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Inaugural session

The COVID-19 pandemic and ensuing occupational disruption: Exposing the lie that "we're all in this together"

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Please note: these are my speaking notes, and as such, do not have the requisite citations (these were included on my power point slides).

It is an honour for me to have been asked to present the inaugural lecture for the University of Brighton's All About Occupation Seminar Series. I'm sincerely grateful to Dr Bex Twinley for this opportunity. This is the first time that I've ever been invited to speak for an event in my home country, so I'm quite excited! I'm particularly pleased that these seminars are free, and am hoping this will open up valuable learning opportunities for all those usually excluded from the goings on in privileged academic enclaves and expensive professional conferences.

The idea that some people enjoy access to educational opportunities that are denied to others leads into the topic Dr Twinley suggested I might talk about today: occupation during the COVID-19 pandemic. So, this will be the core of my presentation, but I shall be weaving in other ideas that provide some context for our current crises – there's more than one - and that situate some of my thoughts about occupation and occupational therapy.

In March 2020, within the first few days of Canada's nationwide lockdown, I was asked by the Canadian Association of Occupational Therapists to write something for our profession's members about what we were all beginning to experience. I called my paper: "Engagement in living during the COVID-19 pandemic and ensuing occupational disruption". In writing it, I wanted to acknowledge the significant life disruption we were suddenly experiencing, and to encourage occupational therapists to recognise the valuable resources and knowledge they already possessed; resources they could draw on to help them adjust to this new and unwelcome reality. Seeking to address the prevailing sense of uncertainty, I encouraged occupational therapists to apply to their own lives the insights they had gained from their clients - people who had learned how to achieve wellbeing despite profound – and often permanent – disruptions to their lives; and I centred my thoughts on what was already known about the centrality of occupation to wellbeing. I wanted to foster hope and a sense of confidence in our individual and collective capacities for resilience.

But because most of my work is underpinned by concerns about injustice and inequity, I also sought to draw attention to the privilege of those occupational therapists who – like me – had tended to enjoy lives of deceptive predictability and illusionary safety. I noted that for many people who shared with me the experience of social privilege, it was frustrating to endure - albeit temporarily - the sort of deprivation of occupational opportunities usually reserved for disabled people and others marginalized and disempowered by poverty and racism; people for whom life is consistently unpredictable and fraught with uncertainty.

That was 15 months ago; and I'm appreciative of this opportunity to look back at my ideas through the rear-view mirror, and to ponder what's been learned in the interim.

Because I'm going to be talking about injustice and inequity, it is necessary for me to acknowledge my position as a White, class-privileged, straight, cis-female, with neither physical impairments nor mental health challenges. If "cis-gendered" is a new term for you, it simply means that the gender the midwife assigned me at birth is the gender with which I have always self-identified. It's another component of my identity - like my white skin and my able body - from which I derive material benefits, occupational advantages

and social privileges that I have never sought and have not earned. But this is how privilege works.

My failure to achieve any degree of competence in a language other than English is symptomatic of the privilege I derive from global Anglophone dominance. I also enjoy the advantages of holding dual citizenships. I'm an immigrant citizen of a colonized territory - Canada - in addition to being a citizen of Britain: a nation that invaded, occupied and influences vast regions of the world as part of its colonial agenda. For half the year I live in Vancouver, on the ancestral, traditional and unceded territory of the Tsleil-Waututh people; and for the other half, in the Souris River valley in Saskatchewan, on Treaty 2 land, which is part of the traditional territory of the Blackfoot Niitsítapi Cree people, and the homeland of the Métis nation. This is where I am now. I recognise the unjust history and problematic present enabling my presence on these stolen lands.

Since the first weeks of 2020, measures taken to try to limit the spread of the COVID-19 virus have disrupted the lives of billions of people around the world. In the early days of the pandemic, as we all shared the experience of unpredictability and uncertainty, and constraints on the abilities and freedoms many of us had tended to view as rights and entitlements, politicians assured us that "we're all in this together". It was a nice idea, but we weren't all in it together. And they knew we weren't.

