

Deinstitutionalization: How the State Budget Has  
Overshadowed Public Policy in Caring for  
Illinois' Mentally Ill

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I. INTRODUCTION

The phrase “mentally ill” carries a stigma that negatively influences the treatment and care of a vulnerable group. In the early 1900’s, the public sought to hide this faction away in large, state-run institutions<sup>1</sup> out of fear they were dangerous or incapable of engaging with society at large.<sup>2</sup> Moreover, states established institutions in the least desirable areas where housing was inexpensive, yet unsafe.<sup>3</sup> For years, civil rights groups protested the state action with little result.<sup>4</sup> By the middle of the twentieth century, sociologists conducted studies of such state-run institutions.<sup>5</sup> The results overwhelmingly demonstrated that conditions in the facilities were deplorable<sup>6</sup> and the asylum structure actually perpetuated several of the patients’ conditions.<sup>7</sup>

The term “deinstitutionalization” describes the policy decisions to close

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1. Arlene S. Kanter, *A Home of One’s Own: The Fair Housing Amendments Act of 1988 and Housing Discrimination Against People with Disabilities*, 43 AM. U. L. REV. 925, 929 (1994).

2. Meghan K. Moore, *Piecing the Puzzle Together: Post-Olmstead Community-Based Alternatives for Homeless People with Severe Mental Illness*, 16 GEO. J. ON POVERTY L. & POL’Y 249, 251 (2009).

3. Kanter, *supra* note 1.

4. Norman Dain, *Critics and Dissenters: Reflections on “Anti-Psychiatry” in the United States*, 25 J. HIST. BEHAV. SCI. 3, 9 (1989).

5. Nancy K. Rhoden, *The Limits of Liberty: Deinstitutionalization, Homelessness, and Libertarian Theory*, 31 EMORY L.J. 375, 380 (1982).

6. *Id.*

7. *Id.*

state-funded institutions and move mentally ill patients into community-based care facilities.<sup>8</sup> Early advocates of deinstitutionalization focused on the humanitarian concerns of living conditions and embraced an overly optimistic view that patients could seamlessly integrate into the community.<sup>9</sup> The movement gained traction in 1955 with widespread introduction of the first anti-psychotic medication, allowing policymakers to explain the release of patients into the community.<sup>10</sup> Ten years later, the enactment of federal Medicaid and Medicare statutes stimulated deinstitutionalization again.<sup>11</sup> Medicaid did not fund treatment for mental illness in state institutions but reimbursed up to seventy-five percent of the costs if the patient instead received care at a private facility.<sup>12</sup> State politicians endorsed the movement when they realized the opportunity to cut state spending while appeasing the public's desire for more humane treatment of the mentally ill.<sup>13</sup>

This article examines how Illinois has embraced deinstitutionalization and what effects, if any, the deinstitutionalization movement has had on the mentally ill. Section II considers the successes and failures of the deinstitutionalization movement in the twentieth century. Section III discusses how litigation has shaped mental health policy in the last fifteen years. Section IV briefly outlines the current state of mental healthcare in Illinois, including cost concerns of the current system. Finally, Section V discusses why Illinois' shift to a community-based care model will fail due to its shortsighted outlook, budget constraints and judicial pressure.

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8. Moore, *supra* note 2.

9. Rhoden, *supra* note 5, at 377.

10. *Id.* at 379.

11. E. FULLER TORREY, *OUT OF THE SHADOWS: CONFRONTING AMERICA'S MENTAL ILLNESS CRISIS*, (New York: John Wiley & Sons, 1997).

