

## **NEW YORK'S CRAIG COLONY FOR EPILEPTICS TRACING THE DEEPEST ROOTS OF DEINSTITUTIONALIZATION**

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**ABSTRACT:** *Under the encouragement and guidance of William Pryor Letchworth, the Craig Colony for Epileptics was established by the State Board of Charities on the site of a former Shaker colony in Sonyea, NY in 1894. Following an idealistic model of colony life popular in Europe, the Craig Colony was the first and only New York State institution specifically designed “to secure the human, curative, scientific, and economical care and treatment of epileptics, exclusive of insane epileptics.” Originally built to house 800 patients, the colony was home to nearly 2,600 epileptics at its peak in 1939. The Colony’s goal was to serve the State’s epileptic population without regard to distance from the facility, but distance decay was in fact a factor in Craig’s catchment. Eventually, an aging population, and a therefore less productive and increasingly dependent workforce, exposed the problems of institutionalization and the flaws of the State’s mission. Using data from the Colony’s detailed annual reports, as well as the Colony Daybook, this paper explores the challenges of demographic management and the ultimate failures of institutionalization experienced in Sonyea, “the Valley of the Eternal Sun”.*

**KEYWORDS:** *epilepsy, Craig colony, deinstitutionalization*

### **INTRODUCTION**

When the State takes on the burden of addressing health care challenges, it must inevitably adopt a spatial framework of referral and treatment. The spectrum of solutions to this spatial challenge ranges from bringing care to the sick, or the sick to care, with many permutations between. Since the 1960’s our society has tried to avoid the problems attendant on permanently lodging the sick in large specialized institutions. In the nineteenth century, however, such central facilities were seen as a solution, not a problem. My paper focuses on one such institution, the Craig Colony for Epileptics, and shows that the path to the circumstances that prompted the de-institutionalization movement was rooted many decades earlier and paved with good intentions that could not ultimately overcome the seeds of failure.

The stigma surrounding epileptics in the late 19<sup>th</sup> century caused many sufferers to be ostracized and mistreated by their families and communities. Although recognized by then as a brain disorder that causes repeated and unpredictable seizures, most Americans continued to associate epilepsy with spiritual or sacred punishment, or with idiocy and feeble-mindedness<sup>1</sup>. As colony proponent William Pryor Letchworth stated, “The epileptic holds an anomalous position in society. In consequence of his infirmity, the epileptic grows up in idleness and ignorance, bereft of companionship”.<sup>2</sup> By 1890, increasing concern prompted the State Board of Charities to introduce a bill to the State Legislature, calling for a committee to select a site for a state epileptic colony. Such an institution would provide epileptics a place to comfortably live, free from the oppressive forces of society, with access to the care and treatment they so deserved. Although delayed due to lack of support and popular sentiment, the search for a site to establish a treatment facility for the epileptic residents of New York State began in 1892, under the direction of three members of the State Board of Charities, President Oscar Craig, for which the colony was named following his death, William Letchworth, and Peter Walrath. The three visited many possible locations downstate, but Letchworth pushed for two sites in western New York, one of them a former Shaker colony in Sonyea. With its “1800 acres of land perfectly adapted to all the needs of the proposed colony”, including its fertile soils for farming, access to two streams and the Keshaua Creek that ran through the property (which would come to serve as “a natural barrier for the separation of the two sexes”), suitable buildings, including barns, stables, and cottages, and its proximity to railroads, the team successfully convinced the State Board that no other site would be a better choice<sup>3</sup>. The land and existing buildings were purchased by the State from the Shakers for \$115,000<sup>4</sup>. The Olmstead Brothers, of Central Park fame, promptly surveyed the site and plans were made for more buildings and landscape embellishments.<sup>5</sup>

The mission of the colony, which remained consistent throughout the duration of the institution, was “to secure the human, curative, scientific, and economical care and treatment of epileptics, exclusive of insane epileptics”.<sup>6</sup> The Board had goals for the establishment and maintenance of the institution. These included: to equally serve every county of New York State, entitling each county “to send to the Colony, one-quarter of its number of dependent epileptics”, “to take cases most likely to be benefited by the care and treatment of colony life”, and to avoid admitting “a totally inferior and helpless class”.<sup>7</sup> The colony was to be self-sufficient, and follow an agrarian lifestyle, employing its residents in occupations to support day-to-day maintenance and upkeep. Such employment was also thought to benefit the patient, because “without (occupation) degenerative processes would proceed more rapidly and largely”.<sup>8</sup>