From the earliest days of the pandemic it was obvious that members of poor, racialized communities in the Global North were significantly more likely to die from COVID-19 than White people enjoying more privileged economic circumstances. First Nations and Indigenous people, Black folk and others from minority ethnic groups have suffered the consequences of a constellation of systemic inequities that have significantly increased their risk of contracting COVID-19, and their risk of death. These factors have included poor quality overcrowded housing in densely-populated communities that have afford few opportunities to enact physical distancing, severe economic disadvantages that have led to difficulties obtaining masks, hand-sanitizer and healthy food, inequitable access to health care resources, limited economic resources that have offered no alternative to the use of public transportation, engagement in precarious employment, or employment in poorly-paid, yet essential jobs providing services to those enjoying the privilege of working from, or staying home; all these factors have conspired to significantly raise the risk of exposure to, and death from the coronavirus for specific groups of people. The burden of the pandemic has not been shared equally across society. We have not been in this together, and social injustice has killed people.

And of course, we knew it would. Decades of epidemiological research into the social determinants of health had already held up a mirror to the inequities and injustices deeply embedded in our societies; and epidemiologists had been insisting for years that "social injustice is killing people". In addition to assuring us that "we're all in this together" politicians have told us that the coronavirus doesn't discriminate. It doesn't. And it doesn't need to. Existing social inequities already guaranteed that certain groups of people would experience significant inconvenience and thwarted plans while other groups would endure significant suffering and death.

Long before the pandemic, it was known that in high-income countries, such as Canada and the UK, 50% of health outcomes are attributable to the social determinants of health. These “social determinants” are the conditions in which people are born, grow, live, work and age; and they include factors such as education (especially early childhood education), employment, food security, housing, transport, economic status, social support and access to health care.

It was already known that people living in poverty have more illnesses and more injuries than do people in middle and upper classes. In fact, epidemiological research had demonstrated clearly that a social gradient exists at *all* income levels, such that each socioeconomic group experiences worse health and lower life expectancies than the group immediately above it. Incidences of all manner of diseases, from diabetes, respiratory diseases and stroke, to mental illnesses, suicide, accidental and violent deaths *all* follow a social gradient, with those who are lower in the socio-economic hierarchy having higher risks: the lower the status, the higher the risk. These inequities are particularly pronounced in profoundly unequal societies, such as Canada, the United States and the UK. Moreover, people who become ill or disabled are at high risk of falling from privilege and plummeting down the socioeconomic hierarchy. It ought not to be surprising that disabled people are disproportionately likely to experience difficult socioeconomic circumstances and inequitable occupational choices that may have little to do with their abilities, and everything to do with their opportunities.

Before the pandemic it was already known that in many American, Canadian and British cities people living in wealthy neighborhoods can expect to live more than 20 years longer than people living in poor neighborhoods within the same city. Clearly, this is unfair. Life should not be a by-product of privilege.

But how can this be possible? Poverty and income insecurity exert profound impacts on health, not solely because of limited access to healthy food, healthy homes and healthy work environments (each of which is identified as being a determinant of health), or because of gender inequities (also a determinant of health), but because people in lower positions in the social hierarchy have less opportunity for control over their lives, and unequal opportunities for full social engagement and participation.

Why is this possible? Well, critical epidemiologists have been telling us for more than a decade that the unequal distribution of health-damaging experiences and inequitable opportunities to participate in society are not randomly distributed, but are produced by social forces and structures that are “the result of a combination of poor social policies and programmes, unfair economic arrangements, and bad politics”. This is why I use the term “inequity” to refer to differences that are avoidable, unfair and unjust, and to differentiate these from differences that are simply unequal. Similarly, critical epidemiologists use the term “health inequities” when referring to inequalities that are avoidable, in recognition that the existence of systematic, widespread, persistent and unnecessary differences in people’s capabilities to be healthy are both unjust and unfair. Because health inequities are avoidable, they are manifestly unfair.

There is a voluminous body of research clearly documenting the impact of inequities on human health and longevity. For example, research shows that recurrent exposure to racism negatively impacts physical and mental health and reduces life expectancies.

The Black Lives Matter movement, which resurged following the murder of George Floyd by a white US police officer, justifiably focused global attention on systemic racism and police violence. But of course Black Lives Matter is not about the wrongful death of one man. It's about the systemic racism that has diminished, imperilled and ended the lives of untold numbers of Black folk and others from minority ethnic groups, across the Global North over hundreds of years. Systemic racism is a determinant of health, and systemic racism kills people.

