

**“A Life in the Community for All?”**

The ongoing de-segregation of Iowans with mental illness

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On the western edge of Iowa City, I'm standing in a building that was most recently inhabited by pigs. Wooden bars divide the building into a dozen holding pens, and at the entrance to one such pen my tour guide points out a curved impression in the wooden frame, near to the ground. She explains that the wood was gradually worn away by the pigs as they were herded into and out of the pens each day.

Entering one of these pens, my tour guide then points out signs of the pens' original inhabitants. Carved writing and scratches fill the wall at eye level, mostly indecipherable after more than 130 years. She shows me where a cot had originally filled about half of the floor space, then points out the slot where food and water were provided each day. Instead of pigs, this pen was originally intended to corral people with mental illness.

The building we are in was once the original asylum wing of the Johnson County Poor Farm. It housed the mentally ill from the 1860s until the 1880s, when it was replaced by a larger county asylum on nearby grounds. According to my guide, the census here originally consisted mainly of "incurables" that were discharged back to the county from Mount Pleasant, home to one of the over-crowded state asylums. While records from this first county asylum are poor, reports of Superintendents from state asylums suggest that admissions may have included those who would today be diagnosed with schizophrenia, mood disorders, dementia, epilepsy, and intellectual disabilities, as well as others who were seen as socially or morally "deviant" at the time<sup>1</sup>. At the time there was no trained

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<sup>1</sup> See, for example, Independence Mental Health Institute's Superintendent's Report from 1871, available for viewing at Independence Mental Health Institute Museum

medical supervision in this county asylum, and the “treatment” was likely farm labor, if anything. So here, on the edge of Iowa City and out of public sight, the “incurables” remained, locked up or laboring, with little hope of rejoining the communities they had left behind.

Now preserved by the Johnson County Historical Society, this facility provides a local demonstration of one of society’s longstanding strategies for dealing with mental illness: segregation. At its best, the removal of people with mental illness from the community provides a period of safety, treatment, and recovery – for some a necessary intervention. At its worst – and the original asylum on the Johnson County Poor Farm seems to have been on this end of the spectrum – the segregation of the mentally ill functions simply as a means of management and control. Arguments about how, when, and to what degree those with mental illness should be segregated or de-segregated have long-shaped the treatment of the mentally ill in Iowa and elsewhere. The centrality of this issue continues in Iowa’s current public mental health re-design. Secondary to a 1999 Supreme Court decision to which we will later return, Iowa—and every other state—has been mandated to de-segregate people with mental illness as much as possible, to maximally enable people with mental illness to participate meaningfully in their chosen communities.

Interestingly, while Iowa’s first steps to care for the mentally ill originally involved segregation in asylums, the spirit of returning people to meaningful community participation was much the same. Before state-sponsored asylums, the mentally ill in the United States were cared for by the other primary institutions of the time, family and

church. Absent these supports, many ended up homeless, or crowding the jails and poor houses<sup>2</sup>. Asylums were proposed largely on post-Enlightenment humanitarian grounds as a place where such people could receive the care they deserved. It was argued that asylums would provide a type of therapeutic refuge, an environment that would engender recovery and then return to community life. Leading proponents such as Dorothea Dix framed the creation of asylums as part of a moral duty to care for some of society's most vulnerable members<sup>3</sup>.

Some of the earliest asylums in the United States appear to have fulfilled this goal of humane refuge and recovery remarkably well. The dominant mode of treatment was "moral therapy," which, while variable, typically sought to engage the patient as blameless and to overcome the illness by promoting diversion and self-control of the mind through a prescribed routine of labor, worship, and other habits. While paternalistic, the modality may have been successful; records from one of the earliest asylums in Worcester, Massachusetts suggest that from 1833-1852 a majority of its patients were discharged back to the community, and of those discharged, a majority were never re-admitted<sup>4</sup>. While it is difficult to pin down the diagnoses of these patients and the reasons for their improvement, the data highlight the orientation of early asylums towards recovery and return to community life.

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<sup>2</sup> See, for example, Roy Porter's *Madness: A Brief History* (2002).

<sup>3</sup> Martin, F. & Flanagan, E. (2011). "The Pre-Community Psychiatry Period," in Rowe, M., et al.'s *Classics of Community Psychiatry*.