Colony life was designed to be quiet and predictable. Living quarters were divided by gender, age, mental status, and illness, and could house anywhere from 12-150 patients.<sup>9</sup> Residents had the opportunity to attend school and engage in common occupations such as farming, sewing, carpentry, gardening, laundry, and other simple jobs that were both necessary to keep the institution running smoothly and were manageable tasks for patients<sup>10</sup>. Field days and dinners were held to celebrate the holidays, complete with events showcasing colonist-led singing groups, bands, and acting troupes. Other means of recreation included sporting events, moving pictures, and excursions to neighboring villages.<sup>11</sup> The State recognized multiple religions, holding Catholic, Protestant, and Jewish worship services on site.

The colony opened its doors on January 20<sup>th</sup>, 1896, serving 133 patients by the end of the fiscal year.<sup>12</sup> By 1939, like the colony, the population of New York State had increased more than four fold since 1900.<sup>13,14</sup> Overcrowding quickly became a central issue, evident in the request for additional funding for the expansion of dormitory buildings in nearly every annual report.<sup>15,16</sup>

Early on it was recognized that the value of epileptic labor fell short of what was originally believed, as “over one half of the patients at the Colony (were) barred from employment of any kind because of marked mental or physical defect”.<sup>17</sup> This not only led to a greater reliance on hired employees to support maintenance of the property, but additional staff were needed to care for those without the means to care for themselves.<sup>18</sup>

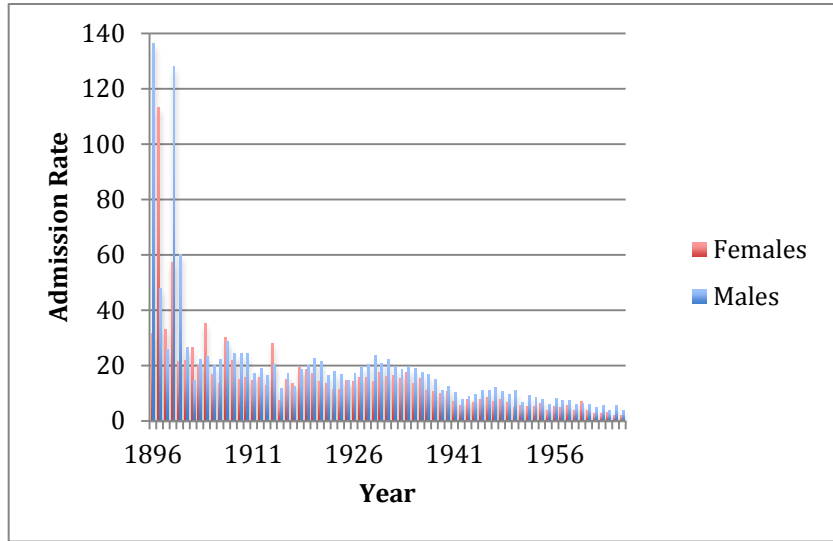
Such concerns foreshadowed the major issues that would eventually come to a head and lead to Craig's ultimate demise. With these issues in mind we turn to the demographic profile and geographic origins of the colonists.

