

Chapter 24

Health Research Behind Bars: A Brief Guide to Research in Jails and Prisons

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While most people make staying out of jail and prison a priority, a growing number of researchers are eager to get into correctional facilities in order to study the criminal justice system, the causes and consequences of incarceration, and the role of corrections in our society.

For health researchers and their collaborators, the audience for this chapter, correctional facilities offer several unique advantages: a population at high risk of many health problems including infectious and chronic diseases, substance abuse, and mental health problems; social and physical environments that can enhance or impede well-being; a setting that is a focal point for the class, racial/ethnic, and gender differences that divide the United States; a site where health and mental health services and prevention programs are offered and can be evaluated; a controlled environment for administration of treatments such as directly observed therapy for tuberculosis; and a stopping point in the cycle of incarceration and reentry that so profoundly affects community well-being.

In this chapter, I consider the benefits and perils of doing health research in jails and prisons. The chapter begins with a brief overview of the different types of health research conducted within correctional facilities and among those leaving jail or prison. I then describe some of the unique obstacles that correctional health researchers encounter and assess some of the methods they have used to overcome these obstacles. Since researchers in correctional settings face significant ethical dilemmas, I next consider recent frameworks for making ethical decisions about this research. Finally, I suggest an agenda for future health research in correctional settings.

Scope of Health Research in Correctional Settings

In recent decades, researchers from a variety of disciplines including health services research, public health, medicine, criminal justice studies, sociology, psychology, anthropology, organizational studies, and others have initiated studies on health in the correctional system. A brief typology of the different categories of questions these investigators have asked will help to set the stage for our consideration of approaches to correctional research.

1. What are the health and social characteristics of people in jail and prison?

Numerous studies have examined the health and demographic profile of incarcerated populations. These vary from large studies based on national samples and using multiple health outcomes such as the reports of the National Correctional Health Care Commission on the health status of soon-to-released inmates (2002a, 2002b) or of the health status of inmates in Texas prisons (Baillargeon, Black, Pulvino, & Dunn, 2000) to studies of a single outcome such as hepatitis C among California inmates (Fox et al., 2005). The various reports of the Bureau of Justice Statistics on mental health, substance use, and other health conditions (e.g., James & Glaze, 2006, Karberg & James, 2005) summarize data across U.S. jurisdictions, providing an opportunity for correctional and health officials to identify incarcerated populations in higher need. Other studies describe patterns of health care utilization among inmate populations (Leukefeld et al., 2006). Investigators often compare the health status of different subpopulations, e.g., men to women (Peters, Strozier, Murrin, & Kearns, 1997), or African-Americans and Latinos to whites (Rounds-Bryant, Motivaus, & Pelissier, 2003). These descriptive studies are used to identify the needs of various segments of the incarcerated populations, to compare changing incidence or prevalence of conditions over time, or to serve as a baseline for the subsequent evaluation of interventions. Research imperatives in these studies are consistent definitions of dependent and independent variables, uniformity in data collection methods in multisystem studies, and sampling strategies that enable generalizations to other settings.

2. How does the health of inmates differ from that of nonincarcerated populations?

A second group of studies compare the health of incarcerated populations with the health of the general population or with samples of nonincarcerated people. For example, Teplin and colleagues' studies of the prevalence of mental health conditions among women and juveniles in Chicago jails found higher rates of some psychiatric conditions in incarcerated populations than in similar populations living in the same catchment area from which inmates had been arrested (Teplin, 1990; Teplin et al., 1996). These studies set the stage for the next group of studies. Methodological issues in this type of study include selecting an appropriate comparison group.

3. How does incarceration itself affect the health of incarcerated populations?

Both correctional and public health authorities want to know whether observed differences between incarcerated and nonincarcerated populations are due to differences in the composition of the populations or to the experience of

incarceration, a variant of the classic epidemiological task of distinguishing between compositional (i.e., characteristics of the population) and contextual effects (i.e., characteristics of an environment). For example, numerous investigators have sought to determine whether the higher prevalence of HIV infection among U.S. prison populations was due to intraprisson transmission or to criminal justice policies that led to incarceration for people already HIV infected (Hammett, 2006; Krebs & Simmons, 2002). Most studies suggest the latter route is more important, reassuring correctional authorities that within-prison transmission, while it does occur, is not a major factor in higher rates. On the other hand, studies in the early 1990s established that TB transmission did occur within the facility, leading to substantial efforts to prevent such transmission (Bellin Fletcher, & Safyer, 1993). Others have investigated whether incarceration is associated with homelessness and mental illness (McNeil, Binder, & Robinson, 2005). The main analytic task in these studies is to distinguish between causal and noncausal associations between incarceration and selected health outcomes.