It is obvious that having fair skin doesn't provide any inherent survival benefit; and it is obvious that being Black or brown doesn't diminish one's health or shorten one's life. But systemic racism certainly does; it has real effects in the lives of real people. As researchers in the UK began to tease apart data from the COVID-19 pandemic, it became apparent that health care workers from Black, Asian and other minority ethnic communities have been disproportionately affected. For example, 94% of medical doctors who died from COVID-19 in the first months of the pandemic were people of colour, yet just 13% of the UK population as a whole are from minority ethnic groups. Clearly, the disproportionately high mortality rates among Black, front-line doctors could not be attributed to poverty, so what could possibly account for this yawning inequality? Critical researchers noted that doctors from Black, Asian and other minority ethnic groups experienced more pressure than White doctors to see patients in high-risk settings without adequate personal protective equipment; and they are twice as likely as White doctors to be reluctant to raise safety concerns in the workplace due to the fear of systemic racism. Systemic racism is a determinant of health, and systemic racism kills people.

So I want to just pause here to revisit what I understand by the term "systemic racism". When someone is labelled a "racist" it tends to be because they have said something hateful, threatened something horrible, or done something reprehensible to someone else because of a warped sense of racial and religious superiority. So naturally, most people don't like to think of themselves as being racist. In fact, because most people see themselves as being fundamentally good they resent the suggestion that they are in *any way* implicated in racism. But that's not what systemic racism is about. It's not about a few "bad apples". In fact, institutionalised racism doesn't need individual bigotry in order to function, because it is "baked in" to every dimension of our lives.

Race, of course, has no actual biological basis, but is a social construction; an invention and tool of colonialism intended to divide people into superior and inferior groups by virtue of their skin pigmentation. This has always been an unscientific endeavour. Over the course of history, English people who looked white but were of low socioeconomic status were not accorded White status; and for a very long time, Irish Catholics were not deemed to be White. Even today, some people are accorded White status in some places and times and not others. But this is because this arbitrary classificatory system is about power, privilege and access to resources; it's not about biology. It never was.

As a White person, my understanding of White privilege is constantly evolving. For much of my life, I honestly didn't know White privilege was a thing. Although I have always recognised the unearned advantages and opportunities that accrue to me because of my able body, to my shame, I didn't recognise the degree to which I am also unjustly advantaged by the colour of my skin. So "systemic racism", as I understand it, refers to the ways in which governments, businesses and professions employ a structure - or system - of policies, practices and decisions that are created, shaped and maintained to entrench White privilege, preserve the unearned advantages of the racially dominant group, reproduce material inequalities, and embed inequities in all aspects of life, including education, employment, housing, justice and health care.

In fact, because this entrenched system of injustices protects and reinforces White privilege – *as it is intended to do* – I often use the term "systemic White supremacy" to identify the function of structural racism and to name the agenda that it is intended to serve.

The racist system of White privilege into which we are born and then thoroughly enculturated, permeates the structure of society in the Global North - shaping the availability of life chances and choices - yet it's invisible to most white people, as it often is to me. So, because race, and other socially-constructed hierarchical categories, such as gender, class and sexuality affect "the perceptions, experiences, and opportunities of *everyone* living in a society stratified along these dimensions", these systems have to be deliberately noticed and consciously "unlearned" and contested if we aspire to achieve a world in which we might reasonably claim to be "all in *anything* together".

So far, I've tried to sketch a little of what is known about health inequities, and to illustrate why exposure to, and death from COVID-19 has been largely determined by social factors. But *occupation* also has social determinants. Evidence demonstrates that class and caste inequities, poverty, sexism, patriarchy and misogyny, colonialism, racism, disablism and gender binarism - that are well-documented determinants of health and wellbeing - are also determinants of occupational opportunity and engagement. Regrettably, these inequities are usually unnamed, unexplored and unchallenged within the occupational therapy literature, as if they don't exist, or don't matter.

