

# The Continuum of Care: A Vision for Mental Health Reform

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## Executive Summary

Mental health care in America is a system in need of reform. Many social challenges related to mental illness continue to persist despite substantive government investment. These include elevated suicide and overdose rates, mass shootings, homelessness, and the high rate of mental illness among the incarcerated. According to some survey evidence, the American public now has a more negative view of the mentally ill than decades ago.

The public mental health-care system's inability to address serious mental illness has forced mental health responsibilities onto many other public programs and agencies, such as criminal justice and transit. This compromises those systems' ability to focus on their own core missions. A more effective mental health system would be one that exercised more responsibility over untreated serious mental illness.

This report will articulate the concept that should guide mental health-care reform, called a Continuum of Care:

- Continuum of Care is a system of programs and services that are community-based, community-oriented, and oriented toward serious mental illness. It's a system that assists seriously mentally ill individuals before, during, and after crisis.
- The Continuum of Care is anchored in residential programs. The number of hospital beds in a given community—including, but not limited to, psychiatric hospital beds—is its core component.
- To stabilize mentally ill individuals in crisis, the programs constituting a Continuum of Care system must somehow function as that: a system. Any given community needs multiple programs to care for the variety of psychiatric disorders that exist and, especially, to care for people in different stages of recovery. But these programs must coordinate with one another to work toward, measure, and account for defined intended outcomes.

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*The Manhattan Institute is a think tank whose mission is to develop and disseminate new ideas that foster greater economic choice and individual responsibility.*

The concept of a Continuum of Care system can guide discussions of accountability in mental health policy. In recent years, mental health has been a leading focus of news coverage, with policymakers at all levels of government regularly questioned as to their plans for reform, though the direction of mental health policy reform is often vague, if defined at all.

To function as a tool for accountability, Continuum of Care must be a term of distinction. Not all public mental health programs serve the seriously mentally ill, and not all programs that provide some benefit to the seriously mentally ill should be considered part of the Continuum of Care.

The development of more robust Continuum of Care programs will require confronting two general challenges:

- **Financing:** insurance is the primary payer of most mental health care, as it is for mainstream health care. Thus, reforming public insurance needs to be a near-term focus of mental health reform. Most notably, that reform must include removing the so-called IMD Exclusion. Longer-term, however, policymakers should explore the development of more targeted, non-third-party-payer programs to address the lack of system capacity in some communities.
- **Data sharing and stewardship:** to function as a system, elements of local Continuum of Care programs must share data. This will require cross-agency and cross-stakeholder collaboration, as well as legal agreements for data sharing with defined purposes and uses. Mentally ill beneficiaries of multiple social programs often face incompatible program requirements and are ill-equipped to navigate the complex systems. The most effective types and duration of programs may vary, given the range of mental illnesses and an individual's given point in time. A Continuum of Care able to take ownership and accountability for meaningful outcomes must be able to coordinate delivery of services while also defining and tracking those outcomes across programs.

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## Introduction: Premodern vs. Modern Mental Health Policy

American government has recognized a responsibility for the mentally ill since colonial times. The public “asylum” programs that began in the 19th century, and expanded continuously until the mid-20th century, constituted the premodern American mental health-care system. This system had three distinctive features. First, it was run almost exclusively by state governments and funded (aside from charity and patient out-of-pocket expenses)<sup>1</sup> out of states’ general revenues.<sup>2</sup> Second, it was highly monolithic. Hospital-based treatment was the primary service provided by the premodern public mental health system, though not everyone with a psychiatric disorder needs hospital-based treatment—indeed, most do not. Third, it operated in a context in which mental health care was seen as separate from mainstream health care.

The structure of public mental health care in the 21st century is entirely different. Insurance—third-party payers—is the primary financing mechanism. Medicaid, the federal and state-subsidized insurance program, is the single largest payer of mental health care in the nation.<sup>3</sup> Individuals with serious mental illnesses also often receive coverage from Medicare, which they can become eligible for after receiving Social Security Disability Insurance (SSDI) for 24 months.<sup>4</sup> The shift toward insurance coverage has coincided with a proliferation of mental health service providers, which are now mostly private and outpatient in nature. Outside a hospital setting is now where most mental health services are “consumed,”<sup>5</sup> where most psychiatrists practice,<sup>6</sup> and to where most mental health spending is directed.<sup>7</sup>

