

A Crisis in Search of Data



The Revolving Door of Serious Mental Illness in Super Utilization

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THE REVOLVING DOOR OF SERIOUS MENTAL ILLNESS IN SUPER UTILIZATION

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EXECUTIVE SUMMARY

Almost as soon as state hospitals began to be emptied in the 20th century, police officers on the beat, homelessness workers on the streets and professionals throughout the healthcare system began observing an alarming new trend: Former patients and individuals who would have been hospitalized in the era before the wholesale closure of public hospitals were now showing up, often repeatedly, on their police logs, in their shelters and in emergency rooms. By the 1980s, the phenomenon of frequent, recurring use of public safety and safety-net services came to be known as the *revolving door*.

Nearly half a century later, the reality that a relatively small number of people make relatively frequent use of high-cost public services at enormous public expense has become common knowledge. From colorful anecdotes like the story of “Jane” of New Jersey, who generated

The Language of High Utilization

The terms “high utilizer” or “high utilization” and “super utilizer” or “super utilization” were narrowly defined in research and statistics in the past. Increasingly, however, they are used interchangeably. For that reason, they are used as synonyms in this report.

“Hot spotting” is a term originally applied to identifying high utilizers of police services in a specific geographic area. It is now often used more generically and is used in the latter manner herein.

For a sample of the many ways these terms are defined, see Appendix A.

\$4.4 million in hospital charges over five years,¹ to colorless data points like the fact that 1% of the US population incurs almost 25% of the nation’s healthcare expenses,² a steady drumbeat of headlines and fact sheets has etched the economic impact of “super utilizers,” “high utilizers” and “hot spotters” into the consciousness of the public and policymakers.

Yet, as it has been in myriad other public health and service crises, the role of serious mental illness (SMI) as a driving force behind the trend has been largely overlooked or underreported, with profound and costly consequences for individuals trapped in the revolving door, their communities and taxpayers.

Accounting for barely 3% of the adult population, individuals with diagnoses of schizophrenia and severe bipolar disorder are known to be overrepresented in the systems most affected by the failure of the US mental health system, principally when untreated. Yet despite the human and economic toll of this pattern, the role of SMI in high

utilization is largely uncharted, and the data essential to track its impact, including cost impacts, for the most part do not exist. They are not collected. Or they are collected incompletely. They are collected locally but not nationally, or they are drawn from public systems that function independently of one another and use unique methods and definitions to collect statistics, producing data incompatible for combination, comparison or scaling up to identify larger trends, including best practices.

Because the welfare of individuals with the most severe mental illness is the focus of our mission, the Treatment Advocacy Center set out in 2015 to narrow this information gap. Our strategy was to identify, collect and analyze existing data on the role of SMI in high utilization across three systems known to be highly impacted by frequent utilizers: healthcare (including inpatient and outpatient emergency care), criminal justice (including law enforcement, courts and corrections) and homelessness.

To this end, the Treatment Advocacy Center recruited the College of Public Health at Kent State University (KSU) in Ohio to conduct a systematic review of academic studies published in English from January 2005 to June 2016 reporting on the role and cost of SMI in high utilization within the target systems. After the researchers removed duplicates and applied

other criteria to an initial set of 3,174 sources, a total of 21 peer-reviewed papers and nine dissertations remained.³ Nearly all the qualifying papers pertained to healthcare.

To supplement the Kent State results, the Treatment Advocacy Center's Office of Research and Public Affairs conducted a broader search that included mass media news reports, government studies, conference proceedings, professional and trade association reports, think tank white papers, and other gray literature that did not meet the standards for the systematic review or was published after June 2016. More than 200 additional sources were reviewed in this process.

The result, *A Crisis in Search of Data: The Revolving Door of Serious Mental Illness in Super Utilization*, is the first published effort to systematically and comprehensively survey what has been reported in government, academic and mass media sources about this public health emergency. As a benchmark, the review illuminates both the intersection of SMI and super utilization and the gaps in knowledge that must be closed if the role of SMI in high utilization is to be analyzed and effective policies to slow the revolving door are to be implemented. Among the findings:

- ◆ **The absence of standardized definitions that are the cornerstone of analysis poses a significant barrier to data-driven policymaking.** There is no common definition for SMI, for example, nor are there common definitions of "high" or "super" utilization. Without common definitions, answering questions such as "What is the impact or total cost of SMI in high utilization?" is impossible.
- ◆ **The role of SMI frequent utilizers on affected systems has been systematically tracked only in healthcare.** Outside of small, localized studies in relatively few communities, statistics are not routinely collected about the impact on law enforcement, corrections, emergency response or homelessness, among other systems. This absence of data limits the ability of policymakers to weigh human or economic costs and benefits when making decisions.
- ◆ **Most of the cost data on SMI in relation to high utilization are collected locally or narrowly.** This methodological approach means that cost data from different locations typically cannot be compared or combined to arrive at cost totals and broad conclusions. Meanwhile, much of what is published outside the academic community is anecdotal, informal or not suitable for statistical analysis, much less for use as a basis for evidence-based public policies that might actually reduce the phenomenon.
- ◆ **Data exchange among those local jurisdictions, universities and agencies that are systemically collecting useful data appears to be relatively limited.** Not infrequently, the authors of *A Crisis in Search of Data* found researchers in one region unaware of related research underway elsewhere, even within the same state.

The inability to share, combine and analyze data is an issue with significant public policy implications.

Without a complete picture of the impact on the component systems, policymakers do not have the information they need to analyze the net impact of SMI on high utilization between systems. This lack of information limits their ability to make evidence-based tradeoffs, including cost-benefit decisions. Moreover, incomplete data may even lead to false conclusions or counterproductive policies. For example, decision makers routinely eliminate public psychiatric beds or increase community services without information on the relation of bed supplies to the demand for and cost of law enforcement, courts, corrections, emergency medical care and other services where individuals with SMI often engage when they do not

receive timely treatment. If individuals trapped in the revolving door account for most of these impacts, knowing the client characteristics associated with super utilization and the patterns and needs of this population is critical to formulating effective policies to reduce super utilization.

Issues such as these are being identified more frequently, initiatives to address them are taking root and academic research is beginning to address the void. Public policies and practices are being established across the United States every single day based on incomplete or irrelevant evidence or headline stories that may or may not reflect underlying human and economic realities. As a consequence, individuals with severe psychiatric symptoms continue cycling through public systems without personal benefit. Public policies and investments are being made to break the cycle of super utilization with little understanding of the significant role played by serious mental illness and the practices that could reduce its role.

RECOMMENDATIONS

To narrow the gap between knowledge and the practices that hold hope for reducing the role and cost of SMI in high service utilization, the Treatment Advocacy Center recommends the following steps:

- ◆ **Researchers and government agencies must collaborate to develop a baseline definition of SMI applicable in state and federal government data collection and academic study of super utilization.**

A commonly used baseline definition is fundamental to comparing or combining data and studies originating from different sources and different locations and, by doing so, to identifying broader trends, patterns and other factors.

- ◆ **Federal, state and local governments must incorporate SMI as a data point in all government collection of super-utilizer statistics.**

Incorporating SMI in all official data collection on super utilization will produce a body of statistics that will better inform policymakers about the magnitude, heterogeneity, regional factors and other characteristics of SMI in the affected population.