<sup>4</sup> Bockoven, J.S. (1956). Moral treatment in American psychiatry. *Journal of Nervous and Mental Diseases* 124: 167-194, 292-321. Reprinted in Rowe et al.'s *Classics of Community Psychiatry* (2011).

Iowa dedicated its first state asylum at Mount Pleasant in 1861, and added three more (Independence, Clarinda, and Cherokee) in the following four decades, a period of rapid construction and growth of asylums around the nation. As articulated by the first Superintendents, the goals of Iowa's state asylums were, like elsewhere in the country – refuge, recovery, and return to the community<sup>5</sup>. However, like asylums around the nation, Iowa's quickly became over-crowded, under-funded, and under-staffed. It became increasingly difficult to provide any of the individualized care and compassion that the original promoters of asylums and moral therapy had envisioned. At the same time, views on the course of mental illness became more pessimistic and expectations of recovery dwindled. Many languished in the asylums for years or lifetimes with little if any treatment<sup>6</sup>. In Iowa and elsewhere, the segregation created by asylums started to become less about recovery, and more about management and control.

While the early 20<sup>th</sup> century brought a number of chemical and physical treatments that promised improvement, none enabled many patients to leave the asylums, or slowed the influx of admissions. In Iowa and elsewhere electroconvulsive therapy (ECT) offered improvement for a few, but treatments such as insulin comas only carried risks, and frontal lobotomies and chemical tranquilizers rendered patients docile and emotionless, preventing any meaningful recovery and committing many to ongoing institutionalization<sup>7</sup>. Like many states, Iowa also initiated a eugenics program, sterilizing hundreds of people

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<sup>5</sup> See "Historical Perspective" in Iowa Mental Health Authority's "Mental Health Planning in Iowa" (1965).

<sup>6</sup> Ibid.

<sup>7</sup> Martin & Flanagan (2011); Independence Mental Health Institute Museum

with mental illness or intellectual or physical disabilities during the period<sup>8</sup>. In retrospect it seems a rather horrifying period in Iowa and elsewhere, and with continued overcrowding, and funding and personnel shortages only exacerbated by the Depression and World War II, the conditions in asylums, Iowa included<sup>9</sup>, were deplorable by many accounts<sup>10</sup>. Far from their original purpose of refuge and recovery, asylums became overcrowded dustbins often struggling to meet the basic human needs of those removed from their communities; at the same time, this very segregation served to prevent the wider public from appreciating the conditions in which many of their loved ones were suffering.

After World War II, however, a number of factors<sup>11</sup> initiated a process of de-segregation that lawmakers, administrators, and practitioners continue to work toward in Iowa today. Public attention to mental health was raised by news of the many returning soldiers affected by the war and by a number of exposés—such as Albert Deutsch's *The Shame of the States*—that illustrated the heartbreaking state of the mental health care across the country, among other factors. Pharmaceuticals targeting psychotic, depressive, and anxiety symptoms debuted, building optimism for symptom management within the community. Further, economic pressure placed an imperative on reducing asylum populations, while the establishment of Social Security Disability Insurance and later Medicare and Medicaid

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<sup>8</sup> Vogel, A. (1995). Regulating degeneracy: eugenic sterilization in Iowa, 1911-1977. *Annals of Iowa* 52(2): 119-143.

<sup>9</sup> See "Historical Perspective" in Iowa Mental Health Authority's "Mental Health Planning in Iowa" (1965).

<sup>10</sup> For example, Albert Deutsch's *The Shame of the States* (1948) and Erving Goffman's *Asylums: Essays on the Social Situation of Mental Patients and other Inmates* (1961).

<sup>11</sup> See Miller, R., Ponce, A., & Thompson, K., (2011). Deinstitutionalization and the Community Mental Health Center Movement, in Rowe et al.'s *Classics of Community Psychiatry*, as well as Grob, G. (1991). *From Asylum to Community: Mental Health Policy in Modern America*.

provided means for more people with mental illness to live in the community. Alongside these changes, successive legislative efforts established the National Institute of Mental Health and provided funds for a reassessing the nation's mental health care, culminating in a 1961 report that recommended a shift to community-based mental health care through significant investment in infrastructure and personnel. Federal funds for construction of community mental health centers was established in 1963, and funding for personnel was added 2 years later. All of these shifts in philosophy, policy, and financing helped drive a de-institutionalization of many people with mental illness, and the US asylum population fell from its peak of about 560,000 in the 1950's to about 170,00 by 1975<sup>12</sup>.