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Our current mental health policy landscape has been shaped by many past waves of reform:

- The use of medications has expanded. Hundreds of millions of prescriptions are written each year for antidepressants and antipsychotics, with one-sixth of the adult population taking some sort of medication for mental health.<sup>8</sup> Psychiatric medication is controversial for many reasons, such as overreliance among children, adolescents, and “worried well” adults; side effects; and the tendency of drugs to fall short of expectations and the achievements of those within mainstream health. Still, for the seriously mentally ill, the availability of drugs such as lithium and clozapine represents a historic improvement over premodern treatments.<sup>9</sup>
- Over 90% of the population has insurance,<sup>10</sup> and government regulations have forced insurance to expand coverage of mental health services.<sup>11</sup> The third-party-payer system has a strong preference for medication over therapy and places restrictions on how much therapy a plan will pay for. Many cite these restrictions as barriers to care.<sup>12</sup> But, generally, implementing these restrictions under managed care has expanded access to therapy far beyond what was the case during the height of the Freudian psychoanalysis era, when only the wealthy could afford therapy’s out-of-pocket fees.<sup>13</sup>
- There has been a significant resource shift from inpatient to outpatient programs. Spending on community mental health services increased by nearly 1,500% between 1981 and 2015.<sup>14</sup>
- Though the causes of serious mental illness are not well understood, preventive approaches remain popular as an “upstream” solution to crisis. There has also been a shift toward prioritizing primary and secondary prevention (preventing disease before it occurs; and detecting and slowing a disease progression, respectively).<sup>15</sup>
- The government share of spending on mental health treatment, since the mid-1980s, has grown from 56% to 63% and overall spending from about \$30 billion to about \$240 billion.<sup>16</sup>
- There are more mental health professionals than ever; for example, counselors, social workers, and psychiatric nurses—among others—provide services that were once provided only by psychiatrists and psychologists.<sup>17</sup> Primary-care physicians have also assumed mental health responsibilities, further expanding access to care.<sup>18</sup> The lack of psychiatrists, especially in rural areas, is an ongoing challenge.<sup>19</sup> But the expansion of other forms of mental health professionals has undoubtedly helped widen access and has taught valuable lessons about the ways in which psychiatrists may not be necessary in less severe cases, much as psychiatric hospitals are not always necessary.
- Billions have been invested into research into the origins and treatments of mental illness. The U.S. National Institute of Mental Health is the largest funder of mental health research in the world.<sup>20</sup>

Many Americans, upon encountering a street homeless individual who appears to have untreated schizophrenia, may believe that government neglect explains why that individual is in that condition. But mental health policymaking has not been neglected—at least, not in a general way. The public mental health-care system today is incomparably better funded and reaches far more people than at any point in the past.

That said, a troubling gap persists between the “input”-type reforms listed above and poor outcomes:

- Of the 13.1 million adult Americans with a serious mental illness, 4.5 million, or about one-third, receive no treatment (medication or therapy). For some serious mental illnesses, such as schizophrenia, as many as half of all individuals go without effective treatment.<sup>21</sup>

- An estimated 15%–25% of the jail and prison population have a serious mental illness, compared with only 4%–5% of the general adult population.<sup>22</sup> A staggering 350,000–400,000 seriously mentally ill individuals are incarcerated.<sup>23</sup> After including those in community supervision, about 1 million are involved with the criminal justice system.<sup>24</sup>
- More than 100,000 homeless Americans are estimated to be “severely mentally ill.”<sup>25</sup>
- An estimated 200–250 mentally ill Americans are shot to death by police every year.<sup>26</sup>
- Some analyses have found the life expectancy of seriously mentally ill Americans to be about two decades shorter than that of the general population;<sup>27</sup> some analyses have found that long-term psychiatric hospital patients live longer than seriously mentally ill individuals in the community.<sup>28</sup>
- Suicide rates have risen over the last two decades.<sup>29</sup> Overdose deaths are at historical highs.<sup>30</sup> Drug-related deaths are the leading cause of death among the homeless.<sup>31</sup>
- Concerns about mental illness–related violence (mass shootings, subway pushings, murders and assaults of caregivers and family members) are as high as they have ever been.<sup>32</sup> More Americans appear to associate mental illness with violence than was the case decades ago.<sup>33</sup>

Mental health reformers have achieved many of their goals, including broader health-insurance coverage and an end to asylum-based care. But that experience has taught that not every mental health reform, or every investment in mental health services, leads to progress—particularly when it comes to the seriously mentally ill.