But inequitable opportunities determine the occupations people can envision doing, can choose to do or are able to do. For example, in every part of the world, disabled people are subjected to prejudice, stigma and discrimination, experience disproportionate levels of poverty (especially abject poverty), and inequitable access to education and employment opportunities; disabled people encounter inadequate housing options, inequitable access to transportation, buildings and technology; to green spaces, arts, cultural, social, religious, recreation and other community resources due to the specific ways societies are structured and organised to benefit the dominant population. I think it's instructive that virtual participation in religious services was rarely available for disabled, ill and elderly people prior to the pandemic, but was made available within days of the first lock-down, when privileged social groups suddenly found themselves unable to access the buildings of their various faith traditions. It's been fascinating to see how equality of access morphed from "unreasonably expensive" to "essential" over the course of one weekend.

Before the current pandemic, it was already well-known that occupational opportunities and the capabilities to enact occupational choices are inequitably distributed. COVID-19 may have illuminated these inequities, but it didn't create them. During the past year, many members of privileged social groups have been able to work from home, enrich their children's education with online access to teachers and other learning resources, engage - not solely with families, friends, colleagues and other social networks - but with yoga classes, cooking classes, language classes, dance classes, music groups, choirs, games and so much more through in-home access to internet platforms. Using this same internet access, and the associated advantage of financial assets, privileged group members have also been able to order books, puzzles, toys and games for home delivery, have enjoyed the luxury of home grocery deliveries and the opportunity to enjoy exercise and relaxation in pleasant, safe greenspaces.

But occupation is socially determined, and those in less privileged social circumstances have been far less likely to have home access to the internet, far less likely to have the resources to bulk-purchase groceries or to buy books and toys for their children, and far less likely to have access to pleasant greenspaces in which to walk and relax, and in which their children might safely play. They have suffered the effects of inequitably distributed occupational choices, and their children, also, have suffered from occupational inequities. This is what occupational injustice looks like.

In many rural areas, even in wealthy regions, reliable, high speed internet access remains an inequitably distributed public resource. In fact, this is why I opted to pre-record this talk! I'm planning - and hoping - to join you for the discussion after my presentation, but because I'm in a remote, rural area, my opportunities to engage in any occupations that require internet access are unpredictable. For the many people unable to afford home computers and internet connections, my occasional inconveniences and annoyances are their unrelenting realities; limiting their opportunities for education, employment, recreation, social and spiritual support and health care. This is what occupational injustice looks like.

As a profession, occupational therapy hasn't expended a great deal of energy in contemplating the two polarities of inequity: unfair disadvantage and unfair advantage; or, indeed, to critiquing the flawed assertions that have been promoted by its leaders. It's nearly twenty years since I began my frustrating attempts to expose and challenge the Western, White, classist, and ableist assumptions in which this profession is deeply rooted. I've tried to contest, for example, the notion of "choice" that is central to occupational therapy's theoretical tradition. For many decades Western theorists have been declaring that individuals choose, shape and "orchestrate", or "compose" their everyday occupations; and have portrayed occupational choice as the product of individual volition and rational deliberation. Despite acknowledging the possibility of physical, social, cultural and institutional influences on occupational participation, occupational therapy's dominant theorists have continually asserted that humans participate in occupations as autonomous agents, claiming, for example, that "through informed and wise choice of occupation" people can influence the state of their health and reduce their incidence of both illness and disability.

Obviously, these influential assertions presume that occupational choices are available to everyone, everywhere, and that the opportunities to act on these choices are also

always available. But my glimpse at the very different occupational choices available to different groups during the pandemic effectively refutes this assumption; a claim that made sense to privileged White theorists but was never grounded in evidence. To the contrary, researchers have noted that opportunities are unevenly distributed and that "people do not have equal choices to act". As Venkatapuram astutely observed, "the choices we make depend on the choices we have". Inequities arising from systemic racism, structural poverty, caste, sexism, disablism, and a multitude of other injustices expose the *lie* - that the ability to envision occupational choices and to act on these choices is a function of individual will, determination and ability. Research demonstrates clearly: the ability to choose depends on the availability of real opportunities; and the availability of opportunities is contextually-determined, being shaped by social structures and systemic inequities. Indeed, the Lancet-University of Oslo Commission on Global Governance for Health concluded that "the context in which all human activity takes place presents preconditions that limit the range of choice and constrain action".