- ◆ **Researchers and government agencies must standardize methodologies for recognizing and reporting the economic costs of SMI in super utilization.**

Evidence-based budget decisions require reliable and comparable evidence about costs. Although the needs, technology and capabilities of different public systems inevitably will vary, only with cost data suitable for aggregation and intersystem study will it be possible to weigh costs and benefits. Common methods for developing this information are needed.

- ◆ **Government must fund an open-source forum or clearinghouse where organizations that are systematically collecting super-utilizer data, including data on the role and cost of SMI, can share and find related projects and statistics.**

Increased visibility of and open access to local and independent data and findings will enable organizations isolated from one another to benefit from the experiences and findings of other groups working toward similar goals for the benefit of the same population.

BACKGROUND

Psychiatric disease is one of the few medical conditions in US public healthcare for which treatment is routinely deferred until people become so sick they require emergency hospitalization and intensive care. Serious mental illness (SMI) is also a disease for which intervention is routinely left to nonclinical facilities such as jails, prisons or homeless shelters. This twin dysfunction has the disastrous outcome of producing a large population of acutely ill people who revolve, untreated or undertreated, through the healthcare and social and criminal justice systems.

Under these circumstances, it is probably inevitable that individuals with the most profound SMI are grossly overrepresented in the nation's criminal justice and social safety-net systems. Making up barely 3% of US adults, individuals with schizophrenia or severe bipolar disorder make up a disproportionately large share of the people presenting in hospital emergency departments (EDs), being admitted to hospitals, generating calls to city police departments, being booked into county jails, living in homeless shelters or on the streets and otherwise falling victim to the dismantling of the US mental health system over the last half century.

As a result, people with treatable psychiatric diseases generate patterns and costs found nowhere else in Western democracies:

- ◆ **Hospitalization:** \$27.7 billion spent for schizophrenia and mood disorder hospitalizations, including bipolar disorder, or \$85.46 for every man, woman and child in the United States (2014)⁴
- ◆ **ED visits:** 10.8 million visits with schizophrenia or mood disorder as the primary or secondary diagnosis, or 7.9% of all ED visits nationwide (2014)⁵
- ◆ **Criminal justice:** 20% of jail detainees and 15% of prison inmates,⁶ with 7.2% of male and 15.6% of female state prison inmates with SMI in solitary confinement⁷
- ◆ **Homelessness:** 20%–76% of the chronically homeless^{8,9}

Even as the overrepresentation of individuals with SMI in the criminal justice and social safety-net systems has become common knowledge, recognition has been growing about another disproportionate pattern: super utilization—the relatively frequent use of high-cost public services by a relatively small group of high-need individuals, at significant public expense. A splashy *New Yorker* article detailed the work of Jeffrey Brenner, MD, and his “hot spotting” of high utilizers in New Jersey,¹⁰ while a dramatic case study highlighted “Jane,” whose 77 hospital visits from 2010 to 2014 resulted in \$4.4 million in charges to five New Jersey health systems.¹¹

What is missing from this picture is light on the intersection where SMI and super utilization meet. On occasions when the intersection is illuminated, its sheer awfulness can make news:

- ◆ **In Miami-Dade County, Florida,** 97 high service utilizers with SMI cost taxpayers \$13 million in criminal justice costs over a five-year period.¹²
- ◆ **In Philadelphia,** 438 chronically homeless individuals with SMI cost the city \$12 million annually in public service costs, 60% of the total service costs for all homeless individuals.¹³
- ◆ **In New York City,** 800 frequent inmates at the Riker's Island jail cost the city \$129 million from 2008–2104; 152 of these high utilizers had a diagnosed SMI.¹⁴

What Is 'Serious Mental Illness' (SMI)?

When the Treatment Advocacy Center uses the term "serious mental illness" or "severe mental illness" in this report or elsewhere, we are referring to the population diagnosed with schizophrenia or severe bipolar disorder. An estimated 8.2 million US adults were living with such diseases in 2016, half of them untreated at any given time.

This is a narrower definition than the ones often used in government or academia, but it is this population, primarily when untreated, that is overrepresented in criminal justice and social safety nets, and most likely to be subject to court-ordered treatment. Using a broader definition would misrepresent the population at risk for these outcomes.

But the headlines are the exception. For all the decades of awareness of the revolving door on the front lines of public service, the role and cost of SMI in super utilization are barely tracked and often not officially recognized or quantified. The meticulously detailed South Central Pennsylvania High Utilizer Collaborative report on the "experience and recommendations of five Pennsylvania programs" is representative: The 80-page report does not mention "serious mental illness," schizophrenia or any psychiatric conditions that law enforcement, hospital personnel and others on the front lines of the mental health crisis know are overrepresented in their super-utilizer populations.¹⁵ Even when the role and cost of SMI in super utilization are being tracked, the data are typically limited to a single system—jails but not courts, for instance—or collected using methods that prevent them from being combined, compared or scaled up to reveal larger trends and the net impacts between and among systems.

As public officials increasingly invest in policies and programs designed to reduce costly high-utilization trends, recognizing and tracking the impact of SMI in the larger phenomenon is not only relevant, it is urgent. In 2015, the Treatment Advocacy Center set out to identify and review all the research published since 2005 on the impact of SMI on super utilization. Our goal was to help to break down these silos to better support evidence-based policymaking.

The review took place in two parts: a systematic review conducted for the Treatment Advocacy Center by the College of Public Health at Kent State University (KSU) in Ohio and an expanded review of academic and gray literature conducted by the Office of Research and Public Affairs (ORPA) at the Treatment Advocacy Center. The reviews both focused on the three US systems known to be most highly impacted by frequent utilizers with SMI: health-care (including inpatient and outpatient emergency care), criminal justice (including law enforcement, courts and corrections) and homelessness.

The result, *A Crisis in Search of Data*, is the first published effort to systematically and comprehensively collect what has been reported in government, academic and mass media sources about this public health emergency. As a benchmark, it sheds light not only upon the poorly illuminated intersection of SMI and super utilization but also on the gaps in knowledge that must be closed if effective policies to reduce the phenomenon are to be implemented.

METHODOLOGY

Using a set of keywords such as "mental illness and high utilizers," "homelessness costs," "schizophrenia and high utilizers" and more than 30 others, KSU conducted a series of literature searches that together yielded 3,174 sources. KSU reported to the Treatment Advocacy Center:

Objective: The primary objective of this review was to identify the role of severe mental illness in high utilization costs and inpatient care across the service sectors of healthcare, homelessness, and criminal justice involvement that includes law enforcement and incarceration.

Methods: We searched databases during May through July 2016 and reviewed the reference lists of identified sources. The research focused on high utilizers diagnosed with schizophrenia, bipolar disorder or psychosis. A quality index was used to determine the rigor of research methods used in selected peer-reviewed studies.

Results: Three separate searches were conducted in order to identify sources. The first search yielded 1,210 sources; the second search yielded 1,180 sources; and the third search yielded 784 sources. After employing the inclusion criteria and [removing] duplicates, authors reduced the number of sources to 21 peer-reviewed articles and nine dissertations/theses ($N = 30$). Limited research was found on criminal justice involvement and homelessness related to high utilizers and [their] costs.¹⁶

KSU's complete methodology is detailed in Appendix B. The KSU review included unpublished master's theses and doctoral dissertations. These have been excluded from the findings in *A Crisis in Search of Data* because they lacked rigorous peer review, and the quality of data reported in them was low. Additionally, international studies reviewed by KSU have been excluded because of the significant differences between the mental health policies and practices of other Western countries and those of the United States.