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## A System of Support: Continuum of Care

With the rise of the modern safety net, certain elements of “care” for the mentally ill were ceded to other programs. Someone who, a century ago, would have been institutionalized may now have his housing provided through a mix of disability and income support programs<sup>34</sup> and rental subsidies, and his treatment may be provided through Medicare and Medicaid. In the past, those expenses would all have been funded directly by state mental health agencies.

Despite the “mainstreaming” of mental health care and the expansion of the safety net, there is still a crucial need for an independent mental health system responsible for the seriously mentally ill.

That portion of the mental health system that is devoted to crisis is known as the “Continuum of Care.”<sup>35</sup>

Most of the 51.5 million Americans diagnosed with some sort of mental disorder, on a spectrum of mild to severe, will not experience psychiatric crisis.<sup>36</sup> Of the smaller cohort of seriously mentally ill Americans—13.1 million, or 4%–5% of the general adult population—crisis will not be a constant state. Various mental health programs (such as supported employment and clubhouses) help keep stable the seriously mentally ill people who are not in a current state of crisis. But serious mental illnesses are lifelong chronic diseases, one of whose symptoms is recurring episodes of crisis. Hence the need for the Continuum of Care.<sup>37</sup>

At present, there is significant policy interest in crisis response from police departments. In 2022, communities across the nation launched “988” systems to provide an alternative to calling 911 for mental health emergencies.<sup>38</sup> Much of this push is motivated by a desire to “divert” mentally ill people from the criminal justice system by minimizing their contact with police. But diversion to where? The Continuum of Care provides an answer.

Federal and state governments operate many programs that provide some benefit to Americans with mental disorders. Many of these programs operate outside the formal mental health system, such as safety-net assistance programs. Others, such as preventive programs, serve mentally ill people who are not in a state of crisis. And many are not focused on the seriously mentally ill at all, such as Mental Health First Aid and school-based programs. The Continuum of Care fills this gap, as it is oriented toward responding to psychiatric crises and stabilizing the seriously mentally ill.

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## Community-Based Care

The Continuum of Care is not one nationwide system but rather a structure that systems based in communities should take. The Continuum of Care is “community-based” in two senses of the term, the first meaning “noninstitutional.” Mental health policy works within a legal framework shaped by the disability rights movement. In its landmark ruling *Olmstead v. L.C.*, the Supreme Court held that it is discriminatory, and a violation of the 1990 Americans with Disabilities Act, to deny community-based services to the mentally disabled when those services would be most appropriate to their needs. The court explained that community-based means providing services in the “less restrictive setting,” the “most integrated setting appropriate to the needs of qualified handicapped persons,” and in “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.”<sup>39</sup>

Taxpayer-funded mental health services exist, in large part, to support mentally ill individuals’ participation in employment, education, family, and social life to approximately the same degree as people without mental illnesses. *Olmstead* affirmed the federal government’s long-standing bias against institution-based care<sup>40</sup> and shaped that bias into a comprehensive legal framework within which all public mental health programs must operate: “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”

The Continuum of Care also means community-based in the sense that mental health service providers are local and rooted in the community. Someone in a state of crisis must rely on whatever personnel and programs are directly at hand. While the local orientation of the Continuum of Care means that systems will differ depending on local particularities—urban vs. rural, wealthy vs. low income—that is also a problem for social services more generally, as available programs and resources vary widely between communities.<sup>41</sup>

This creates challenges for communities with diminished capacity in the sense of weaker tax bases<sup>42</sup> or fewer psychiatrists and other trained professionals.<sup>43</sup> The mentally ill often have more narrow social networks<sup>44</sup> and fewer informal supports<sup>45</sup> than other disadvantaged populations. The risk of straightforward “trans-institutionalization”—placing someone in a criminal justice setting or inadequate nursing home because no appropriate mental health provider is available—could well be greater in rural areas.<sup>46</sup> However, poorer rural communities may also have certain advantages, such as lower housing prices (Mississippi, though very poor, has far less

homelessness than does San Francisco) and more spaces to site mental health programs without facing strenuous neighborhood opposition. On paper, major cities' mental health systems often boast high capacity, but their overall outcomes are less impressive.

