Lessons from Aids, ethics and practice of social solidarity: SILENCE=DEATH, ACTION = LIFE: New Relevance in COVID Pandemic Times

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It has taken me some time to realize how relevant the AIDS activist slogan and perspective SILENCE=DEATH, ACTION =LIFE is to the current context of the COVID-19 pandemic. I have reflected in previous writings on the differences *and* similarities between the AIDS crisis (which continues) and the current pandemic, and what can be learned for resisting and surviving this pandemic from the years of intense AIDS organizing and activism (see references at the end). Here I build on these previous pieces, moving beyond them, but trying not to repeat their basic analysis here.

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These are different viruses with different impacts on/in people's bodies, that affect rather different but also overlapping groups of people. The similarities are mostly in how these health crises are socially organized, including the limitations of public health, problems with the pharmaceutical-medical-industrial complex, the defining of some groups in practice as 'expendable,' and its organization through class, racializing and gender relations, among others. I see this as a series of *preliminary* notes, observations, and perspectives that I hope people will add to and take further. They remain *unfinished*.

All health crises are condensations of social relations, combined in different ways. They are never the simple story of a virus. Both AIDS and the current pandemic involve global relations of race, class, gender, ability, sexuality (more significant in the AIDS crisis), drug use (more prominent in the AIDS crisis), housing/homelessness, the importance of reproductive and caring labour, the limitations of public health, the pharmaceutical-industrial complex, the medical profession and capitalist health from above, relations of overdevelopment/underdevelopment, and more. In the current pandemic there are also the impacts of industrial agriculture, the destruction of biodiversity, and increasing urbanization leading to more chances of cross-over infections from viruses jumping from animal species to human bodies. I stress these are not just health or medical crises but very much social and political crises as well.

Groups like the various AIDS COALITIONS TO UNLEASH POWER (ACT-UPs) in New York City,

across the US, in a number of centres in 'Canada,' and around the world, along with groups like AIDS ACTION NOW! (AAN!) in Toronto that I was involved with, used the slogan/perspective of "SILENCE= DEATH, ACTION=LIFE," to organize the interconnected two-sides of our activism in the context of AIDS in the 1980s and 1990s. First, we challenged the silence on the part of governments, public health professionals, the medical and pharma elite, and mainstream organizations, that was literally leading to the death of people with AIDS/HIV. There were years when no effective action was taken by governments and medical and public health officials since AIDS was supposed to be only affecting 'expendable' groups. We challenged their silence on health emergencies affecting people they defined as 'expendable' (gays and men having sex with men, Haitians and other Black and people of colour, drug users and sex workers). But this was not just a 'negative' critique of social power, for this breaking of silence was immediately coupled with a *direct action* focus, on action for saving lives, especially through getting people access to treatments that could both prolong their lives and produce better qualities of life. This action was not polite lobbying or letter writing but this direct action — often based in direct democratic forms of organizing — was based on people putting their bodies on the line in disrupting, obstructing and putting pressure on institutions of social power through die-ins, occupations of buildings, blocking streets, unfurling banners, smuggling treatments across borders, in practice expanding treatment access, and organizing alternatives like our own community research initiatives, and so much more. It was based on the affirmation that no one was disposable, that there were no 'high-risk groups' only high-risk activities that anyone could engage in, and of health care for all. In contrast to the neoliberal individualism of today it was based on an ethics and practice of social solidarity, safer practices, social support and mutual aid.

In my view we need this form of activism right now. Possibilities for it have been opened up by the global uprising against Anti-Black and Anti-indigenous racism and the police, extensive and often direct action based anti-eviction organizing, the defence of encampments for homeless/un-housed people, in decarceration campaigns to release people from prison and immigration detention, for status for all, for paid sick days, for the right to refuse unsafe work and so much more.

