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The state of research funding from the National Institutes of Health for criminal justice health research

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## **Abstract**

*Background:* Over 20 million Americans are currently incarcerated or have been in the past. Most are from medically underserved populations; one in three African American men and one in six Latino men born in 2001 are projected to go to prison during their lifetimes. The amount of funding from the National Institutes of Health (NIH) to understand and improve the health of criminal justice-involved persons is unknown.

*Objective:* Describe NIH funding for research addressing the health and healthcare needs of criminal justice-involved individuals.

*Design:* Review of NIH grants (from 2008 through 2012) in the RePORT (Research Portfolio Online Reporting Tools) database.

*Setting:* The NIH RePORT database.

*Patients:* Criminal justice involved individuals participating in NIH-funded clinical research.

*Measurements:* NIH research and training grants awarded by number, type, research area, institute or center, and dollar amount.

*Results:* Of more than 250,000 NIH funded grants, 180 (less than 0.1%) focused on criminal justice health research. The three most common foci of criminal justice health research grants were substance use and/or HIV (64%), mental health (11%), and juvenile health (8%). Two institutes, the National Institute on Drug Abuse and the National Institute of Mental Health, funded 78% of all grants. In 2012, the NIH invested \$40.9 million in criminal justice health research, or 1.5% of the \$2.7 billion health disparities budget for that year.

*Limitations:* NIH-supported research that did not explicitly include current or former prisoners but may have relevance to criminal justice health was not included.

*Conclusions:* Federal funding for research focused on understanding and improving the health of criminal justice-involved persons is small, even when compared to the NIH's overall investment in health disparities research. The NIH is well-positioned to transform the care of current and former prisoners by investing in this critical yet overlooked research area.

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## **Introduction**

Over the past 40 years, the U.S. has experienced a historically unprecedented and globally unequalled epidemic of incarceration (1). More than 20 million Americans, or 9% of the U.S. adult population, are currently incarcerated or have been in the past (2). Over 1.5 million Americans are currently serving sentences in prisons (2), 12 million cycle in and out of jails (3) each year to await trial or serve short sentences, approximately 6 million community-dwelling adults have served time in a prison (4), and more than 70,000 children are in the custody of juvenile residential placement facilities (5). On average, prisoners are poor, African-American or Latino, and from low-income urban neighborhoods where health disparities are common and access to healthcare is limited (6-8). One in three African-American males and one in six Latino males born in 2001 are projected to spend time in prison during their lifetimes (4). While criminal justice health systems serve as a cornerstone of healthcare for millions of medically underserved Americans, the body of research describing the health and healthcare needs of current and former prisoners is limited (9,10).

Prisoners have a constitutionally guaranteed right to community standard healthcare as provided for in the 1976 Supreme Court case, *Estelle v. Gamble* (11,12). The knowledge gap about how to best meet their healthcare needs is increasingly relevant as growing numbers of policymakers place correctional institutions among the most important settings of care to address health disparities (10,13-17). As a recent example, the Affordable Care Act has specifically prioritized extending medical insurance enrollment to persons being released from jails and prisons to improve their access to affordable community-based healthcare (18). Prisoners have substantially higher burdens of chronic medical conditions and infectious disease than the general population (19,20) and are at increased risk for hospital and emergency department utilization once they are released (21,22). Over 95% of prisoners will eventually be released

(23), most of them returning to communities where health disparities are common (6-8). Improved medical and mental health treatment in prisons and jails, investment in patient education for prisoners, and better linkages to community care following release from incarceration could yield considerable public health benefits (24,25). However, access to care for many prisoners remains inadequate (26,27), addiction treatment services in prisons and jails and during transition to the community are often outdated or insufficient (28), and mental healthcare services are overwhelmed by disproportionate rates of mental illness among incarcerated populations (29,30). Despite these and other challenges, most correctional facilities lack the quality measures and data collection infrastructure needed to independently develop evidence-based systems of care (31-33).

The relative lack of criminal justice health research and limited capacity for systematic health data collection in jails and prisons have led to inadequate knowledge about how to improve the quality or cost of criminal justice healthcare and best address the health of criminal justice-involved persons. As a result, the National Commission on Correctional Health Care (NCCHC), an organization created by the American Medical Association to evaluate the state of correctional health, has called for coordinated criminal justice health research (34,35). This call to action builds on a 2006 Institute of Medicine and National Academies of Science report that outlines standards for the ethical conduct of criminal justice health research that account for the unique vulnerabilities of prisoners without unduly restricting research that would benefit them (36-38). The report provides a framework that can be used to meet these research standards by defining the prisoner population, describing consistent standards of protection for prisoner participants, establishing the risk-benefit approach to research design, and specifying the standards institutional review boards should follow when evaluating such research (36).

