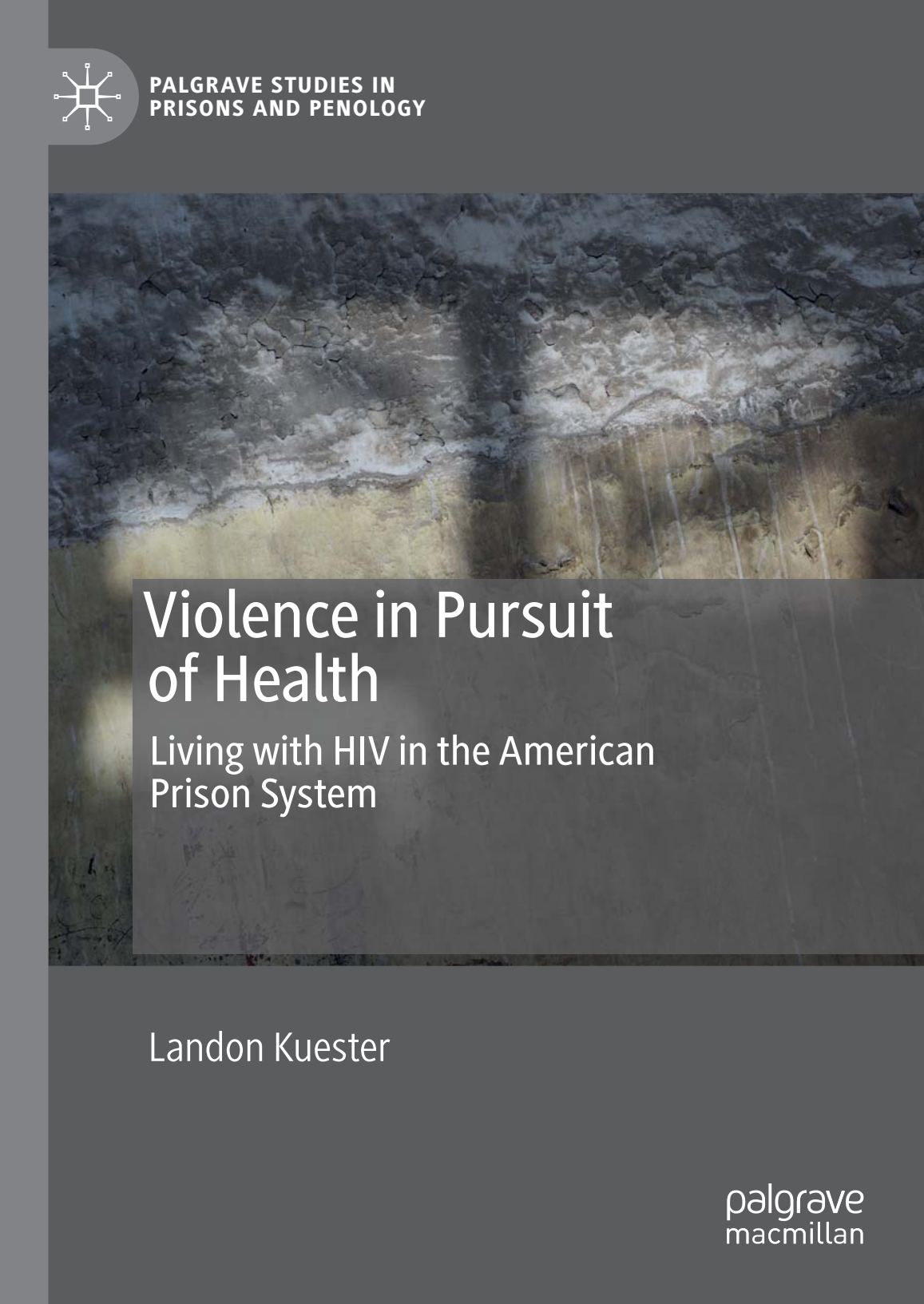
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Living with HIV in the American Prison System
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Acknowledgments

This book offers findings from an ethnographic study in a U.S. state prison system. The research involved spending extended time in several prison facilities and community organisations to understand the experiences of people living with HIV as they move through prison and return to life in the community.