SILENCE=DEATH

We need to re-envision "SILENCE=DEATH" through the lenses of the global uprising against racism and the police and against colonial genocide through bringing it together with "Black Lives Matter" and "No More Silence," regarding genocidal violence against Indigenous women, girls, and Two-Spirit people. In the face of the deaths and sickness that such strategies as 'herd immunity' (prior to any vaccinations being available, basically letting people be exposed to the virus with the hope that some people will become immune), "flatten the curve" (designed only to prevent hospitals from being overwhelmed) and "re-open the economy" (so that profit can be made and capital accumulated) we need to break the silence to point out that without a change in strategy — to a virus suppression or what some people call a COVIDZero strategy from below — that these ruling strategies will continue to lead to more deaths and more variants that threaten to outrun any regulatory impacts of the vaccines developed to address the first form of COVID-19. The development of the "variants of concern" and highlighting that COVID-19 is airborne also underlines the need for more rigorous safe practices and higher levels of PPE that must be made freely available to people. To stay silent on this and not to break ranks to build for a virus suppression strategy based on community organizing and popular education (not official health rules and the police) is really "SILENCE=DEATH" as the strategies adopted by most governments are leading to people's deaths and sickness.

Unfortunately, the climate justice struggle in waging an understandable struggle for recognition and reliance on 'climate science' also ironically constructed the 'progressive' position as being 'pro-science' with the connotation the this 'science' was somehow socially and politically neutral. This

has also been put forward as the response to the ani-masker/fascist convergence that they are just not listening to 'science.' While there is some truth to this in relation to the pandemic much of the public health 'science' has been very inadequate and reliance on 'experts' is not what we need right now. This position validating 'science' in an ahistorical fashion has led people to not remember the long histories of public health being used to exclude people (like sex workers and queer people) and to deny people their rights and has led people not to ask critical questions like which public and whose health is being protected in the current pandemic. Science, while we urgently need people's scientific skills, is always a contested terrain and is always socially and historically made. The current shallowness of this reliance on experts and their 'rules' and the lack of deeply rooted popular education on COVID-19 created some of the social space for the anti-masker/white supremacist/fascist convergence to take place in the first place.

There is also a bureaucratic lag with the policies developed in relation to the pandemic falling behind the development of the virus and its variants. For instance, most of the 'public health' rules were designed with the initial forms of the virus in mind and have not adequately taken into account that COVIID is airborne and especially the higher level of infectiousness of the 'variants.' This is why safe practices now require higher levels of PPE and these *must* be made available to people.

One of the silences that must be broken is the reliance by many governments and public health officials on the vaccines designed to address the first version of COVID-19 as the 'magic bullet' to defeat the pandemic. There are major problems with this. First, vaccines are being denied by the pharmaceutical companies and western governments (including the Canadian government) to most people on the planet and this makes clear the major problems with capitalist ownership, (including pharmaceutical company patents), and with neo-colonialism and imperialism. Capitalist social relations stand in the way of people's lives and health on a global scale. Second, the 'variants' are in danger of escaping the impact of the vaccines and this tendency will increase as more variants emerge as many people, especially in the global south and in poorer countries, are denied access to vaccines. Thirdly, within 'Canada' there have been delays in vaccinating people (and these are not just 'supply' issues) and still some of the most affected communities (including workers in unsafe waged workplaces, and in racialized communities) are denied access to vaccines. The 'roll-out' of the vaccines have become another terrain of struggle and this is another area where "SILENCE=DEATH, ACTION=LIFE."

Other silences that must be broken are on the racialized, class character of the pandemic and its impact on people with disabilities. The state/public health slogan of "Stay At Home" avoided the actualities in many people's lives that they needed to go out for waged work so they and their families can survive, especially when most of them are denied paid sick days. This also required pointing out that many people do not have 'homes' (the homeless and unhoused) and that home can be a very unsafe place for many cis and trans women, and for queer and trans youth. This slogan also implied that somehow the 'private' realm was safer than the 'public' realm when we know that being outside with more air circulation is actually safer. The early 'public health' and state lie that "we are all in this together" must also be challenged and the specific ways in which low-paid, racialized wage workers are impacted, along with their communities must be addressed. This pandemic is socially organized through racialized class relations and this must be addressed in its specificity and in its broader connections with struggles against racist capitalist social relations.

While age has been focused on, especially regarding long-term care residents there has not been the needed focus on people with disabilities and how they are more vulnerable to health risks in the context of the pandemic and how the pandemic itself is increasing the number of people living with disabilities in terms of Long Covid. In the face of the denial of adequate social support for people living in poverty and for those with disabilities part of the silence that must be broken is on the miserably low levels of social support that are provided. Part of the action we take against this is to

create and extend our own networks of mutual aid while at the same demanding significant raises in social assistance and social support rates.