Changes to mental health care in Iowa paralleled those around the nation. The construction of community mental health centers began in the late 1940's and by 1965 there were 15 in the state, while the population of Iowa's four state mental health institutions decreased from 6575 to 2018 during the same period<sup>13</sup>. Like the federal government, Iowa had provided funds for studying and re-orienting the mental health system, and the resulting planning document<sup>14</sup> published in 1965 called for a continuing shift to comprehensive, community-based mental health care that would allow people to be treated in the community whenever possible.

This was a profound shift in the philosophy of public psychiatric care in Iowa and throughout the nation. The drivers and resulting appropriations of this philosophical shift

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<sup>12</sup> Miller, Ponce & Thompson (2011).

<sup>13</sup> Iowa Mental Health Authority (1965). "Mental Health Planning in Iowa"

<sup>14</sup> Ibid.

were complex and varied, but the central tenet was clear: people with mental illness can and should be treated in the community of their choice whenever possible. Rather than making segregation of people with mental illness a default approach—whether or not return to the community was the eventual goal—it proposed removal from the community only as a last resort for the purposes of safety. This goal of community-based mental health care has been affirmed many times since this shift, and it remains a guiding principle of contemporary design of mental health care in Iowa and elsewhere. However, the resources to support this goal have proved much more difficult to mobilize, coordinate, and sustain, and they continue to be fought for today.

As the asylums emptied, the community resources that were meant to replace them were inadequate and fractured. Community Mental Health Centers often didn't receive the funding and personnel to provide adequate care for people with more complex needs, and other sources of support were poorly coordinated or non-existent for many<sup>15</sup>. While the Carter administration committed federal funds to developing a more comprehensive community mental health system, these funds – along with other federal mental health dollars – were cut by the Reagan administration. Additional cuts to entitlement and social programs only worsened the situation for those with serious mental illness<sup>16</sup>. Rather than having a chance to rebuild a meaningful life in the community, many of those who were de-institutionalized throughout this period ended up homeless, and with few supports many eventually found themselves re-segregated in prison or residential care facilities.

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<sup>15</sup> Davidson, L. & Ridgway, P. (2011). The Community Support Movement and its Demise. In Rowe et al.'s *Classics of Community Psychiatry*.

<sup>16</sup> Ibid.



The 1990's brought increased efforts at coordination of resources through case management and widespread initiatives by teams of providers to treat some patients in their home rather than a clinic or institution. Among other factors, these changes have helped more people with mental illness live successfully in the community, but resources continue to be scarce and uncoordinated for many<sup>17</sup>. Forty years after federal community mental health initiatives began, the last federal study of the nation's mental health care, the *New Freedom Commission* of 2001-2004, declared the nation's mental health services "in shambles," fragmented and incapable of providing the type of coordinated care required to support a life in the community for many people with mental illness<sup>18</sup>.

Over this period a similar story can be told of community mental health efforts within Iowa, though Iowa has been even less successful than most states in supporting people with mental illness within the community. Medicaid funded-services are contracted out by the state, while all other public mental health is funded and delivered county-by-county. Many counties—especially the smaller of Iowa's 99—cannot deliver a wide range of services, and coordination among counties and between counties and the state is limited. Further, Iowa ranks near the bottom of the country in mental health spending, psychiatric beds, and mental health providers per capita<sup>19</sup>. A 2006 report by the National Alliance on Mental Illness (NAMI) declared Iowa's mental health system among the most "convoluted" and

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<sup>17</sup> Davidson, L. & Ridgway, P. (2011). The Community Support Movement and its Demise. In Rowe et al.'s *Classics of Community Psychiatry*.

<sup>18</sup> New Freedom Commission (2002, 2003). "Interim Report" and "Final Report," retrievable via <http://govinfo.library.unt.edu/mentalhealthcommission/>

<sup>19</sup> Iowa Civic Analysis Network, University of Iowa. (2006). "An Analysis of Iowa's Mental Health Care System."

deficient in the nation, and Iowa was one of eight states to receive NAMI's lowest rating<sup>20</sup>. For people with serious mental illness, this has meant that those who need long-term care often have difficulty finding it, while those capable of living in the community often lack the support to do so successfully and cycle through emergency rooms and inpatient facilities, or end up in the state prison system, which, as of 2005, was incarcerating over 2900 people with mental illness and operated the largest psychiatric facility in the state, the Clinical Care Unit at the Iowa State Penitentiary in Fort Madison<sup>21</sup>.