Writing this book would not be possible without the generosity and thoughtfulness of all the research participants involved in the study. Therefore, I would like to thank the inmates, prison staff and administrators, ex-inmates and their families, university faculty, hospital staff, social workers, outreach workers, probation and parole board, and leadership at the Department of Health who shared their stories with me.

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The research underpinning this book was conducted a few years ago now, and several other people have been integral to its production. Professor Kamaldeep Bhui, Professor Simon Dein, and Dr. Mark Freestone encouraged the book submission and guided me through the development of its proposal. I am also grateful to Dr. Polly Radcliffe for her support during the final stages of the write-up.

Some of the analysis in the book reworks previously published material, and therefore I am grateful to the publishers for their permissions to re-produce it here.

Chapter 4 & Discussion: Kuester, L. B., & Freestone, M. C. (2020). Time away is time out: narratives of intentional reimprisonment amongst inmates living with HIV in a US setting. Critical Public Health, 1–12. https://doi.org/10.1080/09581596.2020.1737645.

I dedicate this book to Angel and Big Jay, two participants who died during the course of this study. It was an honour and privilege to have spent time with them both. I will forever hold their stories in my heart and mind, and I hope this book does justice to their experiences.

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Introduction: Violence in Pursuit of Health

I felt nervous sitting in the passenger seat of Dr. McGreevy's minivan as he peeled out from the hospital parking lot and raced toward the prison. As we moved through traffic, I tried to wipe the sweat from my hands. The anticipation and anxiety of meeting inmates had become far too real. McGreevy, who seemed unaware of my discomfort, handed me a bible and asked me to recite a morning prayer. I chirped "Awake, my glory, Awake, O-harp and lyre, I will awake the dawn" Dr. McGreevy, an HIV specialist consulting the state prison system, invited me to observe his clinical consultations with inmates. This was my first opportunity to experience life behind bars. On this morning we rushed to meet inmates before officers conducted their morning count, a human inventory that temporarily restricts inmates from coming and going to the medical dispensary.

The heavy door hissed and clanked, rolled back, and I entered the central courtyard of Men's Medium Security Prison. Appearing before me were hundreds of inmates dressed in tan uniforms. While some of the men did pull-ups and lifted weights, others reclined in the grass or walked circles along the perimeter. There was no longer a comfortable distance between myself and the plight of the so-called 'criminal justice-involved population', which, up until this point, I could only sympathise with

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> through media reports and academic texts. Nothing could have prepared me for my first glimpse of mass incarceration. Even now, after spending hundreds of hours inside the prison system, I struggle to comprehend the sheer size of this human experiment.

This book presents research that explored the "lived experience" of 34 male and female inmates living with the human immunodeficiency virus (HIV) as they progressed through a combined U.S. state jail-prison system[1] and into the community. The study of HIV-positive inmates offered a point of entry into understanding how "violence" was situationally created and reproduced between inmates and a range of medical, social welfare, and security staff. Therefore, this book documents the way HIV-positive inmates went about achieving agency through harm to their body and social standing in order to improve their health under conditions of remarkable constraint.

This book draws from ethnographic research conducted inside a New England state prison system and the surrounding community from 2011 to 2013. The setting is hereafter assigned the fictional name "Melville" in order to maintain the study participants' anonymity. The research comprised 77 semi-structured interviews and hundreds of hours of observation across seven correctional facilities ranging from minimum to supermax security. Participants in this research included short and long-term inmates, correctional healthcare providers, correctional officers, prison administrators, ex-inmates, families of inmates, and community-based physicians and social workers. An assortment of public and private peri-carceral spaces collectively comprised the research setting.