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## Hospital Beds

In *Olmstead*, the U.S. Supreme Court issued what became known as its “integration mandate,” clarifying that it did not intend to prohibit institution-based mental health care: “[N]othing in the [Americans with Disabilities Act] or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.... [T]he ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk.”<sup>47</sup>

Mentally ill people in crisis require supervision to remain stable, and supervision, in turn, requires beds, 24/7 service settings.<sup>48</sup> That often, if not always, means psychiatric hospital beds.

Psychiatric hospital beds are operated in general (community) hospitals—in dedicated psychiatric units or as “scatter beds” in nonspecialized units—or in freestanding, specialized hospitals. State governments still operate specialized hospitals (as the former “asylums”), though in much diminished form. Only about 30,000 of such beds in public specialized hospitals remain, down from a peak of nearly 560,000 nationally in the 1950s.<sup>49</sup>

State hospitals not only care for fewer patients but for a much different client mix. Today, state hospitals are best known for serving forensic patients (people found not guilty by reason of insanity, or who are undergoing competency restoration to stand trial) and the sexually dangerous.<sup>50</sup>

Private for-profits and nonprofits also operate specialized hospitals, such as Sheppard Pratt, in Maryland; and McLean Hospital, in Massachusetts. A chief advantage of a specialized hospital is scale. It is more economical to offer robust services in a 200-bed facility than a 16-bed facility. However, federal law makes it financially impractical to realize those benefits of scale because of: (1) Medicaid's IMD Exclusion, a statute that largely restricts Medicaid reimbursement to “Institutions for Mental Diseases,” or IMDs, with more than 16 beds;<sup>51</sup> (2) Medicare's low reimbursement rates for inpatient psychiatric care and limits on days in freestanding psychiatric facilities;<sup>52</sup> and (3) the inability to use federal Mental Health Block Grants for inpatient services.<sup>53</sup>

General hospitals are not barred from Medicaid reimbursement. In fact, general hospitals' expansion of inpatient psychiatric services coincided with the establishment of Medicaid.<sup>54</sup> From the 1970s through the late 1990s, as state hospitals were scaling back, general hospitals' expansion took up some of the inpatient psychiatric burden. However, since the late 1990s, both types of hospital providers have reduced their inpatient capacity.<sup>55</sup> This is a problem because there is no indication that the rate of serious mental illness, or the demand for inpatient care, has declined over this period. Nor have alternative outpatient settings demonstrated the ability to provide adequate treatment in its place.<sup>56</sup>

Many experts estimate psychiatric bed levels in the U.S. to be too low.<sup>57</sup> The beds shortage has manifested most clearly in “boarding” psychiatric patients in emergency departments (ED) for lack of a bed to admit them to.<sup>58</sup> Psychiatric patients may be boarded in EDs more than three times as long as nonpsychiatric patients,<sup>59</sup> even for days or weeks, until an appropriate placement is available.<sup>60</sup> Boarding is far more common for behavioral health disorders than patients presenting at EDs for more standard health reasons.<sup>61</sup>



Hospitals have also cut psychiatric beds for financial reasons. No hospital is required to offer psychiatric services; rather, hospitals choose to offer a set of services for which the cost to the hospitals of providing those services does not erode their ability to remain in operation. Hospital profitability varies,<sup>62</sup> as does responsiveness to financial changes of offering a service or not, based on whether a hospital is public or private, nonprofit or for-profit.<sup>63</sup> Government hospitals offer unprofitable services more than nonprofit hospitals, which offer more unprofitable services than for-profit hospitals.<sup>64</sup> Overall, at least one-third of general hospitals in the U.S. operate on a negative margin.<sup>65</sup> Inpatient psychiatric services are among the least profitable health-care services that a hospital can offer.<sup>66</sup>

The financial incentives for general hospitals to offer alternative, profit-generating health services make them an unreliable source of psychiatric inpatient capacity: there is the consistent risk that they may choose to repurpose those spaces for more economically attractive services than psychiatric<sup>67</sup>—which include most other services. At present, though, general hospitals remain essential to the care of the seriously mentally ill. Though there are more total inpatient beds in specialized psychiatric hospitals, there are more total inpatient psychiatric service-providing general hospitals than specialized psychiatric hospitals.<sup>68</sup> (General hospitals serve, on average, fewer patients.)<sup>69</sup> General hospitals also have onsite access to physical health care, an important consideration, given the high rate of comorbidity among the seriously mentally ill.<sup>70</sup>