4. What are the health effects of criminal justice policies and practices on the health of inmates?

Criminal justice policies often have unintended effects on incarcerated populations. Documenting the positive and negative impact of these policies can serve as a starting point for policy change. For example, a study in a large public hospital in New York City found that many admissions for diabetic ketoacidosis were related to the court practice of denying inmates access to insulin medications in court pens (Keller et al., 1993). Health impact assessment, an analytic method developed to assess the health effects of both health and non-health-related policies, offers a promising approach to consider the health consequences of various prison and criminal justice policies (Davenport, Mathers, & Parry, 2006; Kemm, 2001, Veerman, Barendregt, & Mackenbach, 2005). To date, however, this approach does not seem to have been used to assess the impact of U.S. correctional policies on inmate or community health.

5. What is the impact of interventions designed to care for or improve the health of incarcerated populations?

A key practical question for correctional, public health, and correctional health officials is the effect of the programs they run on the well-being of the populations in custody. Evaluation studies seek to document the utilization of health services (Lindquist & Lindquist, 1999); assess their impact on health or health care utilization (e.g., Chan, Vilke, Smith, Sparrow, & Dunford, 2003; Edens, Peters, & Hills, 1997); analyze the cost-benefits of an intervention (NCCCHC, 2002a); or compare the cost-effectiveness of various approaches to a specified health problem, e.g., screening for HIV or other infectious diseases within correctional settings (Resch, Altice, & Paltiel, 2005; Kraut-Becher, Gift, Haddix, Irwin, & Greifinger, 2004). In these studies, methodological issues include the specification of clearly defined outcomes, the use of standard accepted measures for assessing costs and benefits of various interventions, and the design of evaluation studies that are both methodologically sound and operationally feasible.

6. How does reentry affect the health of incarcerated populations?

In the last decade, correctional health researchers have begun to follow their research participants back into the community, examining their success in finding health services or drug treatment (Jarrett, Adeyemi, & Huggins, 2006; Lincoln et al., 2006), maintaining control of a mental health condition (Wilson & Draine 2006), or in improving HIV care or reducing HIV risk behavior (Bauserman et al., 2003; Rich et al., 2001; Myers et al., 2005). These studies can be part of an evaluation of a reentry program (e.g., Needels, James-Burdumy, & Burghardt, 2005) or a descriptive study of the outcomes of the reentry process (e.g., Freudenberg et al., 2005).

7. What is the impact of incarceration rates on the well-being of communities and populations?

Finally, a growing number of researchers are studying the impact of incarceration and correctional policies on the health of families, communities, and populations. For example, some research looks at the impact of incarceration on children and other family members (Murray & Farrington, 2005; Barreras, Drucker, & Rosenthal, 2005). Researchers have asked whether incarceration policies have contributed to the community transmission of HIV infection (Leh, 1999; Johnson & Raphael, 2006) or other sexually transmitted infections (Thomas & Sampson, 2005), community rates of violence (Rose & Clear, 2003), or disparities in health between black and white U.S. populations (Taxman, Byrne, & Pattav, 2005; Johnson & Raphael, 2006; Iguchi, Bell, Ramchand, & Fain, 2005). These studies can help policy makers consider the impact of various incarceration policy choices.

This brief summary of the types of questions that correctional health researchers have sought to answer illustrates the scope of the field. For neophyte investigators, becoming familiar with the findings and methodological challenges in the extant literature relevant to their question of interest can save years of trial and error in this difficult setting and avoid duplication of effort. For more experienced researchers, a familiarity with the scope of prior research can help them move from descriptive to analytic and intervention studies. Several recent reviews provide a good starting place for becoming familiar with recent correctional health research (Edens et al., 1997; Freudenberg, 2001; Magaletta, Diamond, Dietz, & Jahnke, 2006; Morris, 2001; Pollack, Khoshnood, & Altice, 1999).

Stakeholders in Correctional Health Research

Successful health research in correctional settings requires familiarity with the existing literature described in the previous section, a knowledge of the research methods applicable to the correctional setting, discussed in the next section, and an understanding of the various stakeholders in correctional health, discussed here. Without a map of this organizational landscape, even skilled researchers can lose their way.