The prison was located atop a high hill, rolling up from a river, in an area known as the Melville reservation. Situated 10 miles southwest of a major New England city, the reservation has a university campus-like feel consisting of a series of Victorian stone structures, several twentieth-century colonial revival brick buildings, and an assortment of modern

[1]The Bureau of Justice Statistics defines jails as locally operated, short term facilities that hold inmates awaiting trial or sentencing or both, and inmates sentenced to a term of less than one year, typically misdemeanants. Prisons are long term facilities run by the state or the federal government and typically hold felons and inmates with sentences of more than one year (Bureau of Justice Statistics, 2015). This book uses the term "prison" when referring to the penal system more generally.

cinderblock structures completed between the 1970s and mid-1990s. The reservation was home to seven active penal facilities, which housed up to approximately 3800 offenders at any given moment. Also located on the reservation was the Melville State Sheriff's Department, adult Probation & Parole, the only state psychiatric hospital, correctional officer's union, and prison administrative buildings.

This book depicts the lives of inmates living with HIV and who passed through the Melville prison system during the course of research. In prison, this group had access to HIV and primary medical care, mental health services, dental care, addiction treatment, and integrated case management support linking persons in the correctional setting to the community. Upon release, inmates received continued case management services through community HIV services, primary medical care, addiction treatment, mental healthcare services, health insurance programmes, and other public assistance.

1.1 Who Is Behind Bars?

The U.S. incarcerates 2.2 million people at any given moment, making it the largest prisoner population in the world (Wagner & Sawyer, 2018). By comparison, other industrial nations imprison 5–7 times fewer people than the U.S. (Dyer, 2000). From the 1920s to the 1970s, the growth rate of U.S. incarceration remained relatively stable (National Research Council, 2014). However, in recent decades the number of people behind bars has quadrupled. This historical expansion of the prison system has led scholars to refer to the current period as the era of "mass incarceration" (Garland, 2001). Expansion of prisons can be attributed to strict sentencing guidelines developed during the late 1980s and 1990s (e.g., "get tough on crime", "war on drugs", "three strike policy", and mandatory minimum sentencing laws) (Butterfield, 2003; NAACP, 2015).

The prison population unduly draws from poor urban communities with limited access to health and social resources both before and after incarceration (Mallik-kane & Visher, 2008; Travis, 2000; Travis, Solomon, & Waul, 2001). Racially, the prison population is disproportionately comprised of Black men. In 2013, the Federal Bureau of

Justice Statistics reported that 526,000 African-American men did time in state and federal correctional facilities, representing 37% of the total prison population. Additionally, there were 1,157,000 African-American men on parole and probation during this time (Carson, 2013). Taken together, 1.68 million Black men were under some form of state or federal supervision (excluding local jails) during 2013, a figure that equates to over 800,000 more black men behind bars when compared to the number of Black men listed as "slaves" in the 1850 U.S. census (Mulvaney, 2014).

State inmates average less than eleven years of schooling, up to a third of inmates are unemployed upon entering prison, and the average wage of those who were employed at the time of their incarceration was lower than persons with the same level of education (Western & Wildeman, 2009). Imprisonment does not help people escape from poor community conditions but rather amplifies social and structural deprivation. Western & Pettit found that if a person serves any time behind bars, his hourly wage will decrease by approximately 11%, annual employment by nine weeks, and annual earnings by 40% (Western & Pettit, 2010). Further, incarceration has deep-seated collateral consequences that transcend localised community settings. For example, American epidemiologist Ernest Drucker found that 50% of people sent to prison from New York City came from fourteen neighbourhoods in the Bronx, Manhattan, and Brooklyn, neighbourhoods where only 17% of New York adults reside (Drucker, 2011). In turn, individuals left behind in the community experience fractured social ties, economic losses for dependents, increased divorce rates, and prolonged stress among family and friends. This condition has lasting intergenerational impacts on health and future criminal justice involvement (Barreras, Drucker, & Rosenthal, 2005).