ORPA supplemented the KSU literature review by conducting a broader search than the protocols of a systematic literature review permit. This search included reviewing county, state and federal government reports; conference proceedings; professional and trade association reports; think tank studies; mass media news reports and other gray literature that does not meet the criteria for a systematic review or was peer-reviewed but published after the KSU review ended. All relevant sources were reviewed and evaluated for relevance, methodology and data quality. Approximately 200 additional sources of data were identified by this process. Additionally, literature that KSU initially identified but eventually excluded for not meeting review criteria were examined for relevant data.

FINDINGS

General Findings

The overrepresentation of individuals with SMI in the healthcare, criminal justice and homelessness systems is universally recognized in both the academic and gray literature, as well as mass media. Inconsistencies were found in SMI prevalence estimates within specific sectors, and the variations were sometimes extreme, but there was no exception to the general recognition that SMI is a risk factor for engaging with one or more public services.

The central finding of this review is that the role of SMI in high utilization is uncharted.

However, in only one public sector was the role and cost of SMI found to be systematically collected and reported at a national level: healthcare. The Centers for Medicare & Medicaid Services, among other federal and state agencies, tracks and reports healthcare costs by psychiatric diagnosis. This practice produces a large and robust

body of data on costs for events such as hospitalization for schizophrenia or ED visits for mood disorders, including bipolar disorder. In 2014, for example, the Agency for Healthcare Research and Quality reported the cost of schizophrenia hospitalizations to be \$11.4 billion and the cost for mood disorder hospitalizations to be \$16.3 billion. These numbers make it

possible to identify mood disorders as the third most costly source of hospitalization costs that Medicaid covers and schizophrenia as the sixth.¹⁷

While reasonable estimates are made in the literature, comparable national or state-level data that quantify the role and cost of individuals with SMI on law enforcement, corrections, emergency medical or homelessness services do not exist. Even less information is available about the impacts of the super utilizers within the SMI population. As just one example, data exist to estimate that 2 million individuals with SMI were booked into US jails in 2015¹⁸ but not to determine the impact of the relatively few people being booked over and over again. Without this data, the role of SMI in the super utilization of criminal justice services remains unknowable.

Thus, the central finding of this review is that the role of SMI in high utilization is uncharted and its widely acknowledged costs are unquantifiable, outside of selected healthcare services and a few local communities where systematic point-in-time studies have taken place.

Three of these locations deserve special attention. In San Francisco, three counties of Florida and southern New Jersey, extensive and detailed datasets have been funded and developed for at least some of the affected public systems. These datasets provide policymakers with actionable evidence about the role of SMI in super utilization both within and between systems (e.g., healthcare and criminal justice, or homelessness and emergency services). While none of these efforts is without data gaps, they are vastly more detailed than what is generally found in either academic or gray literature and stand as proof that obstacles to data collection and intersystem study can be overcome.

◆ **Alachua, Broward and Pinellas counties, Florida**

In 2016, the Florida Department of Children and Families and the Louis de la Parte Florida Mental Health Institute at the University of South Florida published an analysis of local, state and federally funded mental health service delivery and costs in three counties.¹⁹ Ordered by Florida Governor Rick Scott, the study aimed to streamline state budgeting and track behavioral healthcare spending across multiple systems. A sample of 120,134 public mental health clients with SMI in three counties was analyzed for the subpopulation's intersystem impacts and costs to healthcare, criminal justice and selected social systems over a four-year period. Although not entirely complete (Broward, the largest of the three counties, did not report criminal justice data), this effort represents the most thorough intersystem study of SMI and super utilization identified during this project.

◆ **Southern New Jersey**

In January 2016, Governor Chris Christie issued a call to action to improve health care delivery for Medicaid super utilizers. In response, Rutgers University Center for State Health Policy analyzed Medicaid claims data from 2008 to 2011 in order to identify super utilizers, defined as the top 1% of users in the health care system.²⁰ Separately, Rutgers has been analyzing healthcare utilization patterns to identify the role of mental illness and substance use in hospital utilization rates and costs.²¹

◆ **San Francisco, California**

In 2007, the San Francisco Department of Public Health launched an effort to identify high users of multiple systems (HUMS) in three service sectors: medical, mental health and substance abuse.²² The original dataset included a sample of 51,796 patients from fiscal year 2010–2011 who were users in any one of the three sectors. A separate sample of 15,712 individuals with SMI was analyzed later based on the HUMS classifications, which focused on use (not cost) of urgent-care services. This enabled the city to identify individuals who might not be among the highest utilizers in a single system but whose combined use of urgent-care services in multiple systems rendered them high multisystem users. The top 5% of users constituted nearly half of the urgent-care costs for San Francisco and a very high percent of burden in terms of premature mortality, homelessness and criminal justice involvement.

Findings from these intensive studies are presented in three case studies following the body of this report. Findings specific to SMI in the super utilization of the criminal justice, homelessness and healthcare systems follow.

Criminal Justice Findings

KSU's review of the literature confirmed the overrepresentation of individuals with SMI in the criminal justice system:

On average, criminal justice-involved adults with schizophrenia or bipolar [disorder] were arrested 1.7 times per year, with an average duration in jail of 157.2 days. The largest proportion of arrests (43%) [involved] minor offenses such as trespassing, breach of peace, prostitution and technical violations of probation. The second largest category of arrests was for property crimes (21%), followed by drug offenses (15%), violent offenses (10%), crimes against persons (9%), weapons (1%) and other felonies (1%).²³

However, while anecdotal reports of criminal justice super utilization by individuals with SMI are common in the media, little data-driven evidence that meets the standards of peer review and specifically addresses the issue in the law enforcement, criminal courts and/or corrections systems was found in academic or other studies or datasets. The KSU systematic review of peer-reviewed literature located only three US studies related to super utilization and criminal justice involvement by individuals with SMI.²⁴ Two of the three studies were comparisons of healthcare use by individuals with and without criminal justice involvement, not examinations of frequent use of the criminal justice system itself (law enforcement, courts and/or incarceration) and its costs.

Thus, although law enforcement officers routinely say they encounter "frequent flyers" with SMI so often that they know these super utilizers' names and birthdays by heart, no data were found in the KSU review to quantify what percentage of law enforcement responses are generated by these high utilizers.

With regard to corrections, if repeated re-incarceration is considered a credible yardstick for measuring high use of the corrections system, then SMI is a risk factor: Inmates with SMI are well documented to return to jail or prison more quickly and more often than those without a psychiatric disease, especially if they have co-occurring substance abuse. Again, however, quantifying, understanding and addressing criminal justice super utilization requires

more and better data. Knowing that an estimated 2 million individuals with SMI were booked into US jails in 2015 confirms that psychiatric diseases are overrepresented behind bars but does not illuminate the role of individuals who are arrested repeatedly or its costs.²⁵ While selected individual jails no doubt track these numbers internally, the data remain undiscoverable at the national and state levels.

