

# A Crisis in Search of Data



## The Revolving Door of Serious Mental Illness in Super Utilization

**Executive Summary**

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**April 2017**



A REPORT FROM THE  
**OFFICE OF RESEARCH  
& PUBLIC AFFAIRS**

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# **A Crisis in Search of Data**

## **THE REVOLVING DOOR OF SERIOUS MENTAL ILLNESS IN SUPER UTILIZATION**

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With a comprehensive literature review conducted by

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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,<sup>1</sup> to colorless data points like the fact that 1% of the US population incurs almost 25% of the nation’s healthcare expenses,<sup>2</sup> 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.<sup>3</sup> 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.

## REFERENCES

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The Treatment Advocacy Center is a national nonprofit organization dedicated exclusively to eliminating barriers to the timely and effective treatment of severe mental illness. The organization promotes laws, policies and practices for the delivery of psychiatric care and supports the development of innovative treatments for and research into the causes of severe and persistent psychiatric illnesses, such as schizophrenia and bipolar disorder.