The ongoing pandemic has provided stark evidence of the degree to which occupational choices are contextually determined, providing support for Brenda Beagan's contention that "occupation simply cannot be adequately understood without attending to oppression and privilege. Everything we do and don't do, the expectations we face, the encouragement or discouragement we receive, the meanings we attribute to occupations, the impacts of our occupational engagements, the barriers to occupation – all are affected by our membership in social groups both oppressed and privileged". In short, occupations are socially determined.

So here's where I want to zoom out and look at the bigger picture. The current pandemic has focused renewed attention from critics on the economic and political ideology that has dominated the Global North since the 1980s: neoliberalism. Neoliberalism upholds a particular form of globalised capitalism that effectively entrenches and widens existing inequalities of wealth and opportunity, as it is designed to do. In the service of this agenda, governments are committed to cutting taxes for corporations and the wealthy, reducing spending on the social programs that assist those forced to the margins, privatizing public resources and services, and slashing regulations and oversights. The gaps created by "hollowing out" our health and social safety nets became apparent when the pandemic hit. And it was disturbing that within mere days of the first lock-down, many private, unregulated, tax-aversive businesses were clamouring for government money.

Neoliberalism promotes the values of productivity, individualism, self-reliance and independence, demeans dependency, espouses notions of individual choice and personal responsibility for one's circumstances, and blames people for the social problems, ill health and economic woes that are viewed as being the products of irresponsibility and poor choices. Neoliberalism is an ableist ideology. The term "ableism" refers to social practices that centre and privilege able-bodied forms and that preserve unfair advantages and opportunities for those without illnesses or impairments.

Neoliberalism promotes the myth of meritocracy - the misplaced belief that one's race, class, sexuality or gender are irrelevant to one's opportunities or achievements. The

idea that success in life is attributable solely to one's will and skill provides racist and sexist explanations for poverty, inequalities and injustices.

My listing of the features of neoliberalism may sound familiar to occupational therapists; and it should, because this ideology has effectively shaped occupational therapy in the Global North. Echoing neoliberal ideology, occupational therapy has prioritised productivity – especially in work, and has enthusiastically promoted independence – especially in self-care, thereby contributing to an oppressive neo-colonial narrative - that dependence on others is unacceptable. This narrative devalues the lives of disabled people and negates the interdependence that is integral to human wellbeing. Through a preoccupation with individualistic, self-focused occupations (self-care, productivity, leisure) and with individualistic, self-fulfilling notions of doing, being and becoming, the profession has missed or dismissed the fundamental importance of all other occupations.

Some of the occupations missed or dismissed by our dominant models include occupations undertaken to contribute to the wellbeing and future of others, to enact reciprocity, enrich relationships, strengthen social roles, and fulfil duties, responsibilities and obligations to others; shared and collective occupations, occupations that foster self-worth, occupations undertaken to engender hope and a sense of life continuity, occupations that foster connections with families and communities, ancestors and ancestral lands, gods, spirits, cultures and nature; occupations undertaken to care for the natural environment; resource-seeking and survival occupations, restorative occupations, occupations chosen to perform gender identities or foster creativity, and occupations enacted as acts of resistance. Many of these valued occupations have been even more important during the pandemic. But by declaring clearly which occupations we believe to be occupations that "matter" – doing self-care and being productive - occupational therapy has also indicated which occupations we believe do not matter – all the rest. This is what occupational injustice looks like.

But there are other, profound, problems with occupational therapy's slavish adherence to a neoliberal ideology.

Fundamental both to colonial and neoliberal ideologies is the Judeo-Christian belief that humans are entitled to dominion over nature; that the natural environment is a commodity, or "resource" that people are entitled to subdue, manage and exploit. This deeply rooted belief is visible within the occupational therapy literature, wherein leading Anglophone theorists have portrayed all people as having an innate and apparently irresistible urge to achieve mastery and superiority over the environment. The lasting impact of a neo-colonial agenda focused on exploiting nature as if it is a "resource" is evidenced in the current climate crisis, and is implicated in the aetiology of the current pandemic.