12. Rhoden, *supra* note 5, at 384.

13. Dain, *supra* note 4, at 7.

## II. THE FAILURE OF DEINSTITUTIONALIZATION

To successfully deinstitutionalize its mentally ill, Illinois must not only reduce the number of mentally ill patients in psychiatric hospitals, but also increase the number of smaller, less isolated community-based alternatives.<sup>14</sup> In the twentieth century, the deinstitutionalization movement unevenly placed its focus on reducing the number of institutionalized patients. Across the country, state-run hospitals moved out as many as ninety-two percent of their mentally ill patients.<sup>15</sup> At the peak of institutionalization in 1955, nearly 559,000 people lived in state mental hospitals out of a total population of 165 million.<sup>16</sup> About forty years later, hospitals had reduced that number to 57,151 patients for a population of about 275 million.<sup>17</sup> Thus, institution rates decreased from 339 per 100,000 capita to twenty-one per 100,000 capita, with some states showing even more drastic reductions.<sup>18</sup> In Illinois, the effective deinstitutionalization rate was ninety-four percent.<sup>19</sup>

For good reason, the exodus of the mentally ill has been called a psychiatric “Titanic.”<sup>20</sup> The movement created a mental illness crisis by causing the discharge of patients from public hospitals without providing medication and rehabilitation services in the community.<sup>21</sup> Lawmakers intended supportive services for those living in the community to include a wide range of help including assistance maintaining income, health care, personal hygiene, housekeeping; budgeting; developing job skills; and

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14. H. Richard Lamb & Leona L. Bachrach, *Some Perspectives on Deinstitutionalization*, 52 PSYC. SERVS. 8, 1039 (2001).

15. TORREY, *supra* note 11.

16. Lamb & Bachrach, *supra* note 14.

17. *Id.*

18. *Id.*

19. TORREY, *supra* note 11.

20. *Id.*

21. *Id.*

monitoring medication.<sup>22</sup> Additionally, lawmakers intended treatment providers to engage in ongoing communication.<sup>23</sup> However, due to insufficient preparation and support for this plan, many of the people who moved out of institutions ended up homeless, in ill-equipped nursing homes, or in jail.<sup>24</sup>

Deinstitutionalization transformed into trans-institutionalization, a large shift of people from one state-funded institution (public mental hospitals) to another (jails, nursing homes, etc.).<sup>25</sup> In the 1960 and 1970s, institutions for mental disease (IMDs) emerged in Illinois to house the most severely mentally ill patients.<sup>26</sup> The IMDs were privately run, for-profit nursing homes, often able to house up to 400 people.<sup>27</sup> Critics argued these facilities were nothing but downsized institutions operated under equally deplorable conditions.<sup>28</sup> State efforts to move patients to more integrated settings were piecemeal at best and far short of the large-scale systemic change needed.<sup>29</sup> Before deinstitutionalization could work, Illinois needed a harder push toward community-based facilities.<sup>30</sup>

### III. THE SUPREME COURT TAKES A STAND

Recently, mental health advocates have found support for community-

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22. John Fallon & Corinne Rearer, *The Corrections System Has Become The Nation's Largest Mental Health Provider*, HOMELESS HEADLINES 1 (Feb. 2011), [http://www.law.uchicago.edu/files/file/HOMELESS%20HEADLINES\\_20110303161841%20\(2\)\\_0.pdf](http://www.law.uchicago.edu/files/file/HOMELESS%20HEADLINES_20110303161841%20(2)_0.pdf).

23. *Id.*

24. *Id.*

25. *Id.*

26. Joe Linstroth & Caroline O'Donovan, *Home Sweet Home: Finding Housing For Mentally Ill Adults*, WBEZ 91.5 (May 4, 2012), <http://www.wbez.org/blogs/bez/2012-05/home-sweet-home-finding-housing-mentally-ill-adults-98815>.

27. Carla K. Johnson, *For-Profit Nursing Homes That Care For Mentally Ill Cost State \$122M*, ASSOCIATED PRESS (Feb. 7, 2010), <http://www.sj-r.com/breaking/x503201872/For-profit-mental-institutions-cost-Illinois-122M>.

28. *Id.*

29. Ira A. Burnim & Jennifer Mathis, *The Olmstead Decision at Ten: Directions to Future Advocacy*, 43 CLEARINGHOUSE REV. 386, 387 (2009).