Key participants in developing and implementing research studies in correctional settings include correctional officials, correctional health providers, public health authorities, other researchers and research institutions, elected

officials, funders, prison and reentry advocacy groups and inmates and their families. Each of these constituencies has the potential both to improve research and to stop studies before they get off the ground. Thus, the practical researcher will want to understand how to enlist each of these groups in supporting the research process.

Correctional officials need to approve and at least not oppose any research study conducted in their facility. Their main concerns are the extent to which research may pose a threat to safety and regular prison routines, fear of bad publicity, cost and liability concerns, or additional demands on their staff. Researchers who can reassure correctional officials on these matters will have an easier time pursuing their studies. Investigators who are unable (or unwilling) to provide these assurances may need to consider other approaches to their research, such as interviewing participants after their release from jail or prison.

In most situations, research studies will need the tacit support of at least three levels of correctional authorities: senior departmental managers (e.g., commissioners/directors or sheriffs); wardens of the facility(ies) where the study takes place; and frontline correctional staff. Each level brings different concerns and requires different assurances in order to allow the research to proceed. For example, frontline correctional officers who may be required to bring participants to the researcher for interviews or medical examinations want to make sure these procedures do not interfere with their routines or increase staff workloads. Wardens often need to be assured that no research procedure will jeopardize security. In another example, a jail security warden was concerned that a stylus for a handheld computer device used for interviews with inmates could be used as a weapon. It took several meetings between a warden and a research team to agree on a type of stylus and interview procedures. Senior officials of corrections departments are sometimes ambivalent about studying illegal behavior such as drug use or voluntary or coercive sexual behavior. If they know that a problem exists, they may have an obligation to address it so that agreeing to research on these topics can have significant administrative, legal, and cost implications. Researchers will need to be prepared to address these concerns.

Correctional health providers have a constitutional mandate to provide health care to people in custody, offering a theoretical rationale for research that helps to improve care or make it more efficient or economical. In practice, however, since the types and quality of these services are often the subject of litigation (Nathan, 2004), health providers often filter requests for participation in research projects through their potential impact on current or future litigation. In addition, similarly to corrections officials, correctional health authorities often believe that if they know about a problem they will be required to take action to address it. This has made some officials reluctant to support research on difficult—and expensive—conditions such as hepatitis C (Spaulding et al., 2004). Researchers who want to study such topics will need to be able to address these concerns.

Correctional health providers operate under a variety of auspices, including public departments of corrections or health, universities, voluntary hospitals, or for-profit companies (Mellow & Greifinger, 2006). These differing organizational sponsorships influence a unit's openness to research and their motivation to participate in research studies. As with other potential stakehold-

ers, researchers need to initiate a straightforward discussion to identify areas of common interest and potential conflict before beginning a study.

In some cases, correctional health providers have themselves initiated evaluation studies to guide practice. For example, the University of Texas, which has a contract to provide health services for inmates in Texas prisons, commissioned an independent evaluation of its services. The report generally lauded the Texas program and made several suggestions for more systematic quality assessment (Texas Medical Foundation, 2005).

Public health authorities often have a legal mandate to provide oversight of correctional health services and always have responsibility for providing core public health services to people returning to their communities. These obligations provide an incentive for research that can identify unmet needs, improve the effectiveness or quality of care or reduce its costs, or demonstrate the impact of interventions. In practice, some state and municipal health departments have close and positive relationships with correctional health researchers and enlist their help in identifying and solving problems. Others, either as a result of fears of litigation, new mandates for service, or unfavorable media attention, may be reluctant to establish partnerships with researchers.

Other researchers and research institutions can provide an important resource for both experienced and neophyte correctional health investigators. They can share their frontline experiences doing research in specific correctional systems or facilities, the study designs and instruments they have used, their solutions to issues of confidentiality and informed consent, or their findings from their previous research. In the last decade or so, a number of research centers focused on correctional health or reentry have been established, gaining valuable experience and producing a body of work that can inform future studies. Some of these are listed in Table 24.1. Since some federal funding agencies prefer multijurisdiction research projects in order to increase generalizability, establishing partnerships with experienced centers can help to design such studies and win funding for them.