We must break ranks and break the silence on all these questions. Maintaining silence on them does literally mean death for many people, especially people with disabilities, people in low-waged work, and Black, Indigenous and other people of colour.

THE REMEDY IS ACTION=LIFE

The other side of this and what Silence=Death was immediately linked to is ACTION =LIFE. ACTION=LIFE must also be rethought in relation to the global uprising against racism and the police and also rooted in the struggles that are currently going on against evictions, against attacks on encampments, for paid sick days, for the right to refuse unsafe work, against anti-Asian racism, for releasing those in detention, for status for all, for defunding and abolishing the police, and more. The Suppress the Virus Now Coalition based in Ontario calls for:

"At least seven **employer-paid sick days for all workers** on a permanent basis, plus an additional 14 paid sick days during public health emergencies.

Adequate personal protective equipment (PPE) for all workers, including respirator masks (e.g. N95s, FFP2s) for all workers in indoor workplaces until COVID community transmission ends, now that we know the virus can remain airborne indoors for hours.

The **right of all workers to refuse work due to unsafe workplace conditions**, and to be eligible for income supports like the Canada Recovery Benefit (CRB) after such work refusals.

Expanded eligibility for pandemic-related state assistance such as the CRB, including for temporary migrant workers, undocumented people, gig economy workers, sex workers, and others.

An immediate ban on evictions; rent cancellation and forgiveness of arrears; a moratorium on encampment policing; **and safe, accessible winter housing** for unhoused people who want it.

An immediate end to the criminalization, racial profiling, and raids that harm migrant and non-migrant sex workers, including anti-trafficking initiatives and repressive bylaws affecting sex workers and workers in massage parlours.

Safe and accessible options for isolation when home isolation is not an option, and transparent communication about options that are already in existence.

Immediate investment to improve ventilation, reduce class sizes, and offer COVID testing to students and education workers; and **robust assistance for students, educators, caregivers, and families when school closures are necessary, like now**.

Redistributing 50% of all police budgets toward resourcing social and health supports in Black, Indigenous, and people of colour communities.

An immediate end to deportations, and regularization and **full immigration status now** for all migrants, refugees, international students, workers (including temporary or seasonal migrants), and undocumented people in the country.

Immediate federal support and funding for **clean water access, appropriate health care, and COVID supports for all Indigenous people on and off reserve**, and the recognition of

Indigenous sovereignty across the country, including heeding demands to immediately classify oil, mineral, and gas extraction as non-essential work, and to hit pause on extraction, exploration, and environmental assessment processes.

Immediate decarceration of people from provincial, federal, and immigration detention facilities, and simultaneous access to sanitation and protective equipment, harm reduction supplies, free communication resources, and appropriate and consensual post-incarceration support for all incarcerated people.

Permanently **increasing Ontario Works and Ontario Disability Support Program (ODSP) rates** to match CERB ($2,000/month).

Making temporary, uneven pandemic pay boosts permanent by **raising the minimum wage for all**.

Taking profit out of long-term care, replacing for-profit corporations with an entirely non-profit and public system. Enforcing national standards that ensure that long-term care workers – who are disproportionately racialized women – have a living wage, health and wellness benefits, and a safe and secure job, in order to provide high-quality care to residents.

Making public transit safe by halting fare inspection, investing in mask distribution, and putting more buses on high-traffic routes to allow for physical distancing.

Increasing research and supports dedicated to COVID "long-haulers," people still suffering from the effects of the virus months after infection."

To this can be added many more demands for action including those regarding testing, treatments and vaccines. These taken together begin to create a sense of what "ACTION=LIFE" is all about for one geo-political area. But this also expands into new areas.

Treatment Access: ACTION =LIFE

ACTION =LIFE also brings treatment politics and activism into the current pandemic. Since the first wave of this pandemic there have been important improvements in treatments for people with COVID-19 infection but still people are dying and living with long-term COVID. One of the aspects of 'scientific' treatment research that AIDS activists confronted in the 1980s and 1990s was the standard 'scientific' use of double-blind placebo controlled, drug research trials. This meant that only some of the participants in the trials got the possible or promising treatment and others got a placebo which would do nothing to improve a person's health. In some of these research protocols "clinical endpoints" were seen as the result (ie deaths) of the use of these placebos and this was justified because it was good, clean 'scientific' research.

