen, and inmates. This heartbreaking reality was also characterized by the silent understanding of a society whose tacit consent upheld its walls, that every patient sent to it’s institutions carried a life sentence, and that among those so condemned, were nine-year-old girls.

This era of American institutions also bore horrifying similarities to encampments erected across the Atlantic, also considered by their architects as a “solution”. A striking dissimilarity however, is that these European camps eventually came to be the cause of public horror, outrage, and embarrassment, while their American counterparts still go largely unknown and unrecognized. Over the course of Nell’s first few decades at Sonoma, over 5000 residents were involuntarily sterilized. Over the next few decades, anywhere from 1,100 to 15,000 patients at Sonoma were selected, numbered and labeled as “specimens” by their government, and underwent experiments on the effects of radiation. Many of these “specimens” confirmed the prevailing scientific understanding, that death was one of the primary effects of radiation on human beings. The great discrepancy among these numbers - eleven hundred to fifteen thousand – reflects with greater accuracy the social status of the victims. Many thousands more died from abuse, preventable illnesses going untreated or unnoticed, or from dehumanizing neglect. Most of those sent to Sonoma State Home in the first half of the 20th century never left, their bodies buried in unmarked pits referred to by the irony-impaired workers as “community graves”. The ashes of thousands of others were commingled and scattered or buried somewhere undocumented on the grounds.

Act 2.

In 1995 a man from Santa Cruz visits the Sonoma Developmental Center, as it is now called. Representing a local non-profit that serves adults with developmental disabilities, he has come to speak to residents about Supported Living, a new service becoming widely available in California, created to help people to secure housing, and provide whatever support they need to live safely in homes of their own.

One of the women, then called patients, now called consumers, in attendance that day, was Nellie. Now an old woman, with chopped white hair, no teeth, and legs extended with frozen muscle, jutting away from her torso as if they were trying to leave the rest of her body and escape on their own. The permanent contracture of her legs, bent inward at the knees to form an “x”, may well have been prevented with physical therapy, therapeutic exercise, or even a simple stretching regimen, but none of these treatments were provided during Nell’s internment. Nell’s teeth may have rotted and fallen out, a likely result of decades of neglected hygienic care. Even more likely, is that many years before, Nell’s teeth were pulled, all at one time by staff at Sonoma. Institutions frequently followed a policy of removing the teeth of any patients who they classified as “biters”, being anyone who, lacking other outlets and means of self expression, turned their rage, pain, or desperation on themselves, biting their own hands or arms; or anyone who, out of frustration, fear, or self-defense, would use their teeth on others to protect themselves. Most institutions found the easiest way to deal with this behavior was not to address the conditions that led to it, or even the behavior itself, but to simply dispose of the patients’ teeth.

For almost an hour, Nell sits, with fifty or sixty other patients, while the man from Santa Cruz addresses the small crowd. No one thinks Nell is listening. For almost an hour, he talks about what it would be like to live in Santa Cruz, to live outside the institution, and the services his agency could provide. For almost an hour Nell listens, then watches him leave.

In the months that followed, a change began to take form in Nell’s behavior. This change, an excitement that erupted at the sound of certain words - *house, home, apartment, beach, ocean* – was marked by Nell’s screeches, and thrashing in her wheelchair, and was ignored or unnoticed by almost everyone in the institution.

Two veteran staff members of Sonoma, both who knew Nell, though not each other, took note of her change. Nell didn’t speak much in the conventional way. She used a few common words, and the names of some of the people she liked, but beyond that few people in her 77 years had bothered to assign any meaning to most of the sounds she made. Those who worked with Nell, if they chose to put forth the little effort it took, could easily decipher the meanings and intentions of her sounds, if not the words they were intended to represent. That two of her staff took notice of her screeching about houses and beaches seemed too unlikely a coincidence to be merely that, though perhaps less unlikely than the idea that she was screeching about actually leaving the institution herself. No one knew if Nell had ever been to a beach, or seen an ocean, or could even really conceptualize that there was a world outside the institution. No one knew much about Nell’s life before the age of nine, and it wasn’t likely that she had ever seen beyond the walls of the institution once she was admitted.

Over the next few months, Nell's intentions grew undeniable to these two staff who cared enough to take note, and they both came to understand what in fact, Nell was demanding, and more importantly, why.

Nell's two staff members knew well that an institution was designed to admit and absorb its residents, to swallow them from sight of the public, and that it did not easily give them back. They knew even better, that if Nell were ever to be released by Sonoma, she would likely only do so as a result of the aggressive effort of a persevering and persistent advocate.

In 1995, Nell's younger sister was her closest living relative. At almost 77 years old, the thought of embarking on a long campaign against a glacial, confounding, and entrenched establishment proved too great an undertaking for her to consider. She had not envisioned spending her final few years buried in this bureaucracy, not even to emancipate the sister she had never known. Despite their description of the new supported living services available, and their conviction that her older sister Nell had become impassioned with the desire to leave Sonoma after almost 70 years, she apologetically told Nell's staff that she was not up to the task. Seeing how deeply these two staff members cared for her sister, she challenged them to continue advocating for Nell on her behalf, and become Nell's conservators - *a type of legally designated stewards and decision makers* - when and if she ever left Sonoma.

In the face of the tumultuous political climate surrounding deinstitutionalization, in a move whose very nature challenged not only their livelihood, but the very principles and ideals upon which the institution was built, ideals that they both believed in firmly as guiding fundamentals of their vocation, Nell's staff did the unthinkable, and accepted the mantle thrust upon them.