Calls for expanded criminal justice health research also coincide with a major push by the National Institutes of Health (NIH) to increase research in health disparities. In its most recent *Health Disparities Strategic Research Plan*, The NIH, dedicated an unprecedented \$2.7 billion annually for 5 years across 28 NIH centers and institutes to reduce health disparities (39). In order to examine the extent to which this funding is reaching criminal justice-involved individuals, this study examines NIH research funding of criminal justice health and healthcare research from 2008 through 2012 to explore the extent to which the NIH has seized the opportunity to improve the health of millions of Americans who have contact with the criminal justice system each year.

## **Methods**

### *NIH funding of criminal justice health research*

We defined criminal justice health research as any study that explicitly addresses the health or healthcare of persons detained in jail, prison, or juvenile residential placement facilities, on probation or parole, or transitioning from the criminal justice healthcare system to the community. To investigate NIH funding of criminal justice health research, we analyzed all NIH-funded research awards from 2008 through 2012 using NIH RePORT (Research Portfolio Online Reporting Tools). NIH RePORT is a publically-accessible database that includes abstracts for all NIH grants awarded after 1990.

To identify all criminal justice health grants, we queried the NIH RePORT database for grants funded in the years 2008-2012 using, first, the search terms “Prison(s)” or “Jail(s)” or “Prisoner(s)” or “Inmate(s)” or “Correctional” or “Detention” or “Detain(ed)” or “Crime” or “Arrest” or “Criminal” or “Criminal Justice” and “United States” and, second, the names of criminal justice health researchers. Our list of criminal justice health researchers included the

first and last authors of all articles returned from a PubMed search using the above search terms (excluding editorial letters and articles referring to non-U.S. populations or healthcare systems) published in 2011 and 2012 and all those who presented research at the Academic and Health Policy Conference on Correctional Health in those same years. We then compared the list of grants generated by our search terms to the list of grants generated by our search of criminal justice health researchers and eliminated all redundancies. Similar methods have been used by researchers in other fields (40,41). For each unique grant, we recorded the grant number, the type of grant (pilot, R01, other research, junior training, or other training), the NIH institute or center awarding the grant, the grant title, the dollar amount awarded in each of the years 2008 - 2012, and the abstract describing the grant. All grants with NIH codes used for research or training grants were included (42). Relevance to criminal justice health as defined above was determined independently by two authors. A third author was used to resolve disagreements by consensus.

### *Analysis*

Descriptive statistics were used to analyze the number of grants funded by each NIH institute or center, the number of each type of grant, the funding amounts allotted to each grant by year, and the number of grants by primary research area. To determine the primary research area research for each funded grant, abstracts for all NIH grants included in these analyses were read and analyzed independently by two authors. A third author resolved disagreements by consensus.

One of the authors is supported by grant K23 AG033102 from the National Institute on Aging at the National Institutes of Health and by Tideswell at UCSF. These funding sources had no role in the design, conduct, or analysis of the study or in the decision to submit the manuscript for publication.

### **Results**

### *Criminal justice health grants funded by the NIH, 2008-2012*

Our keyword and criminal justice health researcher queries of the NIH RePORT database returned 333 unique criminal justice health grants out of more than 250,000 active NIH grants in the years 2008 through 2012. Of these, 27 were excluded because they did not fund research. For example, grants funding the development and publication of textbooks were not included in these analyses even if the textbook included criminal justice health content. An additional 126 grants were excluded because they did not directly address criminal justice health (Table 1). For example, 57 grants (45%) were excluded whose abstracts described criminal justice involvement as a common experience in the study population but did not explicitly include it in their analyses. An additional 49 grants (39%) funded healthcare delivery research or interventions that did not include criminal justice populations or settings but cited potential criminal justice health applications (Table 1). This resulted in a total of 180 research grants for our final analyses.

### *NIH funded criminal justice health research by primary research area*

Of 180 funded research grants, 28% focused on substance use as the primary research area, 22% on HIV, 7% on HIV and substance use equally, 11% on mental health, 8% on juvenile behavioral health risks, and 24% on other areas (Table 2). Overall, 64% of grants described substance use and/or HIV as their primary area of focus while 4% of grants were for healthcare delivery research in correctional or transitional settings of care. Other primary research areas included tuberculosis (1 grant), liver disease (1), and cardiovascular health (2) (Table 2).

### *NIH-funded criminal justice health research by institute or center*

Two institutes funded 78% of all criminal justice health grants; the National Institute on Drug Abuse (NIDA) funded 107 grants (59%) and the National Institute of Mental Health (NIMH) funded 34 grants (19%) (Table 3). Eleven other institutes and centers also funded at least one



criminal justice health grant. Of 180 grants, 70 (39%) were for R01s, 40 (22%) were for investigator-initiated pilot studies, 36 (20%) were for training grants, and the remaining 34 (19%) were for other types of research grants. Among training grants, nearly all (89%) were junior level awards (Table 3). A total of 135 investigators were awarded a criminal justice health grant during the years included in this study: 102 investigators received one grant, 26 received two grants, and seven researchers received between three and five grants.