30. *Id.*

based care in the courts.<sup>31</sup> Specifically, in *Olmstead v. L.C. ex rel. Zimring*, two mentally disabled women brought a discrimination suit against the state of Georgia challenging their confinement to a segregated facility under Title II of the Americans with Disabilities Act (ADA).<sup>32</sup> Both women were voluntarily admitted to the psychiatric ward of a public Atlanta hospital.<sup>33</sup> Although physicians eventually cleared them for community-based programs, they both remained institutionalized.<sup>34</sup> The women argued that the State must provide placement in community care.<sup>35</sup>

In affirming the lower court, the United States Supreme Court held that unjustified isolation and segregation of disabled individuals violated the ADA.<sup>36</sup> The Court concluded that states are required to place mentally ill patients, like the plaintiffs, in community care settings when a medical professional determines placement is appropriate, the patient does not oppose the transfer to a less restrictive setting, and the placement can be reasonably accommodated.<sup>37</sup>

Following *Olmstead*, mental health advocates emphasized that the ADA's integration mandate applied to all institutions including: nursing homes, board and care homes, and residential treatment centers.<sup>38</sup> Organizations such as the Bazelon Center for Mental Health Law stressed that public institutional living perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participation in community

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31. Robert Pear, *U.S. Seeks More Care for Disabled Outside Institutions*, N.Y. TIMES (Feb. 13, 2000).

32. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 581 (1999).

33. *Id.*

34. *Id.*

35. *Id.*

36. *Id.* at 597.

37. *Id.* at 607.

38. BAZELON CENTER, *OLMSTEAD: IMPLEMENTING THE INTEGRATION MANDATE*, <http://www.bazelon.org/Where-We-Stand/Community-Integration/Olmstead-Implementing-the-Integration-Mandate.aspx>.

life.<sup>39</sup> The Bazelon Center explained how institutional life is not conducive to “inclusion in all facets of community life,”<sup>40</sup> and institutional residents suffer regimented lives without opportunities to learn independent living skills.<sup>41</sup> Comparatively, Bazelon argued that community-based living fosters independence by allowing mental health patients to make normal daily decisions about what to eat, when to get up, and how to spend their time.<sup>42</sup>

By 2005, Illinois had largely ignored mental health advocates and made few changes to its community care program.<sup>43</sup> Accordingly, in *Ligas v. Hamos*, a group of institutionalized patients who qualified for community placement filed a class action lawsuit against the Illinois Department of Human Services and the Illinois Department of Healthcare and Family Services.<sup>44</sup> The litigants challenged Illinois’ practice of requiring patients to reside in intermediate care facilities for people with development disabilities (“ICF-DDs”) as a condition precedent for long-term care benefits.<sup>45</sup> Specifically, the litigants in *Ligas v. Hamos* wanted to move out of private state-funded facilities and be placed in community-based services.<sup>46</sup> By 2011, two other disability rights lawsuits had been filed

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39. Statement of Robert Bernstein, President and Director of the Judge David L. Bazelon Center for Mental Health Law (June 22, 2010), <http://www.bazelon.org/LinkClick.aspx?fileticket=qgcUAsuUJsU%3d&tabid=323>.

40. Written Testimony for Olmstead Enforcement Update, BAZELON CENTER (Jul. 6, 2012) <http://www.bazelon.org/LinkClick.aspx?fileticket=E7kUaGesvoU%3d&tabid=533>.

41. *Id.*

42. *Id.*

43. Press Release, Equip for Equal., Ill. Residents Sue State for Violating Ams. with Disabilities Act, Failing to Provide Cmty. Servs. (July 28, 2005).

44. Consent Decree at 1, *Ligas v. Hamas* (N.D. Ill 2011) (No. 05 CC 4331); *see also*, ILL. DEPT. OF HUMAN SERVICES, CLASS MEMBER STATUS, <http://www.dhs.state.il.us/page.aspx?item=58677>.