The prison population experiences a high burden of communicable and non-communicable disease (Flanigan et al., 2009; Maruschak, Berzofsky, & Unangst, 2015), mental health challenges (James & Glaze, 2006), and alcohol and drug dependency (Chandler, Fletcher, Volkow, 2009; Charuvastra et al., 2001). Because of these factors, the prison has been identified as a vital space for delivering public health and safety

(Greifinger, Bick, & Goldenson, 2007). For example, inmates consistently demonstrate elevated HIV levels when compared with the general community (Massoglia & Remster, 2019). In the U.S., HIV is 5-times higher in prison than in the general population (Flanigan et al., 2009). Approximately 1.2 million persons living with HIV, one-sixth of all Americans living with this condition, will pass through the U.S. prison system at some point in their lives (Spaulding et al., 2009).

Over 95% of inmates will eventually leave the correctional setting (Hughes & Wilson, 2004). However, two-thirds of state prison inmates will be re-arrested for a new crime within three years of release, and three-quarters within five years of release (Durose, Cooper, & Snyder, 2014). Inmates leaving prison typically go from a highly structured environment to low-level or no supervision. Returning inmates are often immediately exposed to high-risk places, people, and situations, and few have developed the prevention skills during their incarceration to deal with a range of social, economic, and health risks they commonly encounter during the re-entry period (Mallik-kane & Visher, 2008; Travis et al., 2001). Inmates returning to the community report challenges re-establishing family connections, finding employment, receiving healthcare, and dealing with finances (Travis et al., 2001). All of these factors contribute to a high likelihood of inmate recidivism and greatly jeopardise community health and safety (Clear, 2007; Freaudenberg, 2005; Lincoln, Miles, & Scheibel, 2007; Mallik-kane & Visher, 2008; Travis et al., 2001).

1.2 Prison Healthcare

Prison healthcare models vary from state-to-state and across healthcare providers. In theory, imprisonment offers improved access to medical attention when compared with many community settings (Greifinger et al., 2007). Currently, imprisonment is the only space where Americans have a constitutional right to healthcare ("Estelle v. Gamble, 429 U.S. 97", 1976). While imprisonment intends to deliver "equal access" medical care, the reality is complex and often enables only negligible

care and treatment (Allen, Wakeman, Cohen, & Rich, 2010; Thompson, 2010).

The Estelle v. Gamble ruling entitles inmates to a professional medical judgement, diagnosis, and treatment access. It calls any disallowance of medical care in prison to be a "deliberate indifference to serious medical needs", and thus in violation of the Eighth Amendment of the U.S. Constitution. However, the ruling's precise wording has led to a high threshold in defining "serious medical need", leading some inmates to self-harm to draw attention from medical staff (Thompson, 2010). Equally, "deliberate indifference" sets a low standard of medical care provision, where inmates are not protected from insufficient treatment stemming from an "accident, inadvertent behaviour, or ordinary negligence" (Thompson, 2010, p. 638).

Many inmates with physical and mental illness do not receive adequate treatment in prison, and medical treatment rates further decline after inmates return to the community. A widely cited 2008 study of prison leavers in Ohio and Texas found that two-thirds of men and three-quarters of women with physical health conditions received treatment in prison, a percentage that fell to one-half of men and six in ten women at eight to ten months after they returned to the general community. The study also reports similar patterns for the treatment of mental illness and substance addiction (Mallik-kane & Visher, 2008).