Though Nell's staff didn't acknowledge or embrace this contradiction, many viewed any resident escaping life in a developmental center as a threat to the purported necessity and viability of all institutions. These behemoths were built to shelter those shunned by society, and every disabled person who returned to be welcomed by whatever family remained on the outside, every person who, welcomed by no one put in roots and attempted to embrace an outside community on their own, every person who survived or thrived in life outside an institution, was living proof that these institutions, these monuments to the most marginalized members of society, were no longer needed.

The eventual exodus of residents left in its wake an embittered battlefield on the grounds of any institution threatened with closure. Two cornerstones of a modern society were pitted against each other to be contested as mutually exclusive. On one side, the rights of workers to organize and bargain collectively for thousands of jobs that provided thousands of families with the mortgage payments on their homes, college educations for their children, care for their aging parents, and retirement opportunities for themselves. On the other side, freedom, long forgotten, for those who are institutionalized, and the most basic civil and human rights so long denied to society's most disregarded, disenfranchised human beings.

For the next year and a half, Nell's staff, now her conservators, trenched through this contradiction, laboring against an institution they still respected, still believed in, still believed could be saved, to liberate a woman they now loved, and *knew* could be saved. For a year and a half, they pushed and pressed to perpetuate the cause of one American citizen's right to freedom, to privacy, to unfettered movement. For a year and a half, they guided her cause around the obstacles erected by a half century of harsh and hostile bureaucratic process that had propped up the American institution, a process developed out of self-preservation, to stop or stall the progress of the very people it was designed to protect, a people who's emancipation endangered its existence. After a year and a half, they succeeded.

Act 3.

In 1997 Nell Claraty returned home. In 1997 Bill Clinton is president, World War I, World War II, the Korean War, Vietnam, and the Gulf War are all over, there are 65 women in the House of Representatives, 95% of American households own a car, man has landed on the moon and broken the sound barrier in jets, and Nelson Mandela is president of South Africa after spending 27 years in prison. 1997 is also the year that after 70 years in an institution, Nell Claraty moves into a newly built two-bedroom apartment in Santa Cruz, just a few minutes drive by wheelchair, to the beach on the Pacific Ocean.

At the age of 78, for the first time in her life, Nellie picked out her own clothes, redesigning herself in bold colors, leopard prints, and glittering costume jewelry. She rarely left the house without an assortment of accessories sufficient to open a small boutique- gloves, hats, handbags, scarves, and glasses; and never without pounds of glittering paste jewelry- rings and earrings, bright beaded necklaces, bracelets and broaches, chokers and cameos, clipped or hung from any space available on her 82 pound frame. Nell picked out a new electric wheelchair, in a fitting regal purple, and with her staff at the controls, rolled through downtown almost daily on her way to get ice cream. The panhandlers who prop up the buildings along Pacific Avenue in Santa Cruz came to know Nellie on sight, and when she rolled by would call out to her as "grandma", just to hear her infectious laughter. For whatever reason, Nell found their greetings one of the funniest things she'd ever heard. Perhaps this was simply because the concept of being heckled by strangers was amusing, perhaps because a warm interaction of any kind by strangers was a complete novelty, or perhaps because over her 70 year internment, where days, which seem weeks, may pass without being marked by the view of sunlight, Nell's sense of time, of years and decades, of age, and maturity, had been robbed from her, and so to Nell, who had last traversed public streets as a nine year old girl, the suggestion of her as a grandma could only be met with amusement.

In 1999 Mainstream Supported Living stepped in to provide care for Nellie at the request of her conservators. Mainstream served Nell for five years. In late 2004, at the age of 85, Nell Claraty died. A few weeks after suffering a stroke, she passed away peacefully in her own bed, in a house she called home, and among friends.

Act 4.

It is a long known and well understood universal truth, that in this world there are those with, and those without. By anyone's measure, Nell Claraty was undoubtedly a person who did without. Without the mobility to move an inch on her own, without any evidence or understanding of her rights, without money, without words, and without any identifiable form of power other than insatiable desire, Nell Claraty delivered herself from the prison that had held her for 70 years, and into a new house on the beach.

When we recognize in awe what she accomplished, in light of all that she did without, it is evident that there was one other important thing that she lacked; late in her life, Nell Claraty was also without fear. This unimaginable tenacity, courage, and resilience was aided by one great and fateful stroke of luck; near her every day, within the walls of her prison, worked two people who recognized in Nell's voice her humanity. Nell's achievement, as impossible as it seems, is as much a triumph of the courage, commitment, and conviction of two dedicated and passionate staff as it is about Nell's indomitable spirit.

Claraty Arts takes its name from Nell, not only to remember and recognize a remarkable life, but also to give life to our memories of her, and give form and substance to her spirit. Those memories and spirit now serve as the muse and guide to a group of people constructing a purpose and identity for themselves as a community of artists and allies who will no longer wait for the world to change around them.

As a founding force behind this project, Nell's story and her history demand of this community an evolutionary imperative. Claraty Arts, as it evolves, will sustain the pledge to reflect in its art, actions, and ethos, what Nell Claraty achieved through sheer desire.



The Claraty Arts Project pledges to:

Defy any past that imprisons...

Embrace the unknown for the hopes and possibilities it offers to transform our realities, and...

Accept our responsibility to reject and reconstruct the old imposed identities that defines any human being as unwanted, unneeded, or unknown.