It is time for us all to embrace person-centred language for people in prison and people who were formerly in prison

Brendan L. Harney[1,2,3], Mo Korchinski[4], Pam Young[4,5], Marnie Scow[6], Kathryn Jack[7], Paul Linsley[8], Claire Bodkin[9], Thomas D. Brothers[10,11], Michael Curtis[1,2,12], Peter Higgs[1,13], Tania Sawicki Mead[14], Aaron Hart[15], Debbie Kilroy[16], Matthew Bonn[17,18], Sofia R. Bartlett[6]

1 Disease Elimination Program, Burnet Institute, Melbourne, Australia
2 School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia
3 Department of Infectious Disease, Alfred Health & Monash University, Melbourne, Australia
4 Unlocking the Gates Services Society, Maple Ride, Canada
5 Transformative Health and Justice, School of Nursing, University of British Columbia, Vancouver, Canada
6 British Columbia Centre for Disease Control, Vancouver, Canada
7 National Institute for Health Research Nottingham Biomedical Research Centre, Nottingham University Hospitals NHS Trust, Nottingham, United Kingdom
8 Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, United Kingdom
9 Department of Family Medicine, McMaster University, Hamilton, Canada
10 Department of Medicine, Dalhousie University, Halifax, Canada
11 UCL Collaborative Centre for Inclusion Health, University College London, London, United Kingdom
12 Monash Addiction Research Centre, Monash University, Melbourne, Australia
13 Department of Public Health, La Trobe University, Melbourne, Australia
14 Just Speak, Wellington, New Zealand
15 VACRO, Melbourne, Australia
16 Sisters Inside, Brisbane, Australia
17 Canadian Association of People Who Use Drugs, Dartmouth, Canada
18 International Network for Health and Hepatitis in Substance Users, Sydney, Australia

ABSTRACT

The use of person-centred language is well accepted regarding substance use and infectious disease healthcare and research, and appropriate acronyms have become commonplace, e.g., “people who inject drugs (PWID)” has mostly replaced phrases like “injecting drugs users”. However, the use of the term’s ‘prisoner’ or ‘prisoners’ remains common. Although less common, terms such as ‘offenders’ and ‘inmates’ are also still used on occasion. This persists despite calls from people with lived experience of incarceration, and fellow academics, to stop using these terms. Given the considerable overlap between substance use, infectious diseases, and incarceration, in this commentary we discuss how they interact, including the stigma that is common to each. We propose that using person-centred language (i.e., people in prison or people formerly in prison) needs to become the default language used when presenting research related to people in prison or people formerly in prison. This is a much-needed step in efforts to overcome the continued stigma that people in prison face while incarcerated from prison officers and other employees, including healthcare providers. Likewise, overcoming stigma, including legalised discrimination, that follows people who were formerly in prison upon gaining their freedom is critical, as this impacts their health and related social determinants, including employment and housing.

1 *"When we are not called mad dogs, animals, predators, offenders and other derogatory*
2 *terms, we are referred to as inmates, convicts, prisoners and felons—all terms devoid of*
3 *humanness which identify us as "things" rather than as people. These terms are accepted as*
4 *the "official" language of the media, law enforcement, prison industrial complex and public*
5 *policy agencies. However, they are no longer acceptable for us and we are asking people to*
6 *stop using them."*
7 Eddie Ellis, person who was formally in prison and founder of Center for NuLeadership on
8 Human Justice and Healing
9
10 The above quoted letter written in 2007 by Eddie Ellis passionately advocates for the use of
11 person-centred language with regard to incarceration and clearly identifies 'offenders',
12 'inmates', 'convicts', 'prisoners' and 'felons' as dehumanising terms (Ellis, 2007). Within the
13 fields of substance use and infectious disease healthcare and research, most of these terms are
14 fairly uncommon, however they are still used. Notably 'prisoners' is still commonly used in
15 manuscripts published in leading international journals and abstracts presented at major
16 global conferences. In contrast, the use of person-centred language is common regarding
17 substance use (e.g., people who inject drugs), and infectious diseases (e.g., people living with
18 HIV). Indeed, this language is insisted upon, and in some cases enforced, by many journals
19 and conferences. A major reason for the advocacy of such language is because of the stigma
20 that is all too common regarding substance use and infectious diseases, which adversely
21 impacts on the health and opportunities of people who experience this stigma and related
22 discrimination. Given the considerable overlap between substance use, infectious disease, and
23 incarceration, we suggest that person-centred language should also be used regarding
24 incarceration. In his letter, Ellis goes on to state *"We also firmly believe that if we cannot*
25 *persuade you to refer to us, and think of us, as people, then all our other efforts at reform and*