45. Second Amended Complaint for Declaratory and Injunctive Relief at 1, *Ligas v. Hamas* (N.D. Ill 2009) (No. 05-4331).

46. *Id.*

against the state,<sup>47</sup> and the Chicago Tribune had published an investigation detailing reports of sexual assault, violence, and drug abuse in the state's worst facilities.<sup>48</sup> Governor Quinn worked with state officials to reach a settlement, offering supportive housing and treatment to roughly 5,000 mentally ill adults living in large nursing homes designated as Institutions for Mental Diseases ("IMD").<sup>49</sup> However, the state has made little progress since, falling far short of its first-year move out goal.<sup>50</sup>

#### IV. CURRENT STATE OF MENTAL HEALTH CARE IN ILLINOIS

Illinois' failure to transition from IMDs is draining the state budget and inadequately providing care for the mentally ill.<sup>51</sup> The effects of deinstitutionalization, such as a reduction in the number of state institutions, have a compounding effect in a state already suffering from a deficit of care facilities as new cases of mental illness arise each year.<sup>52</sup> Approximately one in four adults will suffer from a diagnosable mental disorder in a given year,<sup>53</sup> creating an unmet demand for care providers.<sup>54</sup> For example, Illinois closed seven mental hospitals between 1980 and 2010 requiring nursing homes to fill the gap in care.<sup>55</sup> While Illinois manages twenty-six much smaller IMDs,<sup>56</sup> mental health professionals agree IMDs are antiquated,<sup>57</sup>

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47. See *Williams v. Quinn*, 748 F. Supp. 2d 892 (N.D. Ill. 2010); *Colbert v. Blagojevich*, 2008 WL 4442597 (N.D. Ill. 2008).

48. Gary Marx & David Jackson, *Illinois Struggles to Move Mentally Ill Adults Out of Nursing Homes*, CHI. TRIBUNE (July 4, 2012).

49. *Id.*

50. *Id.*

51. Linstroth & O'Donovan, *supra* note 26.

52. TORREY, *supra* note 11.

53. NAT'L INST. MENTAL HEALTH, *THE NUMBERS COUNT: MENTAL DISORDERS IN AMERICA* (2013), <http://www.nimh.nih.gov/health/publications/the-numbers-count-mental-disorders-in-america/index.shtml#KesslerPrevalence>.

54. *Id.*

55. Johnson, *supra* note 27.

56. *Id.*

57. Linstroth & O'Donovan, *supra* note 26.

and Governor Quinn's settlement promised to provide alternative treatment.<sup>58</sup> Additionally, critics argue such institutions are expensive,<sup>59</sup> specifically pointing to the \$122 million Illinois spent in 2009 to operate these privately run, for-profit nursing homes.<sup>60</sup> The IMD homes only accommodate 5,000 mentally ill people while traditional nursing homes serve at least 13,000.<sup>61</sup> Additionally, Medicaid rules prevent Illinois from claiming federal matching dollars for the care of mentally ill people who live in IMDs.<sup>62</sup> Despite these disadvantages, Illinois continues to rely on IMDs more than any other state and pays twice what it would pay if the patients lived in alternative housing.<sup>63</sup> The IMDs' political action committee contributed \$147,970 from 2007-2009, potentially explaining their entrenchment in the state.<sup>64</sup>

Significant portions of the mentally ill not receiving care in an IMD or nursing home find themselves in jail.<sup>65</sup> Mental health treatment is more prevalent in prisons and jails than in hospitals or treatment centers.<sup>66</sup> Cook County Jail is one of the three largest inpatient psychiatric facilities in the country.<sup>67</sup> Specifically, there were over 1,700 people on daily psychotropic medication, which is approximately twenty percent of the jail population.<sup>68</sup> Moreover, eighty percent of incarcerated women have a chronic mental

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58. Marx & Jackson, *supra* note 48.