This was the case for instance with the late 1980s trial for aerosolized pentamidine (AP) as a preventative for pneumocystis carinii pneumonia (PCP) an opportunistic infection — the infections people with AIDS develop because of their weakened immune systems that can kill them. At that point PCP was the leading cause of death for people living with AIDS. AAN! protested this, including delivering mock coffins as part of a demonstration to the hospital where the study was being carried out, arguing for expanded treatment access for AP, including bringing AP across the border from the USA for clinics in Toronto. AIDS activist George Smith and AAN! argued that there was a major difference between the social relations of research (which one enters for altruistic reasons) and the social relations of treatment (where one is looking for treatment for a life-threatening condition) and that there needed to be treatment arms in all these studies where people were guaranteed to get these treatments.

I was rather astounded to recently see promotion in social media for "a placebo controlled randomized trial" for fluvoxamine, a possible COVID-19 treatment for reducing lung injury. This means that not everyone enrolled in the study gets the medication and some receive only a sugar pill or vitamin. Given they are investigating whether this treatment "reduces the risk for developing severe shortness of breath, needing oxygen, and being hospitalized due to COVID-19" and whether it "reduces the risk for reduced functioning or long term symptoms due to COVID-19" (see https://stopcovid2.idtrials.com/home/english) to only receive a placebo when one is infected with COVID 19 with the major risk of lung related problems could do significant harm to those being given a placebo. I have not investigated this further, but this could very well be a more generalized problem with current COVID-19 research.

In my view this form of research would only be ethical if everyone is able to participate in a treatment arm where they knew they were getting the treatment (even if it turns out to not be that effective). The purpose of a treatment arm is to get a promising treatment into the bodies of affected people as soon as possible. In the context of COVID-19, as with AIDS/HIV, we need to argue for expanded treatment access and for treatment arms in all these research studies. This is the way to keep more people from dying and to prevent sickness and injury. People living with COVID-19 Long Term should be represented on all treatment approval bodies to ensure this access and to have input into research designs and plans.

Action =Life: changing definitions and statistics for collecting information for Long-Term COVID.

AIDS activists especially in the USA confronted a series of problems with the official statistical definition of AIDS which was based on initial studies of largely white gay men and therefore included only certain opportunistic infections. This often did not include the specific infections women, many people of colour, and drug users were getting. They were therefore not included in the official statistics and definitions as people with AIDS and therefore were not recognized for treatment and social support. But beyond this it also meant that many women, people of colour and drug users with HIV infection were not diagnosed with AIDS or HIV infection and therefore did not get the treatments they needed. They therefore died much more quickly. AIDS activists in ACT UP NYC and other places waged a long struggle to have these infections included and for a broader definition of AIDS. They were eventually successful.

We now have a major problem with the collection of statistics and information regarding people with COVID. The initial social organization of medical and public health knowledge about it was that when you were infected you either died or you recovered, and this has shaped the way official knowledge and stats have been collected. In 'Canada' and many other jurisdictions they list the number of cases of infection, the number of people 'recovered' and the number of deaths. The problem is with the people who are 'recovered.' This category, which records people who no longer need to be hospitalized and who are no longer infectious, conflates two different groups of people, those who have fully recovered and will suffer no more consequences of their COVID 19 infection and those who suffer long-term health consequences from their COVID infection, with continuing illnesses and disabilities. Currently those with Long-term COVID do not *statistically exist* which creates major problems in getting their health and social needs recognized and addressed. We need a change in the collection of information so that Long-term COVID is also reported. Those with Long-term Covid, or COVID Long haulers, currently encounter fragmented government health and social support policies and they currently get bounced back and forth between the federal and provincial governments. While their main focus is on support, they have a series of demands for recognition (including in government and health policies but also in statistics), research (including research funding on treatments and what causes this condition), rehabilitation (places for treatment and support where people can recover and get better) and benefits (or financial support, including for

those who can no longer engage in wage labour). It is crucial to connect with and to support people who are continuing to live with the impacts of COVID in their lives and bodies.