change are seriously compromised." We wholeheartedly agree with this statement. At the heart of this commentary, we ask the question; if we are accepting of and insistent on person-centred language as one means to try and overcome stigma related to substance use and infectious diseases, do people in prison, or people who were formerly in prison, not also deserve this to try and reduce the discrimination that is endorsed by the structural, social, and internalised stigma they continue to face? In what follows, we explore stigma as a concept, discussing the linkage from ancient roots to modern application. We then focus on stigma in relation to infectious disease, substance use, and incarceration. This is followed by an overview of person-centred language, including with regard to incarceration. We close with our thoughts on how we, as a collective body, can further address this within substance use and infectious disease healthcare and research.

STIGMA, A BRIEF HISTORY

Stigma as a modern sociological concept is oft attributed to Erving Goffman and his work *Stigma*: *Notes on the Management of Spoiled Identity* (Goffman, 1968). It is important to recognise however that stigma is not a new concept that emerged in the mid to late 20th century. Goffman himself noted that stigma originates from ancient Greece – *"signs were cut or burnt into the body and advertised that the bearer was a slave, a criminal, or a traitor – a blemished person, ritually polluted, to be avoided, especially in public places"*. Stigma, as per Goffman, is suggested to be a term used to refer to an attribute that is deeply discrediting (Goffman, 1968). Link and Phelan have built on this and conceptualised stigma as requiring five interrelated components; distinguishing and labelling differences, linking labelled people to negative stereotypes, categorisation of "us" from "them", status loss and discrimination leading to unequal outcomes, and access to power that allows disapproval, rejection, exclusion and discrimination to occur (Link and Phelan, 2001). Building upon this seminal piece, stigma has been recognised as a fundamental cause of population health inequalities (Hatzenbuehler et al., 2013).

More recently, Imogen Tyler focuses on stigma as a practice of exploitation and social control, and frames stigma as a machinery of inequality (Tyler, 2020). This framing by Tyler is potentially most evident regarding incarceration. For example, in The New Jim Crow, Michelle Alexander points out that in the United States of America discrimination directed toward people who were formerly in prison is often perfectly legal regarding employment, housing, voting rights, and access to public benefits (Alexander, 2012). In what follows, we provide a narrative overview of the intersection of infectious diseases, substance use, incarceration, and stigma.

INTERSECTIONAL STIGMA

Many infectious diseases are highly stigmatised including, but not limited to, HIV (Chambers et al., 2015), hepatitis C virus (Paterson et al., 2007), tuberculosis (Daftary et al., 2017) and more recently COVID-19 (Bhanot et al., 2021). HIV, hepatitis C virus and tuberculosis are well recognised to disproportionately affect people in prisons compared to their surrounding communities (Rich et al., 2016). As noted by Rich et al. this is at least partially a result of the criminalisation of drugs, an ongoing legacy of the failed war on drugs. Regarding HIV and hepatitis C virus, enacted stigma, or more simply legalised discrimination, in prisons is shown through the denial of equivalence of care to evidence-based harm reduction including medically prescribed opioid use treatment and needle and syringe programs in many countries (Kamarulzaman et al., 2016). Likewise, despite evidence that hepatitis C treatment is feasible and effective in prison settings, this is still not available in many jurisdictions (Akiyama et al., 2021). Furthermore, the confiscation of other prescribed medicine has been reported by people in prison (Edge et al., 2020). While perhaps more subtle, this is also evidenced with regard to tuberculosis, through the over-crowding of prisons, delayed case detection, and inadequate infection control measures (Dara et al., 2015). These factors are likely what has also contributed to people in prison also being adversely affected by COVID-19 (Franco-Paredes et al., 2020, Oladeru et al., 2020).