Gray literature reported by or for state and local systems only somewhat augments the academic research. In its review, ORPA found:

- ◆ **From Texas:** Inmates with a major psychiatric disorder in Texas state prisons were 2.4 times more likely to have four or more repeat incarcerations in 2007 than those without mental illness.²⁶
- ◆ **From New York:** The 800 most frequently incarcerated individuals at New York City's Rikers Island from 2008 to 2014 had a median of 21 incarcerations per inmate, compared with three incarcerations per inmate in the general population. Slightly fewer than 20% of these high utilizers had a diagnosed SMI, and 37% were receiving anti-psychotic medications.²⁷
- ◆ **From Florida:** In Miami-Dade County, 97 high service utilizers with SMI cost taxpayers \$13 million in criminal justice costs over a five-year period ending in 2010.²⁸

"More needs to be done to better understand how to effectively alleviate the costs and challenges of treating and processing offenders with mental illness in the criminal justice system."

—Barack Obama, "The President's Role in Advancing Criminal Justice Reform," *Harvard Law Review*, January 2017

In the case of local studies, however, the focus typically is so narrow, or the numbers are so incomplete, that they do not lend themselves to being combined for comparative uses or scaled up to look at broader trends. For example, a report that "individuals with psychotic disorders who were at least 40 years old, who had experienced an involuntary psychiatric evaluation, and who had more arrests and mental health contacts had significantly higher aggregate expenditures"²⁹ may be useful to the jurisdiction that developed it. But these data cannot be combined or compared with local data from other jurisdictions that don't make the same distinctions to discover larger trends in utilization.

Cost estimates of the impact of SMI on the criminal justice system suffer from the same absence of specifics about the role of the super-utilizer population. For example, the economic burden of schizophrenia on the criminal justice system in 2013 was estimated at \$14.3 billion.³⁰ Whether super utilization contributes to those costs and, if so, the size and characteristics of the super-utilizer population are not reported. Without such information, developing public policy or practices to reduce the costs attributable to revolving-door individuals is not possible.

The circumstances that converge to produce the relative dearth of SMI-specific criminal justice data are many and beyond the scope of this study. However, it is noteworthy that other organizations and public agencies are beginning to address legal and technical barriers that inhibit data sharing across systems. Among them is the Data-Driven Justice Initiative begun by the Obama Administration and now housed at the National Association of Counties, with support from the Laura and John Arnold Foundation. This initiative focuses on disrupting the cycle of incarceration and includes data-sharing and technological strategies for diverting high utilizers from the criminal justice system, including individuals with SMI.³¹ San Francisco already has blazed a trail by implementing legal memorandums of understanding that facilitate intersystem data sharing. The 21st Century Cures Act of 2016 also includes provisions mandating detailed collection of data about inmates with SMI.

However, until these initiatives succeed and are widely embraced, the role and cost of SMI in the frequent use of criminal justice services is likely to remain too insufficiently documented to provide meaningful guidance to policymakers and thus to offer systemic solutions.

Homelessness Findings

The majority of individuals who are homeless are not chronically homeless, nor are they living on the streets or mentally ill. Nationwide, approximately 80% of the nation's homeless population at a given point in time is living in a homeless shelter, primarily as a result of economic hardship.³² In New York City, where supportive housing services are famously robust, more than 95% of the homeless population is sheltered at any given time, and 71% of the sheltered are adults and children living in families, not single individuals.³³ Thus, for most individuals, homelessness is temporary and ends once their economic circumstances improve.^{34,35}

“Although chronic homelessness represents a small portion of the overall homeless population and the number of people experiencing chronic homelessness is decreasing across the United States, this population consumes more than half of services.”

—SAMHSA, *Homelessness and Housing*, April 26, 2016

The more common image of homelessness as a visibly unclean and clearly disordered individual shambling down city sidewalks talking to himself is largely associated with the outliers of the homeless population: the estimated one in five people whose homelessness is chronic. Members of this 20% subset are estimated to consume more than 50% of homelessness services provided in the United States.³⁶ Thus, chronic homelessness offers a reasonable proxy for super utilization by the homeless.

Yet, like super utilization and SMI itself, chronic homelessness has no commonly used definition. The US Department of Housing and Urban Development (HUD) defines the pattern as four periods of homelessness within three years.³⁷ The Substance Abuse and Mental Health Services Administration (SAMHSA) defines it as spending more than a year homeless or experiencing four episodes of homelessness within a three-year period.³⁸ Other agencies and individual researchers define it otherwise (see Appendix B).

Estimates of SMI prevalence in this population similarly vary. Definitions of SMI used below incorporate a broader definition of SMI than otherwise used in this report.

- ◆ 20% of the total homeless population—SAMHSA (2017)³⁹
- ◆ 26% of chronically homeless individuals in shelters—HUD (2015)⁴⁰
- ◆ 30% of all chronically homeless—Office of National Drug Control Policy (Obama Administration; no date)⁴¹
- ◆ 76% of participants in a collaborative program for homeless veterans—Collaborative Initiative to Help End Chronic Homelessness (2008)⁴²
- ◆ A “large majority” of New York City’s street homeless—Coalition for the Homeless (2016)⁴³

As striking as such numbers may be, the inconsistency in definitions, the variation in statistical methods used to develop them and the failure to attach cost data to them limit their usefulness in the understanding of SMI among super utilizers of homelessness services. The KSU systematic review identified only two peer-reviewed papers directly examining the

phenomenon, from which came the observation that “compared with the general population, individuals who are homeless have higher rates of chronic and acute health conditions, largely related to mental health.”^{44,45,46} The review found reports that homelessness costs anywhere from \$13,000 to \$2 million per person,^{47,48,49,50} a range so extreme that it strains credulity and is useless as guidance for budget or other public policy purposes.

ORPA’s review yielded a number of data points that implicate SMI as a significant contributor to homeless service and intersystem super utilization by individuals who are homeless. Among them:

- ◆ Homeless individuals with SMI had significantly more ED visits and higher hospitalization rates than homeless individuals without SMI, averaging 4.5 ED visits per year, 30% more than homeless individuals without SMI.⁵¹
- ◆ Homeless patients with SMI were hospitalized four times longer than homeless individuals with substance use disorders and three times longer than those with cardiac disease.⁵²
- ◆ Homeless individuals were hospitalized more frequently than the general population, and their resulting healthcare costs were more than three times greater (\$27,000 versus \$8,000 in 2009 dollars). One-third of the frequently hospitalized homeless population had SMI.⁵³

However, with rare exceptions like the final point above, cost data to inform decision-making related to this population was scant or incomplete. Thus,

- ◆ The Frequent Users Service Enhancement Initiative to reduce the interaction of homelessness with criminal justice involvement in New York City found that jail and shelter costs for program participants totaled \$38,351 per person in 2012.⁵⁴ However, the initiative did not collect emergency transportation, psychiatric outpatient or psychiatric inpatient treatment costs, rendering the findings incomplete and understated.
- ◆ A study for the city of Nashville found that \$10 million of its \$16.7 million in homelessness costs in 2007 were spent on the chronically homeless, who made up half the population served.⁵⁵ Costs included services for emergency medical and hospital inpatient treatment; veterans and social services; shelters; police, jail and courts; drug treatment; and housing services. However, the role of SMI in any of this service utilization was not identified and thus remains unknown.