The COVID Long Haulers Support Group, Canada calls for the following:

“Long covid needs to be recognized as a syndrome, given a name, and taken seriously by doctors. It must be counted in Health Canada’s daily statistic counts and the definition of recovered cases must be changed to non-infectious. We are not in fact recovered and 80% of people will have lingering symptoms for weeks and months after the 2 week period mandated by Health Canada. We need to be to be symptomatically and clinically diagnosed by our medical practitioners as many of us in the first wave were denied testing or tested too late to get a positive result. Without that golden ticket we are scrutinized, denied medical help, and blocked from access into research initiatives and rehabilitation.

The government must swiftly fund robust interdisciplinary, targeted research of long-haulers. This a serious issue that needs to be studied diligently and inclusively for all the affected population … The underlying mechanism of long covid needs to be discovered quickly.

A network of inclusive rehabilitation dedicated explicitly to recovery needs to be put in place. These clinics must be accessible to everyone suffering from long covid … People are going to need physical, cognitive, psychological, and financial integrated care centres to be able to get back to work and to a meaningful life … ” (https://covidlonghaulcanada.com/)

This is also the beginnings of self-organization of people living with long-term COVID infection and their identification of, and advocacy for their needs. Groups like this must be represented, as people living with AIDS/HIV infection were, in discussions and on government, medical and pharmaceutical bodies discussing how to address COVID that affects them.

Meeting these demands will expand definitions, expanding the number of people officially impacted by the pandemic and making it clearer that there are a spectrum of responses to COVID infection. This will expand the breadth of the problem and make the official stats more accurately reflect what is going on in people’s lives and bodies. This will also mean the those with long-term COVID must be eligible for social support, for treatments for their conditions, and for research into the health problems they are experiencing. This also means new directions in funding for research and support.

ACTION=LIFE: must be a global politics

As we saw earlier with the politics around vaccines SILENCE=DEATH, ACTION=LIFE must be a global politics. We also see this with the modes through which COVID-19 spreads as it travels in infected human bodies across borders and boundaries. Any virus suppression strategy from below must also be a global perspective. This is up against the national and often nationalist policies of many, especially northern and western states, and the hegemony over world health of the medical/pharmaceutical/capitalist industrial complex, which privileges northern western capitalist countries over the global south and poorer countries.

There is much to learn in this regard from the international efforts of AIDS activism. As just one example, we can look at AIDS activism at the International AIDS Conference in Montreal in 1989, where the opening session was taken over, delayed and disrupted resulting in people living with AIDS/HIV actually being included in global conferences. At that conference, ACT UP NYC and AAN! issued the Montreal Manifesto/Le Manifeste De Montreal, “Declaration of the Universal Rights and Needs of People Living with HIV Disease.” While not going far enough it did signal the need to transfer resources to the global south and to poorer countries in the fight against AIDS, as is

urgently needed in this pandemic. Sections 9 and 10 of the declaration called for “Industrialized nations” to “establish an international development fund to assist poor and developing countries to meet their health care responsibilities including the provision of condoms, facilities for clear blood supply and adequate supplies of sterile needles” and that “It must be recognized that in most parts of the world poverty is a critical co-factor in HIV disease. Therefore, conversion of military spending worldwide to medical, health and basic social services is essential.” In the current context this defunding/re-allocation of funding, or conversion, must be extended to also cover the police, prisons and other carceral relations. These initiatives are needed now, along with free access to vaccines for affected people in global south and poorer countries.

We need to actively oppose the tightening up of borders against migrants and refugees from the global south while we find ways to improve treatment, PPE and vaccine access and social supports for people there. To address the pandemic on a global scale requires that underdevelopment, neo-colonialism and imperialism be confronted with a major transfer of resources to the global south for pandemic needs. In this way “SILENCE=DEATH, ACTION=LIFE” necessitates that rather than abandoning people to the ravages of the pandemic which is what current strategies are largely leading to for the global south — that instead their needs and lives must move to the centre of our responses.

On these and many other fronts the struggle continues! And I hope this discussion continues as well.

Gary Kinsman

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