## **RESULTS**

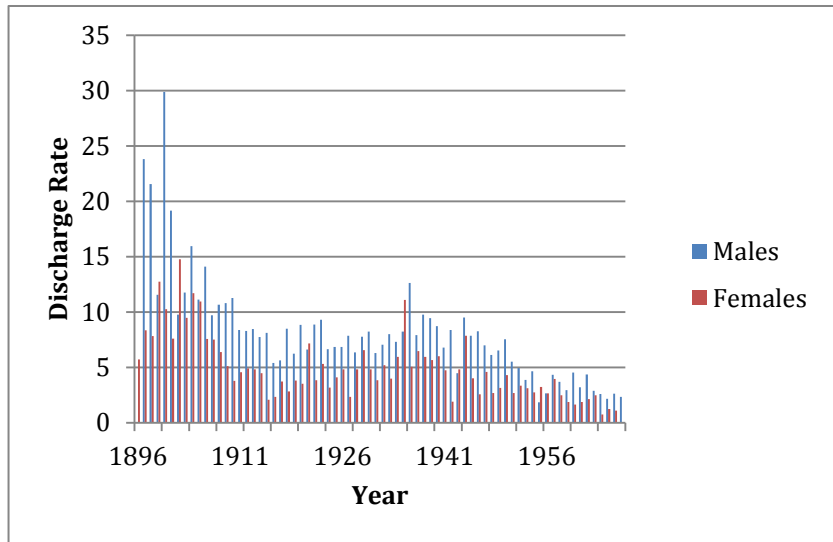
Patient population trends suggest the lifespan of the colony can be broken into three phases. Using annual reports from the entire history of the institution, from 1896 through 1967, annual admission and discharge rates were calculated for both males and females. Discharge rates of males were consistently higher than those of females for the duration of the colony's existence and the slightly higher admission rates for males are indicative of the need to replenish the male patients discharged during each year (Figure 1A). The death rate by gender (not shown) is nearly equal as well. Such consistency implies an additional goal of the colony was to have a near perfect ratio of sexes, although their mingling was not encouraged, obvious in the division between the men and women's quarters by the Keshequa Creek.

Early on admission rates were high, and the colony increased its numbers 10-fold between 1896 and 1910.<sup>19</sup> Phase I marks the growth period of the colony, beginning at its inception in 1896 with a transition into phase II seen only five years later. Phase II is the stabilization phase, with steady growth from 1900 to around 1935. After the colony peaked in population in 1939, at 2,754 residents, it shifted into its third and final phase, a period of steady decline.<sup>20</sup> Even though Craig was officially closed in 1968, it was still home to nearly 2,000 patients in 1967.<sup>21</sup>

Trends in discharge rates follow the same three phases but the discharge phases transition later than their admission counterparts (Figure 2). Like the rate of admissions, discharges were common in the early part of colony existence (Figure 1B). Reasons for discharge included, “improved”, “unimproved”, “recovered”, “transferred”, and “other”.<sup>22</sup> Such statements as “recovered” and “improved” are difficult to believe, as there was not, and still is not, a cure for epilepsy. Classifying patients in the “unimproved” or “other” category may suggest those patients removed from the colony due to issues of mental capability. The stabilization of discharges, phase II, began around 1915 and stayed consistent through approximately 1945 when the colony began to discharge more patients than it accepted, leading to a fixed decline in population.



A.



B.

Figure 1. Admission rates by gender time (A.), discharge rates by gender over time (B).

As to trends in patient deaths, it is evident that colonists were aging along with the colony. In the early years of the colony, patient deaths among children and teens were much higher than among older patients, attributable to poor understanding of how to treat symptoms of epilepsy and a high incidence of infectious disease (Figure 3). In 1967 the death rate among older colonists, was five times that of the prime age residents, aged 35-44, with rates of 1.0% and 5.1%, respectively.<sup>23,24</sup> Colonists were, in effect, aging in place.

In general terms, geographic origins close to the colony always had a larger relative share of patients than settings over 300 miles away. To further investigate this trend, linear regression models were constructed to visualize the origin of patients in a particular year. Comparison of five linear regressions spanning four decades shows a modest distance decay effect over time (Figure 4). The colony came closest to its geographical mission in 1910, evident in the low slope value of  $-.0025$  (Table 1). As noted in the graphs, there were always a handful of high positive and negative residuals, especially in 1920.