Substance use, and particularly illegal substance use, attracts a considerable amount of stigma. It is important to note however a hierarchy within how substances are criminalised (or not) and the level of stigma they attract. For example, there is increasing acceptance of cannabis including decriminalisation and legalisation in several US states, Canada, and a handful of other countries (Hammond et al., 2020, Cerdá and Kilmer, 2017, Cabral, 2017). In contrast, the use of substances such as cocaine, heroin, and methamphetamine remains

criminalised almost universally. While these three substances may be consumed in numerous ways, the literature that is available indicates stigma is more common regarding injection drug use rather than other forms of consumption (Luoma et al., 2007, Etesam et al., 2014). It is also generally recognised that stigma related to the hepatitis C virus is primarily driven by the association with injection drug use (Paterson et al., 2007, Treloar et al., 2013) rather than hepatitis C virus itself. This is evidenced more broadly in Australian society with data indicating people hold more negative attitudes towards people who inject drugs than people living with HIV or hepatitis C (Broady et al., 2020). As discussed by Broady et al., this is likely a result of drug use being a criminalised activity, and being a "modifiable" behaviour as opposed to a medical condition such as HIV or hepatitis C. However, this is revealed differently depending upon the situational sub-group context. For example an Australian study found that among people who inject drugs within prison, hepatitis C stigma was common, having the potential to disrupt networks and lead to social isolation (Rance et al., 2020).

Beyond enacted stigma faced while in prison, stigma continues to impact the life of people who were formally in prison in numerous ways. Research from Canada and the United States indicates that people who were formerly in prison may have difficulty in being accepted as a patient by primary care doctors (Fahmy et al., 2018) and difficulty in obtaining housing and employment upon gaining their freedom (Keene et al., 2018, Hu et al., 2020). In their longitudinal qualitative study, Keene and colleagues highlight structural stigma; that is government policy that enables housing to be denied to people with a history of incarceration, including low-income subsidised housing. They also build on their concept of spatial stigma (Keene and Padilla, 2014) in highlighting how people who were formally in prison often have to resort to staying in accommodation such as homeless shelters, which in turn limits their

ability to find employment as employers are reluctant employ people living in such settings. This stigma, or more bluntly in some cases legalised discrimination, may result in people who were formally in prison having to live in precarious environments which likely exposes them to an array of adverse health outcomes. This may include an increased risk of acquiring infectious diseases such as HIV and hepatitis C virus (Stone et al., 2018, Arum et al., 2021) and also increases their risk of having a fatal overdose (Farrell and Marsden, 2008, Merrall et al., 2010). Likewise, in order to support themselves, and potentially family members, they may have to engage in activity that increases their risk of adverse health outcomes, including being reincarcerated. It is also important to recognise that incarceration not only impacts the lives of those incarcerated; it also impacts families, and particularly children (Myers et al., 1999) of those incarcerated. These families and children are also likely to experience stigma as a result of their family member, mother, or father being imprisoned (Dawson et al., 2013, Phillips and Gates, 2011).

LANGUAGE MATTERS

The words we write or speak have immense power and are part of societal discourse which both influences and is influenced by public policy. We contend that the words we use have the power to respectfully, and accurately, represent people and ideas; they also have the ability to perpetuate ignorance and bias, leading to stigmatisation and discrimination.
One approach to reducing stigma within society is the advocacy for person-centred language. We note this may also be referred to as person-first language, however we use person-centred language as this correlates with the broader concept of person-centred care (Entwistle and Watt, 2013, Håkansson Eklund et al., 2019). Person-centred language has its roots within the disability self-advocacy movement that emerged in the mid 1970’s after decades of

domination by ‘professionals’, who did not always have their ‘clients’ best interests in mind (Wehmeyer et al., 2000). Person-centred, inclusionary language is now broadly advocated for within the American Medical Association Manual of Style (American Medical Association, 2020) and by the American Psychological Association (American Psychological Association, 2021). Person-centred language regarding infectious diseases is also now well established, the first notion of which is often attributed to the Denver Principles (People with AIDS advisory committee, 1983). These principles are now well-accepted within the healthcare and academic research community and generally have been applied to other infectious diseases such as hepatitis C and tuberculosis (Frick et al., 2015).