#### *NIH expenditure on criminal justice health research*

Total funding for all 180 criminal justice health grants from 2008 through 2012 amounted to \$215.1 million. In the year 2012, the NIH invested \$40.91 million in criminal justice health research, amounting to 1.5% of the \$2.7 billion health disparities budget for that year and 0.1% of the NIH's approximately \$30 billion annual budget for medical research. Of the \$40.91 million allocated to criminal justice health research, 72% was granted by NIDA and 79% was spent on grants for which substance abuse and/or HIV was the primary research area.

#### **Discussion**

More than 20 million American adults (1 in 11) are or have been incarcerated in their lifetimes (2,3,5). While research about the healthcare needs of criminal justice involved individuals has been limited, the needs of the public health landscape are changing. In an attempt to reach medically disenfranchised populations, the Affordable Care Act has prioritized medical insurance enrollment for incarcerated populations (18,43). Meeting the needs of these newly insured persons who cycle through the criminal justice system will require clinical research. This study found that fewer than 0.1% of NIH grants and less than 1.5% of the NIH's health disparities research budget in recent years have been directed towards understanding the health of criminal justice involved populations. In the NIH's 5-year health disparities strategic research plan,

criminal justice health received four substantive mentions, each time in the context of substance abuse research funded through NIDA (39). This study's findings suggest that federal funding for research aimed at the health and care of criminal justice-involved Americans is very small in comparison to the number of persons affected, and that the criminal justice system is a largely untapped area for the NIH to expand its efforts to reduce health disparities through rigorous research.

While our findings suggest an opportunity for greater NIH leadership in a relatively overlooked area of research, low levels of NIH investment in criminal justice health research may also reflect a lack of investigator initiative due to concerns over conducting ethical research with prisoners. Fifty seven research grants excluded from this study cited criminal justice involvement as a common experience for their study populations but fell short of investigating the relationship between criminal justice involvement and health. A similar number of NIH-funded healthcare delivery and intervention studies described research with potential, as-yet untested applicability to criminal justice populations and systems of care. Prisoners are among only a few populations that are afforded special protections when participating in medical research. Such protections are motivated by historical abuses including medical experimentation on unknowing prisoner populations and aim to ensure that prisoners are neither exploited nor unduly coerced to participate in research. Fortunately, the Institute of Medicine and the National Academy of Sciences has published a comprehensive guide to the ethical conduct of research with prisoners in which they describe the roles and responsibilities of researchers, institutions, and institutional review boards. The report also delineates standards for ethical research design when enrolling prisoners in research, obtaining voluntary consent from prisoners, and responding to unique challenges of the prison environment (e.g. ensuring privacy, avoiding coercion, and

verifying that research participation does not affect a prisoner's access to quality healthcare) (36-38). These guidelines and safeguards are closely aligned with the goals of the NIH and those investigators whose work addresses health disparities as they are governed by the overarching philosophy that research with prisoners should have the potential to improve the health of prisoner populations. As the report itself notes, "access to research may be critical to improve the health of prisoners" (36).

Many of the 28 institutes and centers in the NIH Health Disparities Strategic Research Plan could improve their impact on health disparities by focusing on former or current prisoner patient groups. Most current and former prisoners are from medically underserved populations (2,3,5), and nearly all former prisoners return to communities where health disparities are common (6-8). The NIH grants for criminal justice health research identified in this study were disproportionately focused on HIV, substance use, and mental health (75% of grants awarded 2008-2012, 87% of 2012 spending). While these are undoubtedly critical areas of investigation, the limited research that has been conducted in other research areas shows that prisoners also experience disproportionately high rates of infectious diseases (20), chronic illnesses (19), symptoms (44), and social and behavioral risk factors (6). Important opportunities thus exist to study the extent to which improved care for criminal justice-involved persons might help reduce health disparities in these areas and in their long-term sequelae such as heart disease, multimorbidity, and accelerated aging (10,14,15).

The NIH's well-funded effort to understand and address health disparities is incomplete absent a coordinated effort to engage criminal justice health systems and prisoner populations across NIH institutes and centers. For example, former prisoners are at heightened risk for hypertension (45) (of potential interest to the National Heart, Lung, and Blood Institute); older

adults are the fastest growing and sickest demographic in correctional systems (15,46) (National Institute on Aging); children who spend time in a juvenile correctional facility are far more likely to engage in health risk behaviors (47) (National Institute of Child Health and Human Development); prisoners have high rates of traumatic brain injury linked to early onset cognitive impairments (48) (National Institute of Neurological Disorders and Stroke); and prisoners are more likely to suffer from diabetes than their age-matched community counterparts (19) (National Institute of Diabetes and Digestive and Kidney Diseases).