While the progress achieved in the last fifty years within the mental health care system in Iowa and nationwide has yet to fulfill the vision of providing comprehensive community-based treatment, the philosophy of minimizing segregation has been affirmed and strengthened. Arguably the most important of these affirmations came in the U.S. Supreme Court decision, *Olmstead v. L.C.*<sup>22</sup>, which, under the Americans with Disabilities Act, asserted the legal right of people with mental illness to receive treatment and services in the most integrated community setting reasonably achievable. This helped spark the aforementioned *New Freedom Commission* of 2001-2004, which made broad recommendations for continued reform of the nation's mental health care system. The onus of reforming the system in a manner consistent with the *Olmstead* decision, however, has fallen on the individual states.

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<sup>20</sup> National Alliance on Mental Illness (2006). Grading the States: A Report on America's Healthcare System for Serious Mental Illness.

<sup>21</sup> Iowa Department of Corrections (2006), "Mental Health: Report to the Board of Corrections."

<sup>22</sup> [http://www.ada.gov/olmstead/olmstead\\_about.htm](http://www.ada.gov/olmstead/olmstead_about.htm)

The reform effort here in Iowa culminated in legislation passed in 2012. The bill calls for public mental health services to be organized on a regional rather than county level and requires a set of core services be made available in each region and in accordance with the Olmstead decision<sup>23</sup>. Workgroups of administrators, mental health providers, and mental health care consumers are currently meeting across regions throughout the state to develop recommendations for how services will be provided and coordinated once regionalization begins later in 2014. Once completed, the range of services that will theoretically be available in each region – including treatment, crisis stabilization, housing and employment support, family support, and jail diversion – could greatly improve the state’s ability to treat and support people with mental illness within their chosen communities. A major concern, though, is that there is no additional funding to provide these services. The hope is that regionalization will improve efficiency and coordination enough to make it possible to offer the full range of services to all who need them, and the workgroups meeting in each region are working earnestly to figure out if and how it will be possible.

At the same time, the rollout of the Affordable Care Act and enactment of the Mental Health Parity Rule will increase the number of Iowans who are able to receive mental health care. On one hand, the increased accessibility of insurance with guaranteed coverage for mental health could make it easier for some people with debilitating mental illness to transition back to employment and community participation. On the other hand, an overall increase in the insured population could put more stress on Iowa’s already over-burdened mental

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<sup>23</sup> <http://www.dhs.state.ia.us/Partners/MHDSRedesign.html>

health care services. This could diminish any improvements in efficiency and coordination secondary to regionalization. What will come of these recent developments is still uncertain, but it is clear that the re-integration of the mentally ill into Iowa's communities is still very much a work in progress.

Back in the asylum at the Johnson County Poor Farm, it is striking to consider that some of the most important contributions to this work in progress have come from the very people that 140 years ago may have been locked up in one of these cells. Since the late 1970's, people with mental illness have become increasingly organized and have done much to promote the importance of services that provide interpersonal, occupational, and other supports that enable people to re-claim functioning and membership within a community, and with it an identity far wider than their illness, even if symptoms persist. People with mental illness have organized both to provide such services to each other, and to promote them as elements of treatment and recovery that are as essential as medications, or often more so<sup>24</sup>. It is in part because of these efforts that the reforms recommended by the *New Freedom Commission* and within Iowa's mental health re-design have the breadth that they do.

A lesson that has been learned, then, is that respecting the dignity and autonomy of people with mental illness by preventing their segregation requires more than medication or psychotherapy. Perhaps as important, though, is the understanding that meaningful re-integration into the community can itself be powerfully healing. It is a chance that

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<sup>24</sup> Lawless, M.S. & Rowe, M. The Recovery Era. In Rowe et al.'s *Classics of Community Psychiatry*.

everyone with mental illness deserves to whatever degree possible. Iowa's mental health reforms are a work in progress and may not prove sufficient, but as many in the state continue to devote themselves to the cause, it is to be hoped that more and more Iowans with mental illness will have a chance to stabilize a life of meaningful membership within their chosen communities.