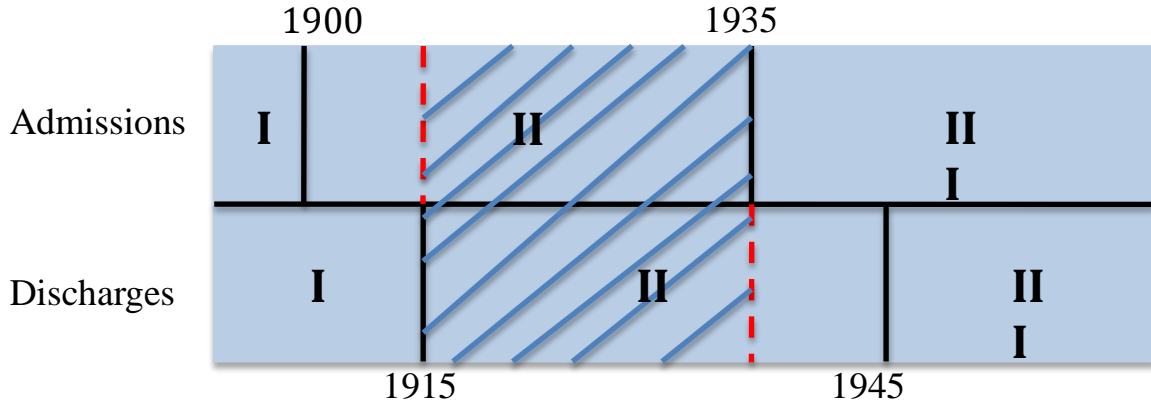


Figure 2. Phases in admission and discharge rates over colony existence.

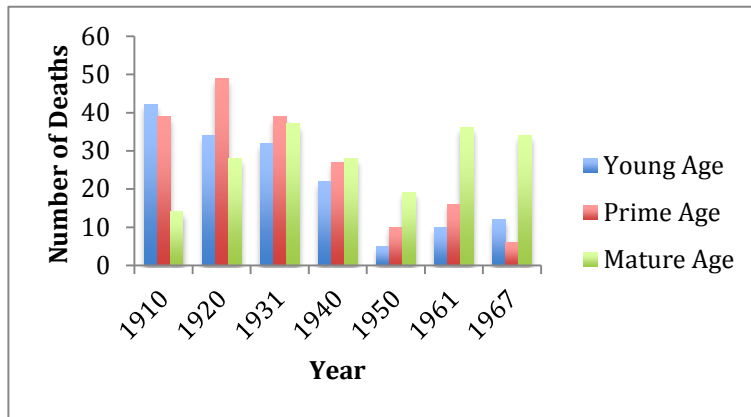


Figure 3. Patient deaths by age bracket over time.

Table 1. Test Statistics for Distance Decay Linear Regressions

Year	Y-intercept (colonists per 10 <sup>4</sup> )	Slope	R <sup>2</sup>	F statistic	P value
1900	1.64	-0.0031	.165	12.92	0.0007
1910	2.06	-0.0025	.091	4.953	0.0299
1920	2.37	-0.0037	.167	11.99	0.0010
1930	2.69	-0.0043	.229	17.79	8.45e-05
1940	3.13	-0.0032	.096	6.399	0.0141

To determine which counties were consistently over and under-represented throughout the Colony's existence, z-scores were calculated. Trends in over representation are marked in red and trends in under representation are denoted in purple (Figure 5). Counties with multiple dots had z-scores greater or less than one for decades spanning 1900-1940. The results show consistent over representation from counties close to the colony and consistent under representation from counties farther away, especially those near New York City. Beyond geographic proximity, reasons for this trend may be due to a lack of awareness in far reaching counties, affecting the number of referrals made by poor houses or hospitals on account of patients. It is also possible Craig administration was searching for patients with occupational

skill sets that would support the colony’s agrarian lifestyle, and with agriculture being the major industry in western New York, patients from the Southern Tier were disproportionately admitted. Additionally, a lack of knowledge farther downstate may have led to fewer New Yorkers and Long Islanders being admitted to Craig, especially among the impoverished immigrant population, a group themselves who were stigmatized, abused, and lacked representation. While the opening of an additional “Home for the Feeble Minded and Epileptics” in Rockland County in 1912 could have intercepted the epileptic cases from downstate, preventing their move to Craig, this was not the case.<sup>25</sup>