59. Linstroth & O'Donovan, *supra* note 26.

60. Johnson, *supra* note 27.

61. *Id.*

62. *Id.*

63. *Id.*

64. *Id.*

65. *All Things Considered: Nation's Jails Struggle With Mentally Ill Prisoners* (NPR radio broadcast Sept. 4, 2011), available at <http://www.npr.org/2011/09/04/140167676/nations-jails-struggle-with-mentally-ill-prisoners>.

66. *Id.*

67. *Id.*

68. David Ormsby, *Illinois Flirts With Its Own Sandy Hook*, HUFFINGTON POST, Dec. 28, 2012, available at [http://www.huffingtonpost.com/david-ormsby/illinois-mental-health-care\\_b\\_2375471.html](http://www.huffingtonpost.com/david-ormsby/illinois-mental-health-care_b_2375471.html).

illness.<sup>69</sup> A 2010 report by the National Sheriffs' Association and the Treatment Advocacy Center found that a seriously mentally ill person is three times more likely to be incarcerated than hospitalized.<sup>70</sup> Bob Bernstein, the Executive Director of the Bazelon Center, believes "[m]ost people [with mental illness] by far are incarcerated because of very minor crimes that are preventable."<sup>71</sup> However, once incarcerated, the mentally ill find it difficult to break out of the cycle,<sup>72</sup> and "[T]hey deteriorate. They can't follow the rules there and so they stay a long time, and they become difficult to release."<sup>73</sup> Few inmates with mental illness receive treatment while in prison because the expense is too high.<sup>74</sup> However, the cost of preventative care before incarceration falls far below prison costs.<sup>75</sup> For example, the Bazelon Center reported a more intensive mental health program in Michigan cost the state \$9,029 per person per year while the average Michigan inmate cost over \$34,000 per year.<sup>76</sup>

Despite the blatant need for community mental health programs across the state, between 2009 and 2012,<sup>77</sup> Illinois continued to cut funding by more than \$187 million, or 31.7% percent.<sup>78</sup> Even before such cuts, the State's per capita spending on mental health was only \$85 compared to the

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69. *Id.*

70. Editorial, *Limit Jail Stays, Add Beds For Mentally Ill*, CHI. SUN TIMES (last updated Sept. 24, 2012), <http://www.suntimes.com/opinions/4722298-474/editorial-limit-jail-stays-add-beds-for-mentally-ill.html>.

71. Alana Horowitz, *Mental Illness Soars in Prisons, Jails While Inmates Suffer*, HUFFINGTON POST, Feb. 4, 2013, available at [http://www.huffingtonpost.com/2013/02/04/mental-illness-prisons-jails-inmates\\_n\\_2610062.html](http://www.huffingtonpost.com/2013/02/04/mental-illness-prisons-jails-inmates_n_2610062.html).

72. *Id.*

73. *Id.*

74. *Id.*

75. *Id.*

76. *Id.*

77. Sara Burnett, *Advocates Warn of 'Broken' Illinois Mental Health System*, ASSOCIATED PRESS (last updated Jan. 28, 2013), available at <http://www.rstar.com/news/x1503808757/Advocates-warn-of-broken-Illinois-mental-health-system>.

78. Ormsby, *supra* note 68.

national average of \$123.<sup>79</sup> Mental health clinics in Lakeview<sup>80</sup>, the South Side, and McHenry County<sup>81</sup> closed in 2012 due to the uncertainty surrounding state funding.<sup>82</sup> Illinois estimated owing at least \$8 billion in unpaid bills to all categories of service providers.<sup>83</sup> Sharon Kayser, long-time executive director of the now-closed Counseling Center of Lakeview, explained the problem to the Associated Press:

“You say, ‘I’m not going to invest in my building this year. I’m not going to replace the systems that are outdated. I’m not going to hire new staff. We’re not going to give cost of living increases. . . You (would) do those things because you think maybe things will change. But it doesn’t change. . . . There is no waiting it out.’”<sup>84</sup>