General hospitals are directly connected to emergency departments.<sup>71</sup> EDs are a vital link in the mental health system, since this is where most people who need inpatient behavioral health services enter the system.<sup>72</sup> Private for-profit freestanding hospitals have, in recent years, increased their share of the supply of inpatient psychiatric services<sup>73</sup> by nature of having the lowest cost to operate within this market. However, this has not relieved the financial burden on general hospitals because freestanding hospitals do not operate emergency departments. General hospitals often also serve a disproportionate share of patients who are un- or underinsured; these patients are thus less financially desirable to a freestanding hospital incentivized to fill its beds with higher-paying, commercially insured patients.

In other words, finance, not just stringent legal restrictions, explains low levels of use of psychiatric hospitalization. Making an accurate diagnosis and identifying an effective treatment regimen entail trial and error<sup>74</sup> and can take more time than the standard seven- to 10-day inpatient psychiatric stay.<sup>75</sup> But long-term commitments that, decades ago, were once standard practice in state hospitals now have trouble meeting insurance companies' "medical necessity" standards.<sup>76</sup>

While the need for hospitalization for most health disorders has declined in recent years, the need for hospitalization for behavioral health disorders is an exception.<sup>77</sup> At community hospitals across the nation, hospitalizations in which behavioral health disorders were the principal diagnosis numbered about 2.2 million in 2016;<sup>78</sup> that increased to nearly 10 million when also considering secondary diagnoses. This means that over 25% of inpatient hospitalizations were primarily or secondarily related to behavioral health disorders.<sup>79</sup>

Inpatient hospitalization should serve as a last resort and be utilized when patients need crisis intervention and stabilization that cannot be attained in an outpatient setting. But mental hospitals are therefore central to the Continuum of Care, for several reasons. Many people benefit from involuntary hospitalization in the sense that the experience leads to clinical improvements.<sup>80</sup> Post-recovery, some mentally ill individuals are either grateful that they were hospitalized during their crisis, or claim that they should have been hospitalized earlier than they were.<sup>81</sup>

Mental hospitals also play a confinement role. The standard legal justification for involuntary commitment is dangerousness to self or others due to a psychiatric disorder, coupled with expert opinion that the individual in question would benefit from inpatient treatment. "Dangerousness" is not a medical standard, but when the concept of involuntary commitment was radically challenged

in the 1960s, dangerousness supplanted “need for treatment,” the traditional justification.<sup>82</sup> Another indirect benefit of confinement is lack of access to street drugs and alcohol, a major cause of instability among the seriously mentally ill.<sup>83</sup> Lack of access to street drugs and alcohol is one reason that state hospital systems can restore competency to so many seriously mentally ill individuals involved in the criminal justice system. Psychiatric hospitalization may also play a certain deterrence role in someone’s course of treatment: he is determined to engage with community programming and stay stable, out of fear that, if he doesn’t, he risks commitment.<sup>84</sup> The concept of “commitment devices”—tools that patients use to help them lock in their desired behavior (staying in treatment, for instance, to avoid involuntary commitment)—is accepted in economics and decision-making for helping individuals overcome short- and long-term preference discrepancies.<sup>85</sup> Even when hospitalization stabilizes someone in crisis only on a temporary basis, that may be preferable to other likely alternatives such as jail, homelessness,<sup>86</sup> and decompensating in a community setting without managing to achieve even the most basic self-care.<sup>87</sup>

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## Transitional Residential Services

In addition to stabilizing someone in crisis, the public mental health-care system must ease the transition back to stability. This requires “transitional” or “step down”-type programs—residential programs that provide some degree of 24/7 supervision. Staffing is less robust and less expert than within a hospital. Mental health-care providers, such as psychiatrists and nurses, may be on call but not necessarily on site. Transitional programs can be used to stabilize before a full-blown crisis hits. Stays are of short term (days) or intermediate length (weeks).<sup>88</sup>

Residential programs that serve the mentally ill population come in many varieties: permanent supportive housing, group homes, homeless shelters, and board and care homes. Beds or units in some of these programs have been growing recently (supportive housing), and others have been declining (board and care homes). In all cases, they relieve some pressure on the Continuum of Care, the formal mental health system.