A notable exception to the lack of data on the topic is a 2010 study of chronic homelessness in Philadelphia. The study matched the homeless shelter and street outreach records for 2,703 chronically homeless individuals with their records for psychiatric care, substance abuse treatment and incarceration to isolate the intersystem impact of SMI on high utilization of all these services. The analysis found that 20% of the highest utilizers consumed 60% of the city’s total service costs for homelessness over a three-year period. Within that subset, 81% of the highest users had a diagnosed SMI.⁵⁶

As with the intersystem studies in Florida, New Jersey and San Francisco, described above, the Philadelphia analysis provides evidence that data illuminating super utilization and SMI in the homeless population can be developed and provides a model for other communities. However, as with the role of SMI in high utilization of criminal justice services, until such data begin to be systematically collected, the role and cost of SMI in the frequent use of homelessness services is likely to remain uncharted. Without such evidence, policymakers will continue to make relevant decisions without the benefit of data-based evidence.

Healthcare Findings

Healthcare is the single largest direct cost of SMI, and data on its use are by far the most thoroughly documented, widely studied and readily available of the public services provided to individuals with SMI. Federal tracking of hospital admissions and discharges, Medicare and Medicaid reimbursement records by diagnosis, and similar statistical metrics generate a large and robust body of data regarding healthcare utilization patterns and costs, including high utilization patterns by individuals with and without SMI. The abundance of raw data and research was evident from the KSU and ORPA reviews, from which the majority of the research identified involved healthcare utilization.

Through its systematic review, KSU found:

Diagnoses most often reported in high utilizers were schizophrenia, bipolar disorder and psychosis.^{57,58} In these high utilizers, having schizophrenia or psychosis increased the odds of having a repeat visit by 74%, whereas having bipolar disorder increased odds of having a repeat visit by 55%.⁵⁹ Moreover, utilizers with diagnosed schizophrenia had significantly more inpatient admissions when compared with other mental health disorders.⁶⁰ Other high utilization research shows that individuals with schizophrenia had three times greater odds of being categorized as a high utilizer, compared with individuals with depression....⁶¹

However, in the comparison of costs, healthcare expenditure for high utilizers diagnosed with a mental health condition is often double, and sometimes triple, the expense of healthcare for high utilizers not diagnosed with a mental health condition.^{62,63}

ORPA's review of government databases and other gray literature found a similar wealth of national data revealing the disproportionate share of inpatient and outpatient expenditures associated with SMI, including:

- ◆ **Hospitalization:** The national bill for schizophrenia and mood disorder hospitalization was \$27.7 billion in 2014—\$85.46 for every man, woman and child in the United States, making the conditions two of the top 10 causes for Medicaid hospitalization reimbursement.— HCUP (2014)⁶⁴
- ◆ **Rehospitalization:** Of individuals with schizophrenia, 22.7% were readmitted to a hospital within 30 days of discharge in 2013, at a cost of \$771 million in hospital billings. – HCUP (2013)⁶⁵
- ◆ **ED visits:** There were 10.8 million visits with schizophrenia or mood disorder as the primary or secondary diagnosis in 2014—7.9% of all ED visits. – HCUP (2014)⁶⁶

But, as with the criminal justice data on jail bookings, while these statistics illustrate the prevalence of SMI in aggregate healthcare utilization, they do not provide the patient-level data to understand the healthcare usage patterns and thus illuminate better practices.

The most detailed individual-level data for decision-making purposes come not from state or federal agencies but from local sources such as cities, counties or limited geographic regions:

- ◆ From New York City: 30% of all patients who made five or more ED visits in the three consecutive years from 2007 to 2010 had schizophrenia or bipolar disorder.⁶⁷

- ◆ From Denver: 40.7% of high users of services at Denver Health Medical Center in 2011 had been diagnosed with an SMI; their healthcare costs averaged \$87,236 per person.⁶⁸
- ◆ From San Francisco: The 511 patients who comprised the top 1% of service users consumed 25% of the jurisdiction's \$2 billion healthcare budget; they averaged 89 services per year each at a cost of \$97,443 per person in 2011.⁶⁹
- ◆ From southern New Jersey: 100% of the 800 patients who visited all five health systems involved in the South Jersey Behavioral Health Innovation Collaborative had at least one mental health diagnosis in 2014.⁷⁰

"Super-utilizers of health care are among the 5 percent of patients that account for more than half of US health care spending."

—Bara Vaida, "For Super-Utilizers, Integrated Care Offers a New Path"
Health Affairs, March 2017

Data like these demonstrate that the magnitude and cost of SMI in healthcare super utilization can be quantified, provided that relevant data are being collected within and between systems. The findings also illustrate the potential for informing public policy. The analysis of super utilization by the Florida Department of Children and Families and the University of South Florida found with SMI in Medicaid reduced re-incarceration rates by 13% for jail inmates and by 41% for prison inmates.⁷¹

This finding provides evidence of a strategy policymakers could consider as a means of reducing incarceration rates.

LIMITATIONS

Although hundreds of studies were considered, the limited body of literature on the role of SMI in super utilization is the chief limitation of *A Crisis in Search of Data*. Additionally, the methodological characteristics of the literature preclude comparison and analysis of the data that do exist, especially when the services are not part of the healthcare system.

Chief among these characteristics is the absence of commonly accepted definitions of core terminology. No fewer than a dozen different definitions of "high" or "super" utilization were encountered in the reviews, including:

- ◆ "Used inpatient emergency psychiatric services three or more times in a fiscal year"⁷²
- ◆ "Two or more hospitalizations in the 18 months before the index hospitalization"⁷³
- ◆ "Persons who have frequent and preventable hospital admissions and/or emergency visits with multiple chronic conditions and behavioral health comorbidities"⁷⁴—without a definition of "frequent" or "multiple"
- ◆ "Persons with three or more hospitalizations in a 12-month period or [who] had both a serious mental health diagnosis and two or more hospitalizations within 12 months"⁷⁵
- ◆ "Persons who accumulate large numbers of emergency visits and hospital admissions, which could have been prevented by relatively inexpensive early interventions and primary care"⁷⁶—without definitions of "large numbers," what defines a preventable condition or what rates as "inexpensive."

Appendix A contains a more complete list that primarily further illustrates how inchoate the field of super utilization, by any name, is today.

The terms “serious mental illness” and “severe mental illness” produce nearly a million Google hits combined, but there is no universally recognized definition of the terms. The lack of a standard term limits analysis of SMI in high utilization because different definitions produce different numbers, populations and population characteristics, which are not necessarily combinable or comparable.

Serious mental illness also is used without a common definition. The federal government has its own definition, and the criminal justice systems of the 50 states and District of Columbia each have theirs. Some mirror each other, but many do not. Academic researchers may embrace one or more of these or develop their own. Some definitions include substance abuse in their definitions of SMI; most do not. When the Treatment Advocacy Center uses the term “serious mental illness” or “severe mental illness,” we are referring to diagnoses of schizophrenia or severe bipolar disorder. This is a narrower definition than the ones often used in government, but it is the population with these disorders,

primarily when untreated, that is overrepresented in the criminal justice system and social safety nets, and most likely to be subject to court-ordered treatment. Using a broader definition would misrepresent the at-risk population.

DISCUSSION

The collective failure to establish reliable, comparable data collection surrounding the role and impact of SMI in the revolving door of super utilization by individuals with SMI has vast implications.