Elected officials in both the executive and legislative branches are sometimes needed to approve funding for research studies (e.g., evaluation of publicly funded health or reentry interventions) or to pose questions that need study to correctional or health officials (e.g., how best to provide substance abuse treatment services to people in and returning from correctional facilities). In order to help these officials take on these roles, researchers can provide them with information documenting the problem, cost arguments on the potential savings from new approaches, and the public health benefits of correctional health services. Many elected officials worry that supporting health services or even research on the health needs of people in jail or prison might lead to charges that they are “soft on crime” or coddling criminals. Research evidence that can reframe the issues as public health, public safety, or economic concerns may help to provide a rationale for interest.

Funders provide the financial support for correctional and reentry health research and thus for this research to develop they must be willing to provide the level and continuity of funding needed to develop the field. Given that both private and public funders always have more requests for support than resources, that prison health is always a less popular choice than, say, children’s health or education, and that many funders change their priorities

Table 24.1 Selected research centers on issues related to incarceration and health.

Research center	Research areas/projects	Selected references	For more information
Abt Associates, Inc.	Research on social, economic, and health policy; criminal justice, HIV/AIDS, public health research	Hammett (2006), Hammett et al. (2002)	www.abtassociates.com (see Research, Criminal Justice or Publications)
Brown University, <i>Infectious Diseases in Corrections Report</i>	National forum for research and discussion of HIV/AIDS and hepatitis issues in corrections	Arriola et al. (2006), Jürgens (2006)	www.idcronline.org/index.html
Rutgers University, Center for Mental Health Services and Criminal Justice Research	Research and evaluation of mental health services, prevalence of mental illness, reentry and mental illness	Draine et al. (2005), Wolff et al. (2005)	www.cmhs-cjr.rutgers.edu/
University of California San Francisco, Center for AIDS Prevention Studies (CAPS)	Centerforce project: HIV prevention education and evaluation research	Comfort et al. (2000), Grinstead et al. (2001)	www.caps.ucsf.edu/projects/Centerforce/
University of Connecticut Health Center	Research on ethical issues in correctional research, psychiatric illness, substance abuse	Lazzarini & Altice (2000), Lewis (2006)	www.connecticuthealth.org/projects/index.html
University of Texas Medical Branch, Galveston, Program on Legal and Ethical Issues in Correctional Health	Training for NIH researchers, needs assessment of health issues for correctional health care workers; research on sex offenders, aging offenders, access to clinical trials	Stone et al. (2000), Stone & Winslade (1998)	www.utmb.edu/imh/CorrectionalHealth/
Urban Institute, The Reentry Roundtable	Forum for research and discussion of policy, social, and health issues affecting formerly incarcerated individuals	Freudenberg (2006), Roberts et al. (2004)	www.urban.org/projects/reentry-roundtable/
Yale University, HIV in Prisons Program, Center for Interdisciplinary Research on AIDS	Consultation and management for HIV/AIDS, TB, hepatitis, STDs; research on HIV/AIDS and antiretroviral therapy	Altice et al. (2005), Springer et al. (2004)	http://citra.med.yale.edu/

regularly, researchers face an uphill battle in winning the resources they need to pursue a comprehensive research agenda on correctional health.

Funders who have provided significant support to correctional health research include public agencies such as the National Institutes of Drug Abuse, Alcohol Abuse and Alcoholism, Mental Health, and Allergy and Infectious Diseases, the Centers for Disease Control and Prevention, the National Institute of Justice, and some state and local governments. Private funders include the Robert Wood Johnson Foundation, the Kellogg Foundation, the Open Society Institute, and the Jeht Foundation, among others.

To ensure long-term support, correctional health researchers will need to educate public and private funders about the connections between correctional health and public safety, public health, and social justice as well as to find ways to integrate correctional health issues into research on a variety of health and social problems.

Prison and reentry advocacy groups serve as important bridge between inmates and their families and the wider community. They also have the potential to influence policy makers, elected officials, and the media. Their opposition to unsafe or unhealthy prison conditions, inadequate medical care, or violations of civil liberties have contributed to the development of standards for correctional health care and greater public attention to these issues (Nathan, 2004).

The mission, scope, and activities of these groups vary widely, from national organizations such as the National Prison Project of the American Civil Liberties Union, which brings legal action against correctional systems alleged to violate inmate rights, and Critical Resistance, an alliance of regional groups dedicated to radical reform of the criminal justice system, to local groups that seek to coordinate reentry programs or organize prison visiting programs.