But many operate outside the mental health system altogether. Investment in supportive housing programs, for example, has come in response to homelessness crises, especially in California. Supportive housing targets the “chronic” homeless population, meaning those with a disability and a long-term experience of homelessness. Thus, supportive housing does not always exclusively serve the seriously mentally ill who, for example, would otherwise be candidates for inpatient hospitalization. And these programs are often funded and operated by homelessness services agencies, not mental health agencies.

Thus, there needs to be a focus on non-hospital, intermediate-stay programs that operate under the oversight of public mental health agencies. Homelessness programs can provide relief by stabilizing seriously mentally ill individuals who would otherwise be at risk of hospitalization, as can families. But these should not be considered links in a local Continuum of Care in the way that “step down” and residential diversion programs are.



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## Continuity

The seriously mentally ill have particular difficulty navigating multiple social-services systems<sup>89</sup> and risk disrupting their care by moving between different systems. Individuals then cease to engage with treatment, they decompensate, and service providers lose track of them. This can lead to violence, victimization, and other tragic outcomes.

To minimize these risks, it's necessary not only to invest in local Continuum of Care programs but to ensure that those programs operate as a cohesive system. This requires safe and effective data sharing at the community level. The mechanism might be a formal collaboration among local agencies and providers using common software or technology to facilitate amenable but controlled cross-stakeholder data sharing and data stewardship.

Despite billions of dollars spent annually on mental health, the federal government does not produce high-quality and timely public statistics on the seriously mentally ill population—to such an extent that prevalence rates, let alone outcomes, are uncertain.<sup>90</sup> While they are represented disproportionately among homeless, incarcerated, and repeatedly hospitalized populations, almost no coordination exists to track the mentally ill population as they use mental health services.<sup>91</sup> The cost of not knowing this information, for mentally ill individuals and for taxpayers, is too high.

Administrative data from public programs provide a way of capturing the circumstances and characteristics of the participating individuals, and they do so more comprehensively than point-in-time surveys.<sup>92</sup> These data allow for new, useful outcome measures to be constructed that help describe, for example, patterns of program participation, engagement, and, importantly, disengagement, over time. Effective use of data can therefore help stakeholders like providers, consumers, and policymakers evaluate and track the ways in which various programs have met their intended outcomes, for which subgroups of people, and to what extent.<sup>93</sup>

Expansive data sharing risks a trade-off with data privacy. Access increases the risk that program participants could be reidentified, or their confidential information disclosed. In the mental health context, reducing hospital readmissions is a useful program evaluation measure, and “frequent utilizers” are thought to be a small cohort—outliers among the broader community.<sup>94</sup> Examining a small number of individuals, paired with granular demographic data that may be specific to even fewer individuals, increases the risk that those individuals would be reidentified unrelatedly to the benefit of their treatment and care, and their privacy would be violated.

Traditional statistical methods to reduce this disclosure risk might include suppressing unique participant characteristics that could make reidentification more likely, or aggregating participants with unique characteristics into a larger group.<sup>95</sup> But participants’ specific individual health information is often precisely what is most useful for program and policy effectiveness. The less granular the data, the less socially beneficial.<sup>96</sup> Frameworks that therefore provide access to granular data, but for specific use cases, among specified stakeholders (such as those within a collaborative Continuum of Care) and in secure environments (safe software or platforms) are thoughtful approaches to balancing the data privacy-utility trade-off.<sup>97</sup> Survey data suggest that society is open-minded about sharing their health, social, and economic data for the sake of informing and improving public policy, if it is done transparently.<sup>98</sup>

Safe and effective data sharing serves several purposes: distinct providers (be it government or nongovernment entities) serving the same individual are better able to coordinate and deliver continuous service toward shared goals, such as managing or heading off crisis situations.