The budgets of all the public systems involved with SMI are housed in independent fiscal silos. Each system is highly protective of its own silo, and policymakers make system decisions one system at a time, as if all the various repositories of public service and cost were unrelated. Yet, as this literature review found, the silos *are* connected. The acute and chronic health conditions commonly affecting individuals who receive homelessness services propel the same people into the emergency medical system for routine and crisis healthcare. The Virginia sheriff who asked that his own budget be cut so the mental health budget could be increased is the rare case of a public official who understood the *intersystem* impact of SMI because he saw that less investment in treatment was producing more inmates in his jail.⁷⁹

Without a complete picture of the interplay of these various systems, policymakers cannot access the information they need to analyze the role of SMI in high utilization of different systems. This lack of information limits their ability to make evidence-based tradeoffs, including cost-benefit decisions. Moreover, incomplete data may even lead to false conclusions or counterproductive policies. For example, decision makers routinely eliminate public psychiatric beds or increase community services without information on the relation of bed supplies to the demand for and cost of law enforcement, courts, corrections, emergency medical care and other services with which individuals with SMI often engage when they do not receive timely treatment. If individuals trapped in the revolving door account for most of these impacts, knowing the characteristics associated with their super utilization and the patterns and needs of this population is critical to formulating effective policies to reduce the phenomenon.

Issues such as these are being identified more frequently, and initiatives to address them are taking root. The Data-Driven Justice Initiative is working specifically to foster data-sharing and technological strategies that will divert high utilizers from the criminal justice system, including individuals with SMI. Among the initiative's early bright spots is broad engagement by communities, academic institutions and for-profit data companies.

Academic research also is beginning to address the void. A groundbreaking study has shown the costs and the impact on jail populations when psychiatric bed numbers are reduced.⁷⁷ Data-based cost analyses such as a recent study of the system savings from using a more effective medication for schizophrenia in Veterans Health Administration hospitals⁷⁸ illustrates that policies, practices and outcomes can be assessed for their combined benefits and costs, provided adequate data are available.

But even as this work progresses, public policies and practices are being established across the United States every single day based on incomplete or irrelevant evidence or headline stories that may or may not reflect underlying human and economic realities. Individuals with severe psychiatric symptoms continue cycling through public systems without personal benefit. Billions of dollars continue being spent to break the larger cycle of super utilization combined with a paltry understanding of how and why SMI impacts the phenomenon and what practices would reduce those impacts.

RECOMMENDATIONS

To narrow the gap *A Crisis in Search of Data* has found between knowledge and the practices that hold hope for reducing the role and cost of SMI in high service utilization, the Treatment Advocacy Center recommends the following steps:

- ◆ **Researchers and government agencies must collaborate to develop a baseline definition of SMI applicable in state and federal government data collection and academic study of super utilization.**

Standardized definitions are the cornerstone of comparable data and analysis. They do not exist for serious mental illness, "high" or "super" utilization and other terms central to the study of SMI in super utilization of public services. Definitions must be standardized sufficiently to compare or combine data and studies originating from different sources and different locations in order to identify broader trends, patterns and other factors.

- ◆ **Federal, state and local governments must incorporate SMI as a data point in all government collection of super-utilizer statistics.**

The impact and cost of frequent utilizers with SMI on affected systems has been systematically tracked only in medical care. Incorporating SMI as a component of data collection involving super utilization will produce a body of statistics that would better inform policymakers about the magnitude, heterogeneity, regional factors and other characteristics of SMI in the super-utilizer population and make it possible to analyze the net costs and benefits of competing policy choices in different systems.

◆ **Researchers and government agencies must standardize methodologies for recognizing and reporting the economic costs of SMI in super utilization.**

Most of the cost data on SMI in high utilization are collected so locally or narrowly that they cannot be combined, compared, or scaled up and generalized to larger geographic areas or populations. Meanwhile, much of what circulates outside the academic community is anecdotal, informal or not suitable for statistical analysis. Although the needs, technology and capabilities of different public systems inevitably will vary, common methods of collecting and reporting cost information are needed.

◆ **Government must fund an open-source forum or clearinghouse where those organizations that are systematically collecting super-utilizer data can share and find related projects and statistics, including data on the role and cost of SMI.**

Data exchange among those local jurisdictions, universities and agencies that are systemically collecting useful data about SMI in super utilization appears relatively limited. Not infrequently, the authors of *A Crisis in Search of Data* found researchers in one region unaware of related research underway elsewhere, even within the same state. Increased visibility of and open access to local and independent data and findings will enable organizations isolated from one another to benefit from the experiences and findings of other groups working toward similar goals for the benefit of the same population.

A CASE IN POINT: FLORIDA

Source: *Reports to the Florida Department of Children and Families in Response to the Governor’s Executive Order 15-175 (2016)*⁸⁰

Jurisdictions: Alachua, Broward and Pinellas counties, Florida

Time period: January 1, 2010–December 31, 2014

Target population: Residents who lived in one of the three counties and received any publicly funded behavioral health services in the time period. Included were adults who had been

- ◆ Admitted to state psychiatric facilities (civil or forensic) or to community hospitals for mental health symptoms
- ◆ Diverted from criminal justice by a mental health court
- ◆ Incarcerated

Systems included

State hospital	X
Hospital	X
Outpatient mental health	X
Emergency department	X
Jail*	X
Prison	X
Emergency medical services	
Other medical services	X
Homelessness	
Cost	X

*Broward Country did not report criminal justice data

Findings

Super utilization by individuals with SMI was found in the following areas:

◆ Criminal justice involvement

More than one in four individuals in the sample with SMI (27.2%) were arrested at least once during the study period.

◆ Co-occurring substance abuse

Co-occurring substance abuse nearly doubled the risk of being in one of the high service utilization groups. More than half (59.1%) of the mental health clients hospitalized or incarcerated during the four-year period had co-occurring substance disorders. Among hospital patients and corrections inmates from the target population, three out of four (75.3%) had a co-occurring substance issue.

◆ Rehospitalization

Among the civilly committed patients, 48.4% admitted once to state hospitals were admitted to community hospitals within six months of discharge. Among all state hospital patients (civil and forensic), 26.3% were readmitted to state hospitals within one year. Even more, 37%, were detained for emergency psychiatric evaluation in the community within six months of hospital discharge. A diagnosis of schizophrenia increased the risk of rehospitalization.

◆ Re-incarceration

Among county jail detainees, 64.9% were re-incarcerated in county jails during the four-year study period; 45.6% returned to jail within the first year of release, and 27% returned to prison. Schizophrenia increased the risk of re-incarceration in jail by 16% and in prison by 19%.

◆ Racial disparities

African-American clients were more than three times as likely as whites with the same disorders to be admitted to a state hospital. They also were arrested and incarcerated at significantly higher rates.

Homelessness service utilization was not included, and complete cost data for the services provided to clients were not available, resulting in a cost analysis that did not include—and thus understated—how much it costs to serve the super-utilizer population.

Even though not all service costs were captured, a small group of individuals with SMI was found to cost more than seven times as much per person as other mental health clients:

- ◆ \$5,650—average annual cost per person for all clients in the sample
- ◆ \$39,640—average annual cost per person for high utilizers

Nursing home residents were not included in the study's definition of high utilizers. However, because more than 10% of the people in the sample experienced extended stays in nursing homes during the study period (averaging 512 days), the cost to Medicaid for nursing home care was \$1.3 billion over five years, suggesting that nursing home users may represent a distinct high-utilizer category.

Origins

In 2016, the Florida Department of Children and Families and the Louis de la Parte Florida Mental Health Institute at the University of South Florida published an analysis of local, state and federally funded mental health service delivery and costs in three Florida counties.⁸¹ Alachua, Broward and Pinellas counties are home to a combined 3 million people and 120,000 clients of public mental health services in 2014. They include the cities of Ft. Lauderdale in Broward County and St. Petersburg in Pinellas County.