Sandy Lewis, the Executive Director of McHenry County’s Mental Health Board, said closing mental health facilities costs the state more in the long run because more mentally ill people will end up in courts, jails, and emergency rooms,<sup>85</sup> and “Providing services has been difficult amid Illinois’ severe budget crisis.”<sup>86</sup> Representative David Leitch is co-sponsoring a bill seeking \$12 million of mental health funding that was left out of this year’s appropriation due to a budgeting error.<sup>87</sup> “Leitch describes the current system as ‘sad’ and ‘pathetic.’ What’s needed, he said,

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79. Burnett, *supra* note 77.

80. David Mercer, *Lawmakers Plan \$1.3B Trim to State Bills Backlog*, ASSOCIATED PRESS, June 10, 2012, available at, <http://www.deseretnews.com/article/765581759/Lawmakers-plan-13B-trim-to-state-bills-backlog.html>.

81. Robert McCoppin, *McHenry Center Latest Domino to Fall in Mental Health Services*, CHI. TRIBUNE, June 27, 2012, available at [http://articles.chicagotribune.com/2012-06-27/news/ct-met-mchenry-mental-health-cuts-20120627\\_1\\_family-service-mental-health-services-bipolar-affective-disorder](http://articles.chicagotribune.com/2012-06-27/news/ct-met-mchenry-mental-health-cuts-20120627_1_family-service-mental-health-services-bipolar-affective-disorder).

82. Ormsby, *supra* note 68.

83. McCoppin, *supra* note 81.

84. Mercer, *supra* note 80.

85. McCoppin, *supra* note 81.

86. Burnett, *supra* note 77.

87. *Id.*

isn't just more money but a total overhaul to a less bureaucratic system."<sup>88</sup>

#### V. CONCLUSION

Governor Quinn's approach to a mental health care solution will fail due to its shortsighted outlook, budget constraints, and judicial pressure. Illinois needs a cost effective solution capable of serving the entire mental health community, not just patients living in IMDs. If the State focuses its few resources on the 5,000 mentally ill addressed by Governor Quinn's settlement plan, more than 13,000 patients living in nursing homes and thousands more living in prisons will be left without help.<sup>89</sup>

Even with its reduced focus, the settlement plan has been ineffective and fallen far short of its first-year target of moving at least 256 people.<sup>90</sup> As of June 2012, only forty-five patients had actually moved into community care or signed a lease.<sup>91</sup> Many patients are unwilling to be assessed for community placement and nearly fifty percent were deemed ineligible once assessed.<sup>92</sup> One group home in Centralia, Illinois is struggling with the Governor to keep its doors open.<sup>93</sup> Despite a vote to keep the center open from the Committee on Government Forecasting and Accountability, Governor Quinn insists upon its closure.<sup>94</sup> Ninety-five percent of the guardians at the Murray Center oppose transfer to less restrictive community-based living because they fear it places their loved ones at risk for abuse and neglect.<sup>95</sup>

Illinois is far from a long-term solution. Given Illinois' deep budget

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88. *Id.*

89. Johnson, *supra* note 27.

90. *Id.*

91. *Id.*

92. *Id.*

93. MURRAY PARENTS ASSOCIATION, <http://www.murrayparentsassociation.com/olmstead-information.html>.

94. *Id.*

95. *Id.*

constraints, the state should focus its resources on the mentally ill who are currently without treatment instead of those satisfied and safe in their living arrangement. A piecemeal approach will only drain the State of money while leaving gaps in its treatment coverage. The State can learn from the failures of the deinstitutionalization movement and focus on developing alternative housing before concentrating on moving patients out of their current homes. While Illinois has made steps in the right direction, a focused approach to the mental health system will not only benefit the mentally ill population, but could also bring much needed relief to the failing state budget thereby helping the entire state.