With specific reference to substance use, person-centred language and the avoidance of stigmatising language has been advocated for by academics (Zgierska et al., 2021) and government bodies such as Health Canada (Health Canada, 2021). Similarly, despite their own problematic name that we contend may perpetuate stigma, the National Institute on Drug (Ab)use now also recommends the use of person-centred language and has published a list of words to avoid, including ‘abuse’ (National Institute on Drug Abuse, 2021). Other groups have also composed guidelines focused on person-centred language usage by journalists in media reporting on issues related to substance use (Health in Justice Action Lab, 2019, AOD Media Watch, 2021).

LANGUAGE MATTERS FOR EVERYONE

The first challenges to the habit of referring to individuals as 'prisoners', or other equally dehumanising terms such as 'inmates', 'felons' and 'offenders' emerged in the early 2000s in the United States, and were led by people with lived experience of incarceration (Cox, 2020). This is also reflected in language policy from mainstream think-tanks working in the 'criminal justice' sector (La Vigne, 2016, La Vigne, 2018). Furthermore, the annual conference hosted by the Academic Consortium on Criminal Justice Health in the USA specifies that stigmatizing language be omitted from the proposals and presentations, and suggests a suitable glossary of terms (Academic Consortium on Criminal Justice Health, 2021). The National Commission on Correctional Health Care in the USA also advocates for the use of person-centred language regarding people who are incarcerated (The National Commission on Correctional Health Care, 2021). Similarly, the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine language guide also indicates that 'prisoner' should not be used (Australasian Society for HIV Viral Hepatitis and Sexual Health Medicine, 2021).

Other groups composed of people with lived experience of incarceration and academics have also discussed the importance of avoiding dehumanising language (Bedell et al., 2019, Tran et al., 2018). Rather than defining people by an experience or one aspect of their identity, Bedell et al. argue that person-centred language is the bedrock for dignity and shared decision making. This is echoed by Tran et al. who remind us that stigma can be created and reinforced by the labels we use. The resultant felt and enacted stigma can lead people to be both excluded from or not seek out required health care. Both Bedell et al. and Tran et al. identify the use of the word 'prisoner/s' as problematic. The terms 'offender', 'inmate' and 'convict' are also considered equally devaluating and dehumanising (Tran et al., 2018) and

alternatives such as *Person who is Incarcerated, Person in Jail* or *Person in Prison* are recommended.

With specific regard to people in prison, the terms used in healthcare and academic research should also recognise the fact that the time people spend in custody is usually temporary and often short lived, therefore being a 'prisoner' is an impermanent state. For example, many people in prison in Australia receive a sentence of less than 12 months, and due to the ongoing legacy of colonialism and racial injustice, Aboriginal and Torres Strait Islanders disproportionately receive short sentences rather than non-custodial alternatives (Australian Law Reform Commision, 2017). In a similar manner, mandatory minimum sentencing laws in Canada disproportionately impact Indigenous people, Black people, and other members of racially minoritised communities (Mangat, 2014, Canadian Association of Social Workers, 2020). It is worth noting that alleged drug offences constituted 75% of all admissions to federal custody in Canada between 2007 and 2017 based on these mandatory minimum sentencing laws (Department of Justice Canada, 2017). Therefore, the continued use of 'prisoner', or other stigmatising terms likely further contributes to stigma and discrimination already faced by people who use drugs due to the automatic association with criminal behaviour within society. Likewise, people who are Indigenous, people who are Black and other racially minoritised communities are over-represented in prisons due to racist policing and prosecution (Banks, 2009). Therefore, we suggest that the continued use of 'prisoners' will potentially perpetuate ongoing stigma and discrimination faced by these groups in their everyday life.

"BARRIERS" TO CHANGING THE LANGUAGE WE USE

A concern with changing this language is contributing more words to often tight word limits. As people who write journal manuscripts and conference abstracts, we empathise with this concern. If really required, this can be overcome by the use of acronyms, however a common instruction in academic writing is to avoid “non-standard” acronyms. As a result, many academics, peer reviewers, and editors have argued that acronyms for people in prison (PIP) are non-standard, therefore cannot be used in manuscripts or abstracts; we emphatically challenge this notion. As we have already discussed, previously people were referred to as “injecting drug users” – this changed to people who inject drugs (PWID) after years of campaigning by the affected community to advocate for the use of person-centred and non-stigmatising language. Our use of this acronym is no longer questioned; indeed, many of the authors have used it multiple times in published scholarly work. Similarly, the use of “homosexuals” has been replaced by more accurate and inclusive terms such as men who have sex with men (MSM) which is commonly used in academic journals.