Individual-level data linked across programs mean that insights can still be drawn when a person no longer appears in the data for a given program. Multidisciplinary team-based programs, such as Assertive Community Treatment, are an effective approach for anticipating and avoiding crises.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) created standards for protecting patient health information from being disclosed without the patient's consent or knowledge.<sup>99</sup> While families of adult children with serious mental illness can often experience HIPAA as a challenge, HIPAA does permit health-care providers to share protected health information about a mentally ill individual with other health-care providers who are treating that individual for purposes of care coordination and continuity, as well as with other public- and private-sector entities that provide social services—such as housing, income support, and job training—if health-care providers believe that those services are a necessary or helpful component of the individual's mental health care. Data sharing between health-care and third-party social-services providers does not require authorization or agreement from the patient.<sup>100</sup>

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## Conclusion and Recommendations

The concept of a Continuum of Care can serve as a standard for accountability for the public mental health system and a focal point for otherwise vague discussions about mental health policy reform. Whenever there's a mass shooting, subway pushing, or other atrocity somehow connected to untreated serious mental illness, mental health authorities in that community should be pressed on the status of the local Continuum of Care. How many beds does a community have, what kind of beds are they, and what kind of coordination exists between the providers of those beds to guard against someone “falling through the cracks”?

The development of strategic plans about homelessness, criminal justice reform, and other areas related to untreated serious mental illness creates an opportunity for strengthening local Continuum of Care programs. To the extent that those plans discuss serious mental illness—and they often do—they should focus on the Continuum of Care to guide discussion on how a reformed public mental health-care system can relieve other systems of burdens tangential to their core missions.

Strengthening the Continuum of Care will require actions at both the federal and state levels.

### Federal Reforms

In years to come, the federal role in mental health, particularly mental health financing, should be expected to grow. High-quality services for the seriously mentally ill are expensive. This reality is sometimes concealed amid misleading debates about the alleged cost-effectiveness of community-based programs over psychiatric hospitals. Psychiatric hospitals are indeed costly programs, but that has much to do with regulations guaranteeing their quality; when someone with schizophrenia lives in a community, the costs are shared across multiple systems, making a full accounting nearly impossible. Warehousing someone in a low-quality isolation hotel, as some cities are choosing to do, may not be expensive.<sup>101</sup> But if we want people to thrive in the community, that will entail investment.

As noted earlier, many jurisdictions are simply too poor to fund quality programs for the seriously mentally ill. That makes any “devolution” of mental health impractical. Further, there is a long history of federalist “shell games” in mental health, dating back to the 19th century. Localities and states, while acknowledging their responsibility for the seriously mentally ill, have sought to shift the fiscal burden onto other levels of government.<sup>102</sup> If it is important, for good government

reasons, to prevent such irresponsible cost-shifting, while also maintaining a commitment to the seriously mentally ill and not requiring poor jurisdictions to bear unreasonable burdens, that points to a larger federal role. The question then becomes what form that role should take.

With insurance, and Medicaid especially, as a key financing mechanism for treatment for serious mental illness, federal reform should begin by repealing the IMD Exclusion. This long-overdue reform would authorize billions in funding for specialized psychiatric hospitals.<sup>103</sup> More specialized psychiatric hospitals would emerge, as these providers are able to realize economies of scale inaccessible to smaller inpatient programs operating out of general hospital psychiatric wards. Bed shortages would ease.

Repealing the IMD Exclusion is the most important act that the federal government could take to shore up local Continuum of Care programs. Importantly, this would benefit nonhospital residential programs, which qualify as “IMDs” and whose scale is thus limited by the IMD Exclusion.

Medicare limits reimbursement for inpatient psychiatric services as well, in terms of coverage and through low rates. Medicare restricts the number of days that patients may be covered for stays in an inpatient psychiatric facility (IPF) over the course of their lifetime, to 190 days.<sup>104</sup> Individuals with serious mental illness may reach this limit without difficulty, given that they often gain Medicare coverage before age 65. The Medicare Payment Advisory Commission (a nonpartisan independent legislative agency that provides Congress with policy analysis on the Medicare program) finds that 57% of individuals admitted to a Medicare IPF in 2015 were under the age of 65, meaning that they were covered based on the qualification of being highly disabled.<sup>105</sup> This 190-day lifetime limit is arbitrary and may not reflect the medical necessity of inpatient treatment for seriously mentally ill individuals, who often experience a lifetime of crisis episodes among periods of recovery. In the Medicare inpatient psychiatric facility prospective payment system, freestanding nonprofits operate at a negative margin, as do distinct for-profit and nonprofit psychiatric units in general hospitals.<sup>106</sup>

The full implications of IMD repeal and removal of the Medicare 190-day lifetime limit are uncertain. While specialized state psychiatric hospitals have the reputation of taking the “hardest cases” (forensic, sexually dangerous), specialized private hospitals have the opposite reputation. Since they do not operate emergency rooms, they serve a large number of patients whose families are motivated to find state-of-the-art care centers and pay whatever costs. Thus, “creaming,” where hospitals seek out the most financially or medically desirable patients to demonstrate the apparent efficiency of their care, within the overall system must be monitored, post-IMD repeal.