For researchers, these groups can provide detailed knowledge about prison conditions, inmate perceptions of problems, and the local political climate on correctional issues including health. Establishing relationships of mutual trust and respect, even when the two parties may disagree on the causes or solution to a problem of interest, can deepen investigators' understanding of the context in which their research is carried out.

Finally, *inmates and their families* can provide the insider knowledge that can determine the success or failure of a research project. Their understanding of the real-world intersection of policy and practice, the actual living conditions of inmates, and the problems that people leaving jail and prison face when they return home can help researchers to design their studies, develop their research instruments, and interpret their findings. Many researchers have noted the benefits of participatory research—deeper knowledge of the problem under study, greater engagement of research participants in the process, and more meaningful interpretation of results (Israel, Schulz, Parker, & Becker, 1998; Metzler et al., 2003).

In summary, correctional health researchers interact with a variety of stakeholders. At worst, these interactions can appear as a gauntlet of opponents, each with contradictory perceptions and demands that threaten the integrity of the research process and have the potential to disrupt or even halt any study. At best, however, each stakeholder can offer unique insights into the research problem, contribute distinct resources to the research process, and assist in

making findings lead to improvements in practice, policy, and health. Thus, developing skills in successfully negotiating these interactions is an essential prerequisite for the correctional health researcher.

Methods of Research

Researchers in correctional facilities have used a wide variety of data sources to study inmate health. These include surveys of inmates or correctional authorities, clinical studies of inmate health, secondary analyses of national datasets, ethnographies, and reviews of existing prison health or criminal justice records. Each of these sources of data has unique advantages and disadvantages. Increasingly, researchers combine different types of data in order to gain deeper insights into the question of interest. For example, many correctional health studies will integrate survey data from participants, medical records from a correctional health service, and official criminal justice records in order to assess the impact of intervention programs.

In general, the methodological questions in correctional health are similar to those in other settings: e.g., how to define variables of interest consistently, how to ensure that the data collected are reliable and valid, and how to select appropriate samples and comparison groups. A variety of standard research texts can help investigators to become familiar with these issues (e.g., Boruch, 2005; Datzker, 1999; Noaks & Wincup, 2004; Patton, 2001).

Research in correctional settings does pose some particular methodological challenges. For example, longitudinal studies that follow inmates into the postrelease period face the problem of locating participants after release. Since people leaving jail or prison often lack residential stability and may not want further contact with those associated with the incarceration experience, achieving acceptable follow-up rates can be difficult. Strategies that have been used to increase follow-up rates include collection of multiple contact names at study entry; frequent interim contacts in order to maintain updated locators, use of both service and financial incentives, and use of public records (e.g., “rap sheets” and criminal records) in lieu of face-to-face contacts.

Correctional health researchers, like other investigators, often struggle to design and implement multilevel studies that seek to understand the cumulative impact of more than one level of organization on inmate or community health. They may collect data on individuals, social networks such as family and peers, communities, correctional facilities, and jurisdictions, then seek to analyze the contribution each level makes to a specified outcome. For example, a study of women and male adolescents leaving New York City jails examined the impact of individual characteristics, the jail and reentry experience, conditions in the returning community, and changing municipal policies on crime, welfare, and housing on returning inmates’ drug use, HIV risk behavior, and reincarceration (Freudenberg et al., 2005). Multilevel analyses consider the contributions of variables at multiple levels to the variability in a particular individual-level dependent variable, e.g., drug use. In public health, multilevel research is increasingly used to assess the relative influence of neighborhood and individual-level variables on health (Diez-Roux, 2001). By comparing these two influences within different jurisdictions, a third level of organization (i.e., city or state policies or services) can be studied.

Health research in correctional settings also faces organizational and logistical issues. These include finding space for confidential interviews (an extremely challenging task in overcrowded jails and prisons), negotiating use of technology such as computer-assisted interviewing devices with prison security officials, providing clearance and escorts for researchers, and gaining consistent and reliable access to research participants within the security confines of the facility.

Solving these logistical problems requires a close and collaborative relationship between researchers and correctional officials. Defining common objectives at the inception of research, developing procedures for resolving conflicts before they emerge, and maintaining open communications with all levels of correctional authorities—from frontline correctional officers to wardens and commissioners—can help to reduce logistical problems. Most importantly, researchers who choose to work in correctional settings must be willing to act as guests in someone else's house, rather than expect to develop their own rules of conduct. Researchers who are unable or unwilling to accept this reality will face difficulty in working in prisons or jails.