So why is the use of people in prison (PIP) not yet de rigor? Likewise, why are we so strongly focused on person-centred language regarding substance use and infectious diseases, but not regarding incarceration? We suggest this is at least in part because people in prison do not have a strong community voice, nor do we routinely seek their input and treat them as partners in research projects. Even when efforts are made to do so, this is often made difficult by prison management and/or government departments responsible for ‘corrections’ and ‘justice’. We contend that this is another way that people in prison are punished, as they are cut off from many forms of communication. The stigma of incarceration can also internalise and stay within for many years, therefore even those people who have returned to the community may not wish to disclose their history of incarceration and may face barriers to

speaking up on their own and others' behalf. Therefore, we suggest person-centred language should become the default language used and that terms such as people in prison, and their acronyms if so required, would become widely accepted the more often and routinely they are used in academic literature and conference presentations, or recommended by peer reviewers and journal editors.

It is important to note that people with lived experience of incarceration may choose to refer to themselves and their peers however they wish. This topic has been discussed in considerable detail regarding autism related research with continued discussion as to whether person-first language or identity-first language is more appropriate (Botha et al., 2021, Vivanti, 2020). This also draws parallels with concern about the erasure of sexual identity when the terms men who have sex with men (MSM) and women who have sex with women (WSW) are used (Young and Meyer, 2005). Indeed, the reclamation of gay and bisexual identities is evident with the increasing use of the term "gay, bisexual and other men who have sex with men" and the related acronyms GBM or gbMSM in academic literature. This alludes to the point that the language used in academia, and society more broadly, is constantly evolving and we need to be humble and accepting of this evolution. Even the language used by the first author, someone without lived experience of incarceration, in the initial drafting of this commentary changed following the input from a co-author with lived experience of incarceration.

Some may wonder if the language used by academic researchers is of any concern to people with lived experience of incarceration, as they are rarely in the audience at scientific conferences and too few of them have access to pay walled literature. Indeed, this was a point raised by some of the people with lived experience of incarceration who were involved in the

writing of this commentary. While it could not be agreed how much people in prison care about being referred to as 'prisoners' in journal articles, it was agreed that the language used by prison officers and the media to refer to people in prison is frequently dehumanising, hurtful, and degrading. Similarly, we contend that prisons are often by design an intentionally dehumanising, hurtful, and degrading environment; and that imprisonment is more often than not an inadequate solution to address decades, or centuries, of racist and classist policies enacted by both 'left-wing' or 'liberal' and 'right-wing' or 'conservative' governments globally. This commentary should not be taken as an effort to neglect this reality. Rather we hope that the use of person-centred language may in due course hopefully contribute to a more positive societal discourse that starts to address this.

It is important to note that it remains an open question as to what terminology is most appropriate. The first draft of this commentary as an example used the term people who are incarcerated regarding people who are currently in prison. We ultimately chose to use the term people in prison as this was emphasised by some authors with lived experience of incarceration to be their preferred term. In addition, the focus of our commentary was on research related to people who have received a prison-based sentencing order as opposed to people in jail or people on remand awaiting sentencing. For full transparency, some authors with lived experience of incarceration and their organisations still do use the term prisoners and are primarily focused on the language used post-incarceration and the related stigma and discrimination that continues to occur. As already discussed, people with lived experience can refer to themselves and peers however they wish to. What we suggest is that healthcare professionals and researchers should make a conscious effort to pro-actively ASK people how they would like to be referred to in any subsequent publication of research they are involved in. While acronyms may be used, they are not always required; after establishing the

setting i.e., a prison, perhaps we could simply refer to people as participants, or maybe even people? If the opportunity does not present itself to ask this question, we suggest that person-centred language should be the default in research related to people in prison or people formerly in prison.

WHERE TO FROM HERE?