The NIH is also well-positioned to lead the development of better data and evidence-based interventions to improve healthcare quality and cost-effectiveness within the criminal justice system (31). Compared to 4,999 community hospitals nationwide (49) there are over 5,100 prisons and jails spread across the U.S., more than half of which provide direct medical assessment and/or care to their inmates (nearly 100% of state and federal prisons and approximately 38% of local jails) (50,51). Yet correctional healthcare systems are challenged by their limited capacity to conduct epidemiologic and comparative effectiveness research, share data, and develop and implement evidence-based quality measures across systems (32). By acknowledging that criminal justice systems serve as essential primary care settings within the U.S. healthcare system (18), the NIH could motivate researchers to engage with correctional facilities as partners in ethically rigorous clinical research and ensure that jails and prisons across the country are themselves working in the service of reducing rather than exacerbating health disparities.

There are five immediate actions the NIH could take that would increase the knowledge needed to improve health outcomes for current and former prisoners (Table 4). First, the NIH could fund efforts to identify current and former prisoners in existing national health datasets by

adding simple questions to questionnaires or re-coding study participants (9). This would immediately enable large-scale data analyses to better understand the role incarceration plays in perpetuating health disparities. Second, criminal justice health research could be included in appropriate solicitations for investigator-initiated research applications (R series grants) across each of the 28 centers and institutes included in the health disparities research strategic plan. This would draw needed attention to the role that criminal justice systems play in public health and would incentivize researchers from outside the world of criminal justice health to consider any of the nation's 5,100 jails and prisons as potential partners in crafting research programs to address health disparities. Third, the NIH could ensure that funding solicitations inviting researchers to consider criminal justice systems and/or populations are accompanied by the guidelines for conducting such research (36-38). Fourth, training and career development awards could be established to support trainees and early researchers interested in working at the intersection of health and criminal justice. Of the 180 correctional healthcare grants identified in this study, just 20% were for training or career development awards. As advocacy and media organizations like Human Rights Watch, the ACLU, the Pew Center on the States, the Urban Institute, The New York Times, The Wall Street Journal and others continue to call for improved criminal justice health (52-57), it is likely that a growing number of junior researchers will be drawn to this issue. Finally, the NIH could continue to highlight efforts and innovations in this emerging area of investigation via its Agency for Healthcare Research and Quality as it has, for example, with the Michigan Pathways and Transitions Clinic projects (58,59).

The results of this study should be considered in light of several limitations. First, we did not include NIH-supported research that did not explicitly address the health or healthcare of persons detained in jail, prison, or juvenile residential placement facilities, on probation or

parole, or transitioning from the criminal justice healthcare system to the community. For example, research investigating new Hepatitis C treatments would disproportionately benefit prisoners without necessarily enrolling prisoner populations or addressing corrections-based healthcare delivery systems. However, the goal of our study was to describe NIH efforts to capture a public health opportunity by *explicitly* directing research to the intersection of health and criminal justice. We used this approach because research that may benefit prisoners but does not directly address the unique characteristics and limitations of the criminal justice environment or the unique challenges faced by former prisoners in community healthcare systems risks having little impact on health disparities, which the NIH acknowledges are “complex, dynamic, and multidimensional... shaped by the interaction of multiple factors, including: social, environmental, behavioral, and biological factors” (39). Second, we do not know how many criminal justice health research applications were submitted to the NIH to produce the 180 funded grants identified in this study. It is possible that the NIH funded a high percentage of criminal justice health research applications. However, even in that case, our recommendations for ways in which the NIH could lead the way on generating additional research in this critical area – for example, by incorporating criminal justice health research more broadly in its health disparities research strategic plan and related funding solicitations – remain valid.

Experts and scholars are calling for researchers and policymakers to address the health needs of millions of Americans who are involved in the criminal justice system each year and millions more who have used or may use correctional healthcare services over the course of their lives (6-8,10,14,16,24,25). Our findings show that the NIH is well-positioned to lead this effort. Research and evidence-based interventions in criminal justice health supported by the institutes and centers included in the NIH’s Health Disparities Research Strategic Plan could enable

critical improvements to the health of current and former prisoners while greatly reducing health disparities across the nation. As the U.S. enters its third decade with more than one million Americans in prison (18,60), nearly all of those currently incarcerated will eventually return to our community healthcare systems. Expanded support of research at the intersection of criminal justice involvement and health could strengthen the NIH's effort to address health disparities nationwide.

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