Yet for more than a year, the near-total international preoccupation with COVID-19 has effectively diverted attention from the even greater threat to global health of environmental degradation and climate change; crises that some scientists believe will inevitably contribute to future pandemics. In 2009, a *Lancet* commission declaring climate change as the "biggest global health threat of the 21st century" recommended that the health effects of climate change should be placed high on the agenda of every

academic journal, scientific and professional conference and university curriculum. Even before the pandemic, there was scant evidence to suggest that occupational therapy had risen to this challenge. During the pandemic, many commentators have sought to highlight the profound importance to human wellbeing and mental health of occupational engagement in nature, yet despite recognition that occupations inevitably occur within environments, our research has only rarely sought to understand how occupations are shaped or dictated by the demands of the natural environment, on the specific places within nature in which people may wish to undertake their occupations, of the meaning of these natural places and spaces to the motivations, responsibilities and rewards inherent to specific occupations, how occupations are impacted by environmental degradation and climate change or of how environmental degradation inequitably impacts the occupations, health and wellbeing of economically-deprived people, Indigenous people and rural people.

I've already talked a little about occupational therapy's promotion of the neoliberal idea that individuals are all in positions wherein they can make wise occupational choices. This has relevance to the looming climate crisis, which has politicians urging individuals to make wise occupational, lifestyle and consumer choices to avert this imminent catastrophe. The idea that our global environmental crisis might be ameliorated by individual consumer choices is a manifestation of the neoliberal ideology that many view as having created this crisis in the first place. As individuals, we aren't going to recycle our way out of this. Critical thinkers and global health experts contend that monumental political and corporate changes will be required if any meaningful progress on climate change and environmental devastation is to be achieved; and that the notion of individual choice is, anyway illusionary, being circumscribed by opportunities already limited or eliminated by political agendas and corporate decisions. Indeed, one of the triumphs of neoliberalism is widespread acceptance of the notion that individual lifestyle choices and individual actions will somehow solve problems rooted in political and socioeconomic conditions. This is not to suggest that individual efforts towards environmental sustainability are unimportant, but to assert that they are insufficient.

I want to wrap up by re-stating that my intention in this presentation was to look back at my ideas of March 2020 through the rear-view mirror, and to ponder what we've learned in the interim. I think, perhaps, my use of the word "learned" was a bit optimistic. After all, nothing I have said in this talk is new; the epidemiological knowledge is not new; the profoundly unfair impact of the pandemic on people's occupations and lives was entirely predictable; it was already known that racialized and poor people would suffer most in a pandemic; and they did. Only another look in the rear-view mirror – perhaps a decade from now – will show whether anything has actually been learned.

The COVID-19 pandemic has been awful. It has profoundly disrupted billions of lives, tipped millions of people into deep poverty; and ended millions of lives. But it has also opened up opportunities to imagine other ways of living and doing in the future. Many people express a desire to return to "normal" when the pandemic finally ends, but environmental scientists indicate that returning to how things were in 2019 isn't a viable option. We must do better.

The Build Back Better approach, which was initiated in the aftermath of the 2004 Indian Ocean Tsunami, has been implemented following various international disasters as a way to enhance human wellbeing through reducing inequality and by focusing on social justice and ecological health. It's being used by various governments as a template for their post-pandemic futures. In the UK, Marmot and colleagues have asserted that after the COVID-19 pandemic, it is important, not just to build back better, but fairer; addressing both inequality and the climate crisis. As occupational scientists and occupational therapists concerned with human wellbeing and with the attainment of occupational rights, the idea of Building Back Fairer might also provide *us* with an opportunity to imagine other ways of living and doing in the future; and especially, to imagine other ways of doing occupational therapy. Striving to modify individuals such that they can become more productive and independent, and fit better within a world designed for others cannot be our sole raison d'être.

I'd like to close with Arundhati Roy's thoughts on the pandemic as a portal, which encapsulate the ideas I have sought to advance in this talk.

> "Historically, pandemics have forced humans to break with the past and imagine their world anew. This one is no different. It is a portal, a gateway between one world and the next. We can choose to walk through it, dragging the carcasses of our prejudice and hatred, our data banks and dead ideas, our dead rivers and smoky skies behind us. Or we can walk though lightly, with little luggage, ready to imagine another world. And ready to fight for it".