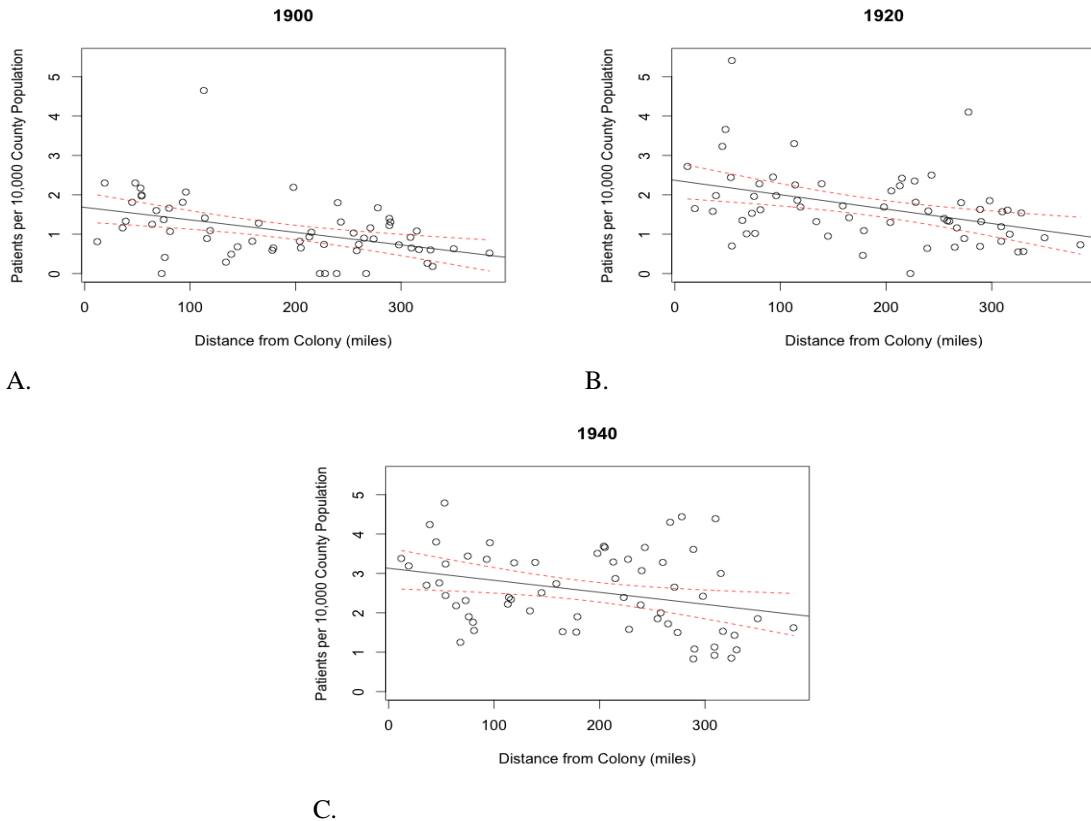


Figure 4. Distance decay of patient origins, year 1900 (A), distance decay of patient origin, year 1920 (B), and distance decay of patient origin, year 1940 (C).

Within ten years of the opening of Craig, the State Board of Charities once again began the search to select another site to establish an institution to care for New York’s mentally disabled and epileptic populations. In 1907, when the search began, the four current state institutions were all located upstate – the Home for Feeble Minded Children in Syracuse, the Home for Feeble Minded Women of Child Bearing Age in Newark, the Home for Feeble Minded Persons and Idiots in Rome, and the Craig Colony for Epileptics in Sonyea – so it seemed practical to locate the State’s fifth facility closer to New York’s largest metropolitan area.<sup>26</sup> Using Craig as a model, the committee proposed a site in the town of Thiells, 40 miles north of New York County. Originally called the Eastern New York Custodial Asylum, the name of this new facility, which would serve as a home, school and laboratory for the feeble minded, especially those of school age, was changed to Letchworth Village, in honor of William Pryor Letchworth and his dedication to the State’s mentally handicapped. The name change was also described as a symbolization of “a new day in the lives of retarded intellect”.<sup>27</sup>