The Community Mental Health Centers Act of 1963 recognized that inpatient treatment in the community would play a key role in the successful transition from total asylum-based care. The Mental Health Services Block Grant—the present incarnation of that law—does not allow states to use funding toward inpatient services, though it targets adults with serious mental illness<sup>107</sup> for whom the Continuum of Care is also meant to serve. More flexible use of these dollars could be afforded for inpatient treatment at certain “safety net”-type psychiatric hospitals that provide inpatient treatment, along with a range of other psychiatric services.

An example of such a hospital is Sheppard Pratt, a nonprofit provider in Maryland that offers a wide range of inpatient and outpatient psychiatric services and serves as a safety net accepting all patients, including those who have been turned away from other hospitals in the state. Individuals requiring longer inpatient services are only a small portion of the entire patient population served by Sheppard Pratt, which offers a wide array of alternative programming, from structured outpatient day services, therapy, medication management, care coordination, and in-home services, among many others.<sup>108</sup> But funding for those inpatients bolsters the financial security of a safety-net hospital while also improving access to services for other Medicaid and

uninsured populations. This type of use is in line with the goals of Disproportionate Share Hospital payments,<sup>109</sup> which some government hospitals use to help maintain what limited capacity for inpatient psychiatric services still exists.<sup>110</sup>

Separately, in more recent years, the federal government has worked toward improving data sharing. This spirit was manifest, for example, in the 21st Century Cures Act—federal health-care legislation signed into law in 2016 that contained a significant number of provisions for mental health and illness<sup>111</sup>—which impressed the value of interoperability among stakeholders. The Cures Act requires health-care providers to make an electronic health record (EHR) system to share data with authorized organizations by banning the practice of blocking patients' health data from entities that have legitimate need to access that data.<sup>112</sup>

### **State and Local Reforms**

Continuum of Care programs are local systems, making local leadership imperative in their development. Our ongoing crisis in mental health is also, in many respects, local. State and local leaders are often pressed for reforms in response to other mental illness-related crises, such as mass shootings and homelessness. Mayors and other local officials should commission studies of their existing networks of residential mental service providers who care for seriously mentally ill individuals. They should also simply talk up the concept of a Continuum of Care to promote more focus and coherence in the mental health reform debate. Jurisdictions with their own resources, such as New York and California, should maximize those resources toward the development of local Continuum of Care programs. There will be cases when local communities will need to rely on state and federal resources to develop these systems. Relying on this concept will help ensure better targeting of any future mental health resources.

Networks of service providers rooted in their respective communities will function as a system only if they share data among themselves. State, and especially local, leadership will often need to facilitate data sharing. State and local agencies may have some advantages for data sharing in terms of what legal regulations exist. For example, in the case of education agencies and student data, states have far more access than the federal government.

While still developing, local and regional data-sharing arrangements have become increasingly more common. Collaborative efforts can be formalized through legal contracts under which parties involved agree to the purposes, use, and level of access to their respective data.<sup>113</sup> Two examples are worth highlighting: in Bexar, Texas,<sup>114</sup> a renowned program of collaboration,<sup>115</sup> agencies meet regularly and use a private software platform to maintain a Continuum of Care system that allows for capturing the intended safety-net constituency of the seriously mentally ill at any point in which they have contact with the system, whether that be through a 911 call, a law-enforcement encounter, or a hospital ER visit.

A second platform, which has garnered support from the Bill and Melinda Gates Foundation, Walton Family Foundation, and others, is the nonprofit startup Coleridge Initiative,<sup>116</sup> which maintains a cloud-based computing platform for agencies at all levels of government to securely host their administrative data in order to foster cross-state and cross-agency collaboration on a common platform.<sup>117</sup> Coleridge facilitates data stewardship for agencies in more than 15 states, and Regional Data Collaboratives<sup>118</sup> have sprung up organically through this connection to study, among other topics, cross-state post-college-graduation labor-force outcomes.<sup>119</sup> The platform has also been used by state agencies in partnership with local workforce boards to understand the patterns of unemployment to reemployment during the Covid-19 pandemic across subgroups.<sup>120</sup>

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