Ethical Issues in Correctional Health Research

Perhaps the most challenging aspect of health research in correctional settings is meeting the competing demands for ethical research practice as mandated by various bodies as well as the researcher's own ethical standards. Prisoners pose ethical dilemmas for researchers not only because they lack the freedom to make the choices that most individuals in the free world take for granted, but also because so many prisoners experience other problems that make them vulnerable as research subjects: low levels of literacy, HIV infection, mental illness, victims or perpetrators of violence, as well as being adolescents. Ethical questions correctional health researchers must address include:

- What procedures ensure that all incarcerated people involved in studies have been given the opportunity to give informed and voluntary consent to participate in the research?
- What research practices can guarantee that inmates have as much right to choose to participate in research as any other population?
- How do correctional health researchers balance their ethical responsibilities to the correctional officials who commission their work or provide access to inmates with their responsibility to inmates?
- What level of individual or population benefits in correctional health research balances potential risks?
- How can researchers ensure that participation in correctional health research studies will not lead to harm through disclosure of confidential medical or criminal justice information to third parties?
- What ethical responsibility do researchers have to bring the findings of their research in correctional settings to policy makers or others who can act on these findings?

A brief review of the recent history of ethical issues in prison research helps to illustrate the competing forces and changing policy priorities. More in-depth discussion of this history can be found elsewhere (Gostin, Vanchieri, & Pope, 2006;

Kalmbach & Lyons, 2003; DeGroot, Bick, Thomas, & Stubblefield, 2001; Haney & Zimbardo, 1998; Hornblum, 1998).

In 1997, Hornblum observed that “from the early years of this century, the use of prison inmates as raw materials became an increasingly valuable component of American scientific research” (Hornblum, 1997). For example, in the 1960s, major pharmaceutical companies, Dow Chemical, and the U.S. Army tested 153 experimental drugs at the Holmesburg Prison in Pennsylvania (Hornblum, 1998). In 1976, based in part on disclosures of research abuses in prisons, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (1976) issued a report that set the framework for subsequent federal involvement in setting ethical standards for human experimentation. Their report called for additional protection for certain “vulnerable” populations, including children, neonates, pregnant women, and prisoners. In 1978, the Commission issued a report titled “Additional Protections Pertaining to Biomedical and Behavioral Research Involving Prisoners as Subjects” (U.S. DHHS, 2005). The main goal of these early guidelines was to protect incarcerated individuals from serving as involuntary or coerced “guinea pigs” in research that offered no direct benefits and had the potential for harm.

In the 1980s and early 1990s, the AIDS epidemic raised new ethical concerns for correctional health researchers. In some cases, prisoners with HIV infection or AIDS were not permitted to join clinical trials for new AIDS medications, based on various beliefs including their inability to give truly voluntary consent and their perceived unwillingness to comply with prescribed regimens. Some health researchers and prisoners rights advocates argued that such a ban violated ethical principles and that prisoners should have the same access to experimental treatments and clinical trials as other sectors of the population. From this perspective, ethical guidelines should place a priority on ensuring access to potential beneficial treatments (Dubler and Sidel, 1989) — a priority that may conflict with the previous emphasis on protecting inmates from researchers.

In 2006, the Institute of Medicine commissioned another review of ethical issues involved in prisoner research (Gostin, Vanchieri, & Pope, 2006). Based on several reviews of the more recent literature and testimony from dozens of witnesses including researchers, inmates, and correctional officials, the Committee on Ethical Considerations for Protection of Prisoners Involved in Research made fourteen recommendations in five broad categories (Table 24.2). These recommendations strive to find an appropriate and updated balance between the protection and access imperatives embodied in previous ethical standards. Whether these Institute of Medicine recommendations lead to changes in federal guidelines for prison research or in practice remains to be seen.

In practice, among the vexing problems correctional health researchers face are obtaining voluntary consent in jails or prisons, informing research participants about the benefits and risks of research, getting consent for randomized trials in which some participants receive no potential benefit, protecting the privacy of research participants, and negotiating with IRBs that may lack expertise in the realities of prison research.

Defining “voluntary” consent in the coerced environment of a correctional facility is sometimes difficult. Among the practices that can compromise free choice are promises of services not ordinarily available to inmates (e.g., certain

Table 24.2 Institute of Medicine committee recommendations for revisions to DHHS regulations for protection of prisoners involved in research.