1.3 HIV Policy and Care

While HIV prevalence in correctional settings has decreased since the late 1990s, an increase in the size of the incarcerated population has resulted in a consistent number of HIV cases in prisons and jails (Spaulding et al., 2009). This current state has been described as a persistent HIV epidemic (Westergaard, Spaulding, & Flanigan, 2013). Clark, Stine, Hanna, Sobota, and Rich (2001) and Hammett (2006) describe high-risk sexual behaviour, injection drug use, and tattooing as contributing factors for HIV, hepatitis, and other STI transmission within correctional settings. Most new infections within prison have been linked to male-to-male sex and tattooing practices (Centers for Disease Control

and Prevention, 2006; Jafa et al., 2009). However, Beckwith, Zaller, Fu, Montague and Rich (2010) identify how research findings on the prevalence of HIV-transmission within prisons vary across settings. For example, a study in the Georgia Department of Corrections found that 88 new HIV infections occurred within prison from 1992 to 2005. Around the same time, another study in the Rhode Island Department of Corrections followed 587 inmates for 12 months and found that all participants were HIV-negative at baseline, and none of these individuals seroconverted during a 12-month observation period (Macalino et al., 2004). While Hammett (2006) highlights a real risk for infections occurring within the prison setting, Beckwith et al. (2010) claim that a majority of HIV transmission occurs in the public community before a person's incarceration.

Given the large number of people living with HIV who pass through prisons and jails, there has been increased recognition that the criminal justice system should serve as an intervention point for identifying and linking persons with HIV into care and treatment. The Centers for Disease Control and Prevention (CDC) has called for routine adult HIV testing since 2006 (Branson et al., 2006; CDC, 2009). However, due to logistical challenges, described in previous reviews (Beckwith et al., 2010; Flanigan et al., 2010), adequate testing practices are still underutilised in over half of all correctional facilities nationally (Westergaard et al., 2013).

Not all HIV-positive persons will require immediate treatment upon becoming incarcerated, but all should have appropriate screening and regular laboratory testing. Highly active antiviral therapy (HAART) has been shown to most effectively treat HIV-positive individuals and decrease the incidence of opportunistic infections and AIDS-related mortality (Beckwith et al., 2010). However, a 2005 national survey of correctional facilities reported that 59% of city and county jails and 71% of state and federal prisons provided HAART to inmates with

CD4 counts[2] of 300 or higher[3] (Hammett, Kennedy, & Kuck, 2007). Although, a later study in 2007 estimated far bleaker statistics, reporting that only 33% of inmates with HIV receive HAART in the U.S. correctional setting (Zaller, Thurmond, & Rich, 2007). Both studies highlight a range of treatment standards and non-consensus on when it is appropriate to commence antiviral therapy for HIV-positive inmates.

There are several obstacles to delivering antiviral treatment in the correctional setting. Challenges specific to corrections arise over the loss of confidentiality because many HIV-positive inmates are placed in separate housing, are seen by specific medical staff, and have their status easily identified through other mechanisms (Earnshaw & Chaudoir, 2009). Medication dispensing protocols also create barriers to treatment adherence, and inmates often experience treatment disruptions when transferring facilities (Belenko, 2013).

1.4 Community Re-Entry and HIV Support

Over 12 million people (representing 9 million individual cases) pass through U.S. jails each year (Ramaswamy & Freaudenberg, 2007). Additionally, some 600,000 inmates will leave state and federal prisons annually, equating to about 1600 prison leavers every day (Hughes & Wilson, 2004; Travis et al., 2001). Many inmates leaving prison remain under some level of state supervision, a status known as "community-based corrections" or "parole". At year-end 2013, an estimated 4,751,400 ex-inmates were on active parole (Herberman & Bonczar, 2014).

Persons leaving prison will often go from a highly structured environment to low-level or no supervision. Upon leaving prison, people face challenges, including access to food, housing, social integration, and legal and parole conditions (Rich et al., 2013). This transitional time has also

[2]Cluster of differentiation 4 (CD4) is a surrogate biological marker to determine an HIV-positive persons response to antiretroviral treatment (Egger et al., 2002; Mellors et al., 1997).