The goal of the project, ordered in September 2015 by Florida Governor Rick Scott, was to streamline state budgeting and track behavioral healthcare spending across multiple systems. A sample of 120,134 public mental health clients with SMI* in three counties was analyzed for the report, and case studies of 31 adult high utilizers within the sample were conducted.

Broward County did not report criminal justice statistics, depriving the analysis of data from the most populated and urban of the three counties.

* Adults were considered to have SMI if they met one of four criteria: one state hospitalization, two emergency detentions for dangerousness to self or others, one nonstate hospitalization with a specified SMI diagnosis or two outpatient events associated with a specified SMI diagnosis.

A CASE IN POINT: NEW JERSEY

Source: Reports from Rutgers University Center for State Health Policy and the Camden Coalition of Healthcare Providers^{82,83,84}

Jurisdiction: 13 low-income regions in New Jersey*

Time period: 2008–2011

Target population: High utilizers, defined as those with

- ◆ Four or more inpatient stays within the four-year period
- ◆ Six or more visits to an ED over a two-year period

Findings

The Rutgers University analyses reported high rates of utilization by individuals with SMI in the following areas:

◆ Emergency medical care

Patients with SMI made up 13.9% of ED high utilizers at a cost of more than \$12.5 million in 2011 dollars. Patients with SMI made up 18% of ED high utilizers insured by Medicaid. Individuals with SMI who were not high utilizers accounted for only 2.1% of all ED visits in the time period, roughly their proportion in the general population.

◆ Hospitalization

Patients with SMI represented 26% of all high users of inpatient care, at a combined cost to the systems of \$228.8 million. Within that population, 44% were insured by Medicaid; their hospitalizations resulted in \$45.32 million in billings.

The Camden Coalition of Healthcare Providers found that more than one-third of the top 1% of Medicaid spenders in New Jersey had SMI. This prevalence increased to 38.5% in persistently high-spending groups (i.e., those in the top 1% for three consecutive years). Within this population, high rates of utilization were found in the following areas:

◆ Criminal justice involvement

Dual-sector high utilizers, defined as those with seven or more police encounters and more than 15 ED visits during the study period, totaled 226 people.

◆ Homelessness

Of individuals who were high users of both the healthcare and criminal justice systems, 42% were homeless.

◆ Co-occurring substance abuse

Of individuals with high dual-system utilization who underwent psychiatric hospitalization, 85% had a co-occurring substance abuse diagnosis.

Systems included

State hospital	
Hospital	X
Outpatient mental health	
Emergency department	X
Jail	
Prison	
Emergency medical services	X
Other medical services	
Homelessness	
Cost	X

* Camden, Greater Newark, Trenton, Asbury Park–Neptune, Atlantic City–Pleasantville, Elizabeth–Linden, Jersey City–Bayonne, New Brunswick–Franklin, Paterson–Passaic–Clifton, Perth Amboy–Hopelawn, Plainfield, Union City and Vineland–Millville.

◆ Comorbid physical conditions

Super utilizers in all five hospital systems of southern New Jersey had an average of seven chronic conditions; the highest user in the subpopulation (“Jane”) had 23.

The cost of treating the 800 super utilizers who visited all five of the participating health systems more than doubled from 2010 to 2014. Median hospital charges for this highest-using subset increased from \$53,633 in 2010 to \$123,518 in 2014. The average billing was \$378,732 per person over the five-year period, but the average payment received by the health system per patient was \$45,849.

Origins

Independent but sometimes cooperative efforts have been underway from three sources to quantify and analyze super utilization in New Jersey. In January 2016, Governor Chris Christie issued a call to action to improve healthcare delivery for Medicaid super utilizers. In response, the Rutgers University Center for State Health Policy analyzed Medicaid claims data from 2008 to 2011 in order to identify super utilizers, defined as the top 1% of users in the healthcare system.⁸⁵ Rutgers already had been analyzing healthcare utilization patterns to identify the role of mental illness and substance use in hospital utilization rates and costs.

In addition to the Rutgers studies, a group of hospital systems, providers and community members called the Camden Coalition of Healthcare Providers was formed by Jeffrey Brenner, MD, a primary care physician from Camden who conceived the idea of creating a healthcare delivery model to meet the medical and social service needs of the most vulnerable residents of impoverished communities such as Camden. In 2016, the coalition was awarded \$8.7 million to create a national center to improve care to super utilizers. It partnered with law enforcement and other agencies to create a data-driven hot-spotting process to identify intersystem high users of both the healthcare and criminal justice systems. In addition, the South Jersey Behavioral Health Innovation Collaborative was created in 2014 to incorporate coordination of treatment for SMI. For the SJBHIC needs assessment, more than 1 million Medicaid patients, who made more than 3.6 million visits to five health systems, were analyzed.⁸⁶

Despite all of these interagency efforts, the role of SMI in super utilization of services and the resulting high costs were explored only in the Rutgers study of 13 low-income regions.⁸⁷ This original dataset included 2,527 hospitalizations at a cost to the systems of \$880 million, 25% of all inpatient behavioral health costs for the state. The total number of ED visits by the population was not reported.

A CASE IN POINT: SAN FRANCISCO

Source: Reports from the San Francisco Department of Public Health (SFPDH)^{88,89}

Jurisdiction: City / County of San Francisco

Time period: Fiscal years 2010–2011 and 2012–2013

Target population: Adults who were patients in at least one of the following systems and who utilized one:

- ◆ **Medical:** Emergency medical service transports, ED visits, 24-hour inpatient services, medical respite centers, urgent care clinics at the Tom Waddell Urban Health Clinic and general hospitals
- ◆ **Psychiatric:** Psychiatric emergency services (PES), Dore Urgent Care Clinic (PES for homeless), 24-hour psychiatric inpatient hospitals, 24-hour adult diversion units, Westside Crisis Clinic mobile crisis units
- ◆ **Substance abuse:** The Sobering Center, 24-hour residential medical detox centers, 24-hour residential social detox centers

Systems included

State hospital	
Hospital	X
Outpatient mental health	X
Emergency Department	X
Jail*	X
Prison	
Emergency medical services	X
Other medical services	
Homelessness	X
Cost	X

*Health service provided in jail

Findings

A total of 511 patients made up the top 1% of high users across all three systems. These patients used an average of 89 services each in the three sectors during the study year at an average cost per patient of \$97,443 and a total cost to the jurisdiction of \$49.8 million, or 25% of the \$2 billion budgeted for the three sectors.

High rates of utilization by individuals with SMI were found for the following areas:

◆ Criminal justice involvement

HUMS patients with SMI were more than twice as likely to have a history of jail health records during the study period than high users of the medical system alone.

◆ Emergency medical care

Patients with schizophrenia made up 46% of the city's nearly 16,000 residents with SMI but accounted for 67.2% of the city's total outpatient hospital costs.

◆ Homelessness

The top 10 HUMS patients all had a history of homelessness, and 86.2% of all HUMS patients with schizophrenia had a history of homelessness.

Complete cost data for all the services provided to clients were not available. As a result, cost projections understated how much it costs to serve the super-utilizer population.

Origins

In 2007, SFPDH launched an effort to identify high users of multiple systems—HUMS, in the city's parlance. Three service sectors were identified—medical, mental health and substance abuse. Individuals who were users of urgent-care services in any one of the three sectors were identified.