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1. Expand the definition of prisoner to include all those involuntarily confined in a penal institution, including detainees, parole violators, and those in alternatives to incarceration programs.
 2. Ensure Universal, Consistent Ethical Protection
 - Establish uniform guidelines for all human subjects research involving prisoners, not just those funded by NIH or other federal agencies.
 - Maintain a public database of all research involving prisoners in order to make it easier to provide ethical oversight on this research.
 - Ensure transparency and accountability in the research enterprise.
 3. Shift from a Category-Based to a Risk Benefit Approach to Research Review
 - Apply a risk–benefit framework to research review, shifting from the current model based on categories of excluded work to a system based on weighing of risk and benefits for the individual research participant.
 4. Update the Ethical Framework to Include Collaborative Responsibility
 - Use a collaborative research approach that obtains input on research design and conduct from prisoners and other relevant stakeholders.
 - Ensure adequate standards of care such that prisoners are not encouraged to participate in research simply to get care that should be available to all.
 - Support critical areas of correctional research.
 5. Enhance Systematic Oversight of Research Involving Prisoners
 - Strengthen monitoring of research involving prisoners.
 - Strengthen local IRBs abilities to reach independent decisions on prison research.
 - Enhance the Office of Human Research Protections capacity to provide systematic oversight of research involving prisoners.
 - Ensure voluntary informed consent for all prisoners involved in research.
 - Protect the privacy of prisoner involved in research.
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Source: Gostin et al. (2006).

types of health services), the presence of correctional officers in the area where consent is being solicited, the unavailability of the independent advice on participation that is normally available to research participants in the free world, or the implied offer to use participation in research in exchange for a shorter sentence or favorable consideration by a judge or parole board. Since no set of rules can govern all the situations that can jeopardize voluntary consent, for any particular study the ethical researcher ought to consult experienced correctional researchers, correctional officials at the study site, prisoners rights advocates, and current and former inmates in order to obtain a variety of perspectives on the best procedures to insure voluntary consent.

Similarly, the process of informing research participants in correctional settings of the risks and benefits of a study can be challenging. Many inmates have low levels of literacy; many distrust correctional and health authorities, sometimes based on their own past experiences; and, unlike most research in medical settings, an added risk is disclosure of information that can cause harm to participants from other inmates, correctional staff, legal authorities, or the wider public. Research on stigmatized conditions such as HIV infection, mental illness, and substance use almost always poses such risks. Methods that researchers have used to overcome these obstacles are to engage current and former inmates in the design of informed consent materials and as members of

IRBs, to hire independent advisors who are not part of the research team to help inmates make decisions about participation, and to obtain federal certificates of confidentiality to minimize risk of disclosure of confidential information.

While some inmates and ethicists express concerns about the coercion implicit in any research in the correctional setting, the recent IOM report (Gostin et al., 2006) also noted that other inmates strongly oppose restrictions on inmate participation in research. Some are concerned about lack of access to cutting-edge treatments for HIV or cancer; others object to the loss of opportunities for compensation or enhanced living situations.

A specific problem facing researchers involved in clinical trials in which some forms of treatment are withheld from some participants is convincing both staff and participants of the rationale for a randomized trial. From a researcher's point of view, the lack of definitive evidence of the benefits of an intervention is sufficient rationale for such a trial but for staff and participants, withholding services perceived to be beneficial may seem unethical. When staff are not convinced of the morality of a research study, they may intentionally or unintentionally undermine the study, either by providing services to the "control" group or by communicating their discomfort to research participants, thus discouraging enrollment in a study. For this reason, it is important for researchers to address this issue forthrightly.

Strategies to minimize this problem include offering all research participants some level of services above the standard care in the correctional facility, comparing different interventions to each other rather than to no special services, educating research staff about the ethics of offering unevaluated services to all participants, and, as the Institute of Medicine report on correctional research suggests (Gostin et al., 2006), joining advocacy efforts to improve the basic standard of care in all correctional facilities.