[3]The U.S. Department of Health and Human Services and the International Antiviral Society guidelines for HIV treatment recommend antiretroviral treatment be provided to all HIV-positive persons, regardless of CD4 cell counts. Other clinical advisory groups such as the British HIV Association and the European AIDS Clinical Society offer alternative guidance for antiviral therapy (Lundgren, Babiker, Gordin, Borges, & Neaton, 2013).

been associated with a heightened risk of mortality. One study in Washington State found that the risk of mortality among former inmates was 12.7 times higher during the two weeks after an inmate leaves prison when compared to other members of the community (Binswanger et al., 2007). The leading causes of death among returning inmates include drug overdose, cardiovascular disease, homicide, and suicide (Binswanger et al., 2007).

Support offered to inmates leaving a carceral setting is often minimal. Only 10% of persons leaving prison received discharge planning, a percentage of prison leavers that have shrunk over recent decades (Dumont, Kuester, & Rich, 2014; Mellow & Greifinger, 2005; Travis et al., 2001). Nevertheless, there is a growing effort from a range of individuals, including medical practitioners, public health professionals, and government organisations to develop comprehensive discharge planning and re-entry support. Some have referred to this movement as an emerging "re-entry industry" (Thompkins, 2010).

Current prisoner re-entry programmes are typically divided into three phases: programmes that work with inmates within prison, programmes that connect ex-inmates to services during release, and programmes that provide sustained support and supervision after inmates transition to life in the community. Most inmate re-entry programmes focus on health and involve multi-sector collaborations. For example, in Massachusetts, Hampden County Jail has coordinated support between the county sheriff's office, public health department, local medical centres, and public health centres to provide discharge planning, case management services, and healthcare delivery for inmates leaving regional jails. While evaluations of this programme remain incomplete, they do indicate some improved inmate and community health, decreased recidivism, and cost savings (Conklin, Lincoln, & Wilson, 2002).

Since 1990, there have been three major community-based public payers of HIV care for returning inmates, including the federal-funded Medicare, federal- and state-funded Medicaid entitlement programmes, and the discretionary Ryan White HIV/AIDS Program (AIDS Drugs Assistance Program (ADAP)). These programmes have remained critical to the Affordable Care Act (ACA) today (Montague et al., 2012). The ACA provides new opportunities to address low insurance coverage

rates among newly released offenders (Bandara et al. 2015). However, Medicaid has a longstanding policy of excluding coverage to those who are incarcerated, a policy that remains under the ACA (Department of Health & Human Services, 2016). Nevertheless, this changing healthcare landscape has led to some states adopting policies to suspend rather than terminate coverage as a measure to improve continuity of care for released inmates (Medicaid and CHIP Payment and Access Commission, 2018). That said, delays in lifting suspended coverage persist due to communication failures between Medicare Services and the prison system and challenges with patient record sharing (Department of Health & Human Services, 2016). Persons who have their coverage terminated while incarcerated face substantial delays and reapplication. Consequently, prisoners who received Medicaid before imprisonment often lack this health insurance on release. Similarly, disenrollment practices for Social Security Income (SSI) and Social Security Disability Income (SSDI) result in returning offenders suffering without benefits for months or longer, exacerbating financial challenges for those unable to work (Wakeman, McKinney, & Rich, 2009).

Among people living with HIV, formerly incarcerated persons have a higher prevalence of mental illness, substance use, and homelessness, making their transition back into the community incredibly daunting (Haley et al., 2014; Springer & Altice, 2007; Travis et al., 2001). Since 1996, case management interventions to facilitate connections between correctional-based and community-based resources have been developed in settings for HIV re-entry support (Petersilia, 2003; Rich et al., 2001; Westergaard et al., 2013). Previous evaluations provide details of these programmes (Draine, 2011; Springer, Spaulding, Meyer, & Altice, 2011).

Evidence of the achievements of case management programmes remains mixed. Numerous studies demonstrate short-term benefits to linking individuals into care through case management (Avery, Ciomica, Gierlach, & Machekano, 2019; Baillargeon et al., 2009; Gardner et al., 2005). However, a highly cited randomised control trial observed no significant difference between case management and standard discharge release programmes on critical health outcomes, including immediate linkage to care (Wohl, 2011). Other observational studies have shown