In this commentary we have highlighted how changing the language used in relation to infectious disease and substance use has been used to address the stigma associated with them. The acceptance and promotion of person-centred language is a tool that has been underutilised in efforts to overcome the stigma associated with incarceration. People in prison or formerly in prison deserve to be treated with humanity, and one of the first steps towards this is academic journals, and conferences, requiring person-centred language to be used in research regarding people in prison or people formerly in prison. While we note that the International Journal of Drug Policy, and Elsevier, have a policy on the use of inclusive language, it makes no mention of conveying respect to people who are incarcerated. As a group of co-authors consisting of people with lived experience of incarceration, people who deliver frontline services, prison abolitionists and reform advocates, healthcare professionals, and academics conducting research related to the health of people who experience incarceration, we are calling on the editorial boards, reviewers, and contributing authors of all journals to reflect on their language choices; and especially in relation to work regarding the overlapping issues of infectious disease and substance use.

All journals already have extremely detailed author instructions; the use of person-centred language could easily be added to these instructions including a language guide based on

those already cited in this commentary with that from the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine being a particularly comprehensive example (Australasian Society for HIV Viral Hepatitis and Sexual Health Medicine, 2021). Although still a minority compared to healthcare providers and academic researchers, people with lived experience of infectious diseases and substance use are slowly being more commonly included as co-authors on publications and as speakers at conferences. Some of these people also have lived experience of incarceration, including co-authors of this commentary. Regardless of lived experience of infectious diseases and/or substance use, further efforts should be made to engage people with lived experience of incarceration in educational sessions for academics and healthcare providers, and as partners, rather than solely as participants, in designing and evaluating health care interventions.

We recognise that evidence of person-centred language having direct impact on stigma reduction is lacking. This may seem counter-intuitive to our advocacy for person-centred language for people in prison and people formerly in prison, however, this is somewhat true of stigma reduction interventions generally, with mixed results reported (Rao et al., 2019, Kemp et al., 2019). In addition, as we have already discussed, dehumanising language can perpetuate stigma and it is generally accepted that stigma can have a detrimental causal impact on health outcomes (Hatzenbuehler et al., 2013). Therefore, if stigma causes detrimental health outcomes, it perhaps is a reasonable argument that efforts to reduce stigma, including through the conscious use of person-centred language, has a theoretical underpinning. It is also important that the advocacy for person-centred language should not be seen as an isolated intervention. Rather, just as with any well-designed health care intervention, it should be one part of a suite of interventions targeted at multiple levels including individuals, their immediate communities and broader society (Stangl et al., 2019).

Likewise, as discussed by Hatzenbuehler et al. and Stangl et al. people often experience stigma for more than one reason. This adds complexity to interventions to overcome and reduce stigma however it is crucial that this be acknowledged and addressed.

There are some areas of incarceration we have not discussed in this commentary. We have focused this commentary on people in prison or who have been in prison as a result of a court-based sentencing decision as opposed to people who have been arrested and jailed and/or are being held on remand, (i.e., pre-trial detention). There is much overlap between these groups and therefore we suggest that any related work among people in jail or on remand should also follow the use of person-centred language. Similarly, we have focused on the adult prison system however we also strongly advocate for and emphasise that person-centred language should be used regarding children who are incarcerated in juvenile detention, which ultimately is just prison for children. Immigration detention is another area we have not touched on in any detail. While there are a multitude of problems with this system globally and no doubt associated stigma, this area is beyond the lived experience and work experience of the authors of this commentary; therefore, we do not feel qualified to provide detailed commentary. This is an area that should be explored further by those working in that field and with lived experience of immigration detention.

While we have focused on the overlap of infectious diseases, substance use and incarceration, we would like to emphasize that we support the use of person-centred language for everyone, including the practice of engaging with research participants to understand what their preferences are regarding how they are referred to in publications and presentations. We also recognise that we did not always use the language we are advocating for here. In a similar manner, we do not suggest that terms such as ‘prisoners’ or similar terms have been used

intentionally by our colleagues to perpetuate stigma; as such, we made a conscious decision to not cite examples. However, after critical thought, reflection, and engaging with research participants on this topic, we now prioritise the use of person-centred language when speaking or writing about people in prison or people formerly in prison, and we feel it is time we all take up this practise. It is the intention of this commentary to raise awareness of the need to be self-reflective and conscious about language choice, as the names we use for our potential or actual patient and research populations may either harm or enhance their health and well-being. Throughout history, society has deemed people in prison or people who have formerly been in prison as the lowest of the low; as such we finish with a quote from Nelson Mandela to reflect on; *"No one truly knows a nation until one has been inside its jails. A nation should not be judged by how it treats its highest citizens but its lowest ones."*

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