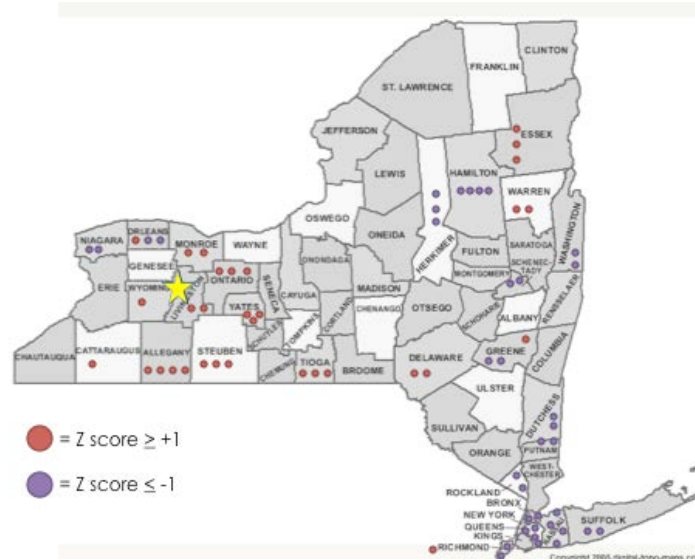


Figure 5. Counties showing over and under patient representation at Craig. Z-scores  $\geq 1$  are indicated in red, and z-score  $\leq -1$  are indicated in purple. The yellow star denotes the location of the Craig Colony. Counties with multiple dots show consistent over or under representation over time.

When the search committee's report was submitted in 1908, it was believed that "practically all epileptics...are mentally deficient" and thus the epileptic and feeble minded had similar needs and could be cared for in the same institution. Letchworth Village began accepting patients in 1912, before the facility, which was built to house 3000-3500 patients, was fully completed.<sup>28</sup> By 1920 there were 348 patients at Letchworth, and two years later the population had reached 1444.<sup>29</sup> Infrequently do the annual reports by Letchworth Village's Board of Managers mention anything about the epileptic population at the facility, but the 1922 annual report records only 20 epileptic patients.<sup>30</sup> Four years later, with only 1.7% of the institution's population having epilepsy, it was recommended that the reception of epileptics be discouraged, as epileptics create a "special problem group requiring a different type of attendance and care". Instead, it was suggested that a second state colony be established for the explicit care of epileptics, in turn alleviating the burned on Craig and address the demand coming from the Eastern Metropolitan section of the state.<sup>31</sup> This we know never came to be.

## CONCLUSION

A number of compound factors led to the ultimate demise of the Craig Colony. Evidence supports the notion that Craig had become a milieu of last resort, full of a dependent population that was both elderly and developmentally disabled. The issue of overcrowding was slow to be admitted and could never be resolved. And although data are lacking, if trends in distance decay continued as they did after 1940, through the 1960's, the State would have deviated further from its "state-wide" mission, as more patients would have originated from western New York. News reporter, Geraldo Rivera's exposé of the Willowbrook State School was the nail in the coffin for Craig, revealing the horrendous conditions of state-run facilities, including overcrowding, poor sanitation, and incidents of physical and sexual abuse.<sup>32</sup> Patients were moved into Intermediate Care Facilities, some of which were located on colony property, others of which expanded into nearby counties. Run by what became known as the Craig Developmental Disabilities Service Office (DDSO), these facilities marked a transition into deinstitutionalization, and a new popular philosophy of the best way to care for those who cannot care for themselves.<sup>33</sup>

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<sup>1</sup> *Atlas: Epilepsy Care in the World*. 2005. The World Health Organization, Rep Geneva: WHO. Web. 26 Apr. 2012. <[http://www.who.int/mental\\_health/neurology/Epilepsy\\_atlas\\_r1.pdf](http://www.who.int/mental_health/neurology/Epilepsy_atlas_r1.pdf)>.

<sup>2</sup> Reiman, Daniel, L. 1988. *CRAIG: A Tradition of Caring*. The New York State Office of Mental Retardation and Developmental Disabilities. Bulletin.

<sup>3</sup> State of New York. *Report of the State Board of Charities on the Selection of a Site for the Organization of an Epileptic Colony*. (Albany, New York; Transmitted to the Legislature January 11, 1893), Print.

<sup>4</sup> Hurd, H.M., Drewry, W.F., Dewey, R., Pilgrim, C.W., Blumer, G.A. 1916. *The Institutional Care of the Insane in the United States and Canada*. American MedicoPsychological Association. The John Hopkins Press. Baltimore, Maryland. 3: 251 – 257.

<sup>5</sup> *ibid.*, 251-257

<sup>6</sup> State of New York. Department of Mental Hygiene. 1896. *Annual Report of the Craig Colony at Sonyea, NY*. Vol. 3. Sonyea: Craig Colony.