The original dataset identified 51,796 service recipients in fiscal year 2010–2011. Ten percent of the population was sampled for HUMS patterns. SFDPH then stratified the users into the top 1%, top 2% to 5%, all others above the median or below the median. This approach enabled the city to track service utilization patterns across the three silos and identify individuals who might not be among the highest utilizers in a single system but whose combined use of urgent-care services in multiple systems rendered them high multisystem users.

To break down real or perceived barriers to data sharing between systems, memorandums of understanding were negotiated between relevant departments. Thus, for example, when paramedics respond to a medical emergency in San Francisco today, they immediately have access to the medical, mental health and substance abuse histories of the patient.

Although jail health records were included in the patient profiles, the criminal justice system data (e.g., (reason for and outcome of incarceration) were not incorporated in the HUMS datasets. High utilization of law enforcement and of corrections resources have separately been examined by the San Francisco Civil Grand Jury, which conducted an investigation of the Sheriff’s Department that resulted in a report titled *San Francisco County Jails: Our Largest Mental Health Facility Needs Attention*.⁹⁰ The study was released about a month after the San Francisco Budget and Legislative Analyst’s Office released a report on the rise of incarceration of the mentally ill and its costs.⁹¹

APPENDIX A

Glossary of Terms

TERM	DEFINITION(S)
Chronically homeless individual	An individual with a disability who has been continuously homeless for one year or more, or has experienced at least four episodes of homelessness in the last three years in which the combined length of time homeless was at least 12 months ⁹²
Frequent flyers	Slang term often used by law enforcement and emergency room personnel for individuals repeatedly arrested or seen in emergency rooms ⁹³
Frequent users	Individuals who had visited the psychiatric emergency room two or more times in the 12-month observation period ⁹⁴
High utilizer	<p>A person who used inpatient emergency psychiatric services three or more times in a fiscal year⁹⁵</p> <p>A person who received treatment from the Los Angeles County Department of Mental Health for at least three years between 1988 and 1993, and who had an average annual treatment cost of \$30,000 or greater⁹⁶</p> <p>A person with two or more hospitalizations in the 18 months before the index hospitalization⁹⁷</p> <p>A person with two standard deviations above the mean annual number of urban psychiatric emergency service visits, or six psychiatric emergency service visits per year or four psychiatric emergency service visits per quarter⁹⁸</p> <p>A person with four or more inpatient stays, or six or more emergency room visits, within a four-year period⁹⁹</p> <p>Creating a “super-utilizer map,” a color-coded map of resident hospital utilization and costs, to identify geographical regions of high utilization¹⁰⁰</p>
Hot spotting or hot spotter	<p>“Hot spotting is segmentation. It’s taking big data sets [and] segmenting them into a strategy so that you can target different pockets of need. Hotspotting is making sure that people who are in need get their needs met, in a rigorous, data-driven way.”¹⁰¹</p> <p>Locating patients who live in specific geographic areas—on the scale of city blocks and buildings—with particularly high healthcare spending per capita¹⁰²</p>

APPENDIX A (continued)

Glossary of Terms (continued)

TERM	DEFINITION(S)
Mental health high-cost patient	Someone for whom mental health–related services accounted for at least 50% of total healthcare costs ¹⁰³
Rapid readmission	Unplanned readmission of psychiatric patients within 30 days of discharge from the index admission ¹⁰⁴
Rehospitalization	Being hospitalized for mental health more than one time ¹⁰⁵
Repeat users	<p>Occasional: those with two to four visits in 24 months; frequent: those with five or more visits in 24 months, or at least one post-index admission¹⁰⁶</p> <p>Persons who have frequent and preventable hospital admissions and/or emergency visits with multiple chronic conditions and behavioral health comorbidities¹⁰⁷</p>
Super utilizers	<p>Individuals whose complex physical, behavioral and social needs are not well met through the current fragmented healthcare system and as a result typically bounce between emergency departments, inpatient admissions/readmissions and institutionalizations¹⁰⁸</p> <p>Persons with three or more hospitalizations in a 12-month period, or with both a serious mental health diagnosis and two or more hospitalizations within 12 months¹⁰⁹</p> <p>People with three or more chronic conditions and two or more hospitalizations in six months, or three or more emergency visits in six months, or two or more emergency visits in 30 days¹¹⁰</p> <p>People with three or more hospitalizations, or with two or more hospitalizations and two or more emergency visits within a six-month period¹¹¹</p> <p>Persons who accumulate large numbers of emergency visits and hospital admissions, which could have been prevented by relatively inexpensive early interventions and primary care¹¹²</p> <p>Individuals who are often chronically homeless individuals with mental illness, substance abuse and health problems, who repeatedly cycle through multiple systems, including jails, hospital emergency rooms, shelters and other services¹¹³</p>

APPENDIX B

Kent State University Systematic Literature Review Methodology

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) method was used to guide this review. PRISMA is an evidence-based methodology useful for reporting information obtained from different types of research and is especially useful for evaluating interventions and programs.¹¹⁴ All procedures, including the literature search, literature selection and data extraction were conducted independently by two authors. Discrepancies were identified and discussed among all authors until a consensus was reached.

Search Methods

Twenty-one databases, including Academic Search Complete, Cochrane Database of Systematic Reviews, Criminal Justice Periodicals Index, MEDLINE/PubMed, PsycINFO, Social Sciences Citation Index, SocINDEX, CINAHL, and ERIC were searched using the following terms:

- ◆ *Mental illness and high utilizers*
- ◆ *Severe mental illness and high utilizers, homelessness costs, law enforcement costs, correction costs, cost, utilize*, high utilize*, cost reduction, homelessness, corrections, law enforcement*
- ◆ *Serious mental illness and high utilizers, homelessness costs, law enforcement costs, correction costs, utilize*, high utilize*, cost reduction, homelessness, corrections, law enforcement*
- ◆ *Schizophrenia and high utilizers*
- ◆ *Bipolar and high utilizers*
- ◆ *Depression and high utilizers*
- ◆ *Psychotic disorder and high utilize*, cost reduction, homelessness, corrections, law enforcement*
- ◆ *Psychosis and high utilize*, cost reduction, homelessness, corrections, law enforcement*

Selection Criteria

Studies in this review were included if they 1) were published in 2005 or later 2) focused on high utilizers 3) were available in English and 4) included severe mental illness defined as bipolar disorder, schizophrenia and/or psychosis.

APPENDIX B (continued)

Selection of Studies

All abstracts and titles were reviewed in relation to the inclusion criteria and categorized into three categories: meets criteria (include), may meet criteria, and does not meet criteria (exclude). For sources categorized as “may meet criteria,” researchers examined the full article and reached consensus on whether to include or exclude the source. Two authors independently searched the databases and compiled a list of studies. Discrepancies between the two lists were discussed among all authors until a consensus was reached. A quality index adapted from that of the National Institutes of Health was used to assess the methodological rigor of each study.¹¹⁵

Data Extraction

The researchers used Dedoose (an online application) to extract information from all included studies and to guide the analysis of qualitative and quantitative information through data management, descriptors and coding. Data extracted included demographic information, sample size, time frame, type of intervention (if applicable), mental illnesses addressed, costs, results, definition of high utilization and policy recommendations. Discrepancies were discussed among all authors until a consensus was reached.

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