BREATHING SPACES: CRISIS, DENIAL AND BUILDING COLLECTIVE CARE IN THE AGE OF PANDEMICS

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HEALING JUSTICE LDN

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ABSTRACT

This report reflects on the Covid-19 pandemic, the denial of its ongoingness and how folks who are positioned as most vulnerable to the virus continue to organise to collectively respond to the current moment. It seeks to make sense of Covid-19 within a social justice framework questioning mainstream right wing political discourses of denialism. It aims to reflect on what 'normal' we have returned to, and the ways in which Covid denial has emboldened the very structures we are struggling against. It centres the experiences and organising of Covid safer, disabled and clinically vulnerable communities and what we can learn from them in building for our current moment. It asks us what it means that they have been marginalised within our movements and what Covid has taught us about the capacity and preparedness of our movements for organising in our current moment of polycrisis.

REFLEXIVE PREFACE

‘Illness is a philosophy whether you choose it or not. Your body forces you to study time, suffering, and survival in ways capitalism will never admit are knowledges’

Beatrice Adler-Bolton[1]

When folks ask what I am working on and I say Covid-19 organising I see a narrowing of the eyes and flickers of confusion (but Covid is over?), tiredness and withdrawal (not this again?), and uncertainty (how is this relevant? are you credible?). Covid denial is wearing, both professionally and personally. These questions are mirrored to me over and over, as I move in the world as a Black mixed queer and non-visibly disabled woman.

I began this project towards the end of 2024 full of confidence and self-assuredness, rooted in Covid organising communities. However as I write this in the autumn of 2025 I am tentative and uncertain of myself - feeling unmoored having to navigate what i have described as the ‘dizzying split’ between the world of Covid and the world of Covid denial, with the latter swirling around me making me question my own reality.

Alongside the research over the last year I have experienced the descending of chronic fatigue onto my bodymind, having to make sense of the ways in which I have become differently disabled, living with the uncertainty of these changes, while trying to make myself and my disability legible to the rest of the world.

There are interesting parallels between doing work on Covid denial and navigating a condition that is also contested. As disabled folks there is pressure for us to share ‘evidence’ of our disability, as well as to prove the conditions of Covid denial and ableism and how these impact us. HJL’s Deaths by Welfare research shows how the State creates a ‘burden of proof’ for disabled people and folks who claim welfare - who are constantly asked to prove their disability and deservingness. An emphasis on proving one’s case can loop us back into the very systems our movements are struggling against - those built on the denial of suffering and the politics of scarcity, austerity, and disregard for those deemed surplus.

These tensions are within the research. Covid organising and my own grappling around my newer forms of disability has sometimes meant leaning on the systems we also critique, a plea towards authorities around evidence - if only there was more research on the impacts of Covid or Covid mitigations (there is already so much research); if I have a diagnosis or evidence of the ‘real’ physicality of my fatigue I will have answers and appropriate healthcare, adjustments, care (what does the experience of other folks with energy limiting conditions suggest? And what of the history and present of austerity and welfare cuts?). Additionally, saneism can discipline us into treading the tightrope of presenting our ‘reasonableness’, saneness, credibility when challenging Covid denial for fear of further gaslighting and disregard, or the threat of being positioned as a malingerer - the danger of being marked as Trouble. In both cases there can be a turn towards the systems that have ‘failed’ us - public health, healthcare and welfare systems that are actually working as designed for maximum extractive abandonment. A focus on evidence and reasonableness feeds into more reformist approaches, and we can

> This work also encourages us to think outside of state institutions to what a Covid response would look like that centred disability justice and the building of life-affirming infrastructure for the age of pandemics and polycrisis. What might a response look like that centred all care for all people? That rejected the logics of scarcity, neoliberal evidencing, denial, and burden.

1. Adler-Bolton, B. (2025, September 14). *Beatrice Adler-Bolton (@blindarchive)*. Substack. https://substack.com/@blindarchive/note/c-155828821

be recouped back into liberal ideas of appealing to authority and proving our deservingness.

At the same