<sup>7</sup> *ibid.*

<sup>8</sup> *ibid.*

<sup>9</sup> Patients were segregated by class, a distinction determined by their mental capacity. The best class lived in homes holding 12-18 persons, the middle class, which made up the majority of patients, was housed in buildings holding 24-30 patients, while the worst 20% of cases resided in “infirmaries for the irresponsible and infirm”, which held 100-150 people each. The 11<sup>th</sup> annual report of the colony reflects this practice, stating “there is no reason within our knowledge why epileptic idiots, imbeciles, and dements cannot be cared for in a single large building”. See: State of New York. Department of Mental Hygiene. 1904. *Annual Report of the Craig Colony at Sonyea, NY*. Vol. 11. Sonyea: Craig Colony.

<sup>10</sup> State of New York. Department of Mental Hygiene. 1941. *Annual Report of the Craig Colony at Sonyea, NY*. Vol.47. Sonyea: Craig Colony.

<sup>11</sup> Hurd, et. al, *op.cit.*, 251-257.

<sup>12</sup> State of New York. Vol 3, *op.cit.*

<sup>13</sup> State of New York. Department of Mental Hygiene. 1967. *Annual Report of the Craig Colony at Sonyea, NY*. Vol. 74. Sonyea: Craig Colony.

<sup>14</sup> State of New York. Department of Economic Development. 2000. *Population of New York State by County, 1790 to 1990*. State Data Center.

<sup>15</sup> State of New York. Vol 3, *op.cit.*

<sup>16</sup> In 1939, the medical superintendent, Dr. William Shanahan, reported the colony was 350 patients over capacity, yet his rationale for the need of more funding to expand housing was “to diminish the possibility of overcrowding”, failing to admit this was already the case. See: State of New York. Department of Mental Hygiene. 1939. *Annual Report of the Craig Colony at Sonyea, NY*. Vol. 46. Sonyea: Craig Colony. Craig’s population peak in 1939 may be attributable to the compounding factors of having reached absolute capacity, which could only be remedied by the expansion of dormitory space, of which the funding for was deviated to support the efforts of World War II. See: State of New York. Department of Mental Hygiene. 1943. *Annual Report of the Craig Colony at Sonyea, NY*. Vol. 50. Sonyea: Craig Colony.

<sup>17</sup> State of New York. Department of Mental Hygiene. 1915. *Annual Report of the Craig Colony at Sonyea, NY*. Vol. 21. Sonyea: Craig Colony.

<sup>18</sup> State of New York. Department of Mental Hygiene. 1903. *Annual Report of the Craig Colony at Sonyea, NY*. Vol. 10. Sonyea: Craig Colony.

<sup>19</sup> State of New York. Vol. 74. *op.cit.*

<sup>20</sup> *Ibid.*

<sup>21</sup> *Ibid.*

<sup>22</sup> State of New York. Vol 3, *op.cit.*

<sup>23</sup> State of New York. Department of Mental Hygiene. 1961. *Annual Report of the Craig Colony at Sonyea, NY*. Vol. 68. Sonyea: Craig Colony.

<sup>24</sup> State of New York. Vol 74, *op.cit.*

<sup>25</sup> State of New York. *Report of the Commission to Select a Site for the Eastern New York State Custodial Asylum*. (Albany, New York; Transmitted to the Legislature February 24, 1908), Print.

<sup>26</sup> *Ibid.*

<sup>27</sup> State of New York, Department of Mental Hygiene. *Life at Letchworth Village: The Fortieth Annual Report of the Board of Visitors, for the Fiscal Year Ended March 31, 1948*. Thiells: Letchworth Village.

<sup>28</sup> State of New York, Department of Mental Hygiene. 1920. *Annual Report of the Board of Managers of Letchworth Village*. Vol 11. Thiells: Letchworth Village.

<sup>29</sup> State of New York, Department of Mental Hygiene. 1922. *Annual Report of the Board of Managers of Letchworth Village*. Vol 13. Thiells: Letchworth Village.

<sup>30</sup> Ibid.

<sup>31</sup> State of New York, Department of Mental Hygiene. 1926. *Annual Report of the Board of Managers of Letchworth Village*. Vol 17. Thiells: Letchworth Village.

<sup>32</sup> Rivera, Geraldo. *Willowbrook: A Report on How It Is and Why It Doesn't Have to Be That Way*. New York: Random House, 1972.

<sup>33</sup> Reiman, op.cit