In my experience, many correctional health researchers complain about the extensive and lengthy process required to get IRB approval for their research study and suggest that it can discourage them from pursuing worthy projects. In some cases, several different IRBs need to approve a single study and occasionally offer conflicting guidance on how to proceed. These complaints have a variety of sources: some investigators prefer the old way of business where researchers alone decided on the conduct of their studies. But even researchers who support the importance of protecting prisoners note that IRB members often lack expertise in the day-to-day realities of correctional institutions and the nonresearch risks inmates encounter daily. They also report that IRB committees often reflect the wider tension between protecting participants from research harm and ensuring access to beneficial services and in their effort to maximize both of these aims impose unreasonable demands on researchers.

A possible solution is to assist IRBs to find a member who is experienced in correctional settings and correctional research—not only to meet the DHHS regulatory requirement to include such a person but also to obtain practical advice on devising realistic and ethical resolution of problems. For example, one state prison system IRB included an attorney who specialized in inmate litigation. Another solution, as recommended by the IOM report (Gostin et al., 2006), is to develop universal national standards for review of prison research so that all research is reviewed using uniform criteria.

Developing a Research Agenda on Correctional Health

At present, correctional health researchers respond to a variety of heterogeneous influences — other criminal justice, medical, public health, and public policy researchers; local, state, and federal correctional and health officials; correctional health providers; a variety of professional organizations; elected policy makers; and various criminal justice and health advocacy organizations, among others. It is therefore not surprising that in this anarchic and complex environment correctional health researchers have yet to develop a coherent and comprehensive research agenda driven by existing scientific knowledge and public policy imperatives. However, the fact that it may be difficult to envision and articulate such an agenda should not stop the effort. In fact, as health and correctional officials and researchers request additional support for correctional health research, it is inevitable that they will be asked to set priorities. And if researchers themselves fail to take the lead in this process, others will impose an agenda on them.

While the development of a comprehensive research agenda for correctional health is beyond the scope of this chapter, I conclude by suggesting some steps that might move the field in this direction.

First, we need to begin a national dialogue on research needs that include researchers, correctional and health officials, policy makers, and advocates. Questions to discuss include: what are the most promising avenues of research to lead to short- and middle-term improvements in the health of incarcerated populations? What are potential stable funding streams for this research? How best can we develop consistent frameworks for research so that clinical, practice, and policy decisions can be more evidence-based? Who are the constituencies that will support a national research agenda on correctional health and how can these constituencies be organized into a coherent force? What correctional research might be particularly beneficial both to the health of the incarcerated and to the larger health of the public?

Organizations that can play a role in this national discussion include the National Institute of Justice, NIH Institutes and the Centers for Disease Control and Prevention, the National Commission on Correctional Health Care, various health professional organizations, and the Reentry Policy Council.

Second, researchers need to synthesize the existing and disparate literature on correctional health to identify common findings, gaps in the literature, and future priorities. This literature is dispersed in several different disciplines and among the peer-reviewed and “gray” literatures, i.e., public and voluntary organization reports and studies. One possible sponsor for such a critical review would be the Institute of Medicine.

Third, as recommended by the recent IOM report on correctional health research (Gostin et al., 2006), the United States should establish more consistent and uniform guidelines for ethical health research among incarcerated populations. Such guidelines will protect researchers and inmates and help to resolve the continuing debate between protection from researchers and full access to the benefits of research.

Fourth, any agenda should consider the range of settings in which correctional health plays out, including courts, jails, prisons, parole and probation services, alternatives to incarceration, and reentry programs. Too often, each setting has been its own silo with a cadre of researchers and officials. The evidence

of the past decades suggests that in fact these settings constitute a single if sometimes disorganized system in which changes in one component affect all others. Thus, health research needs to examine these systemic interactions in order to avoid shifting problems for one sector to another.

Finally, correctional health research has to be considered a branch of population health research and therefore address the broadest questions that affect the health of the public. In the past, some correctional health researchers have limited their attention to those individuals served in correctional health settings—the patients who walked through their clinic doors. While these concerns will continue to be important and warrant focused investigation, they are not sufficient to realize the full opportunity for correctional health researchers to improve health.

Research questions that need to be addressed in the coming decade include: How does incarceration influence socioeconomic, racial, and gender disparities in health in the United States? How does incarceration affect the health of the families and communities of incarcerated individuals? What role can correctional health services play in reducing community incidence, prevalence, severity, or costs of conditions such as HIV infection, hepatitis C, diabetes, asthma, addiction, violence, depression, or lack of health insurance? By expanding their focus to these questions, correctional health researchers have the potential to contribute to solving our nation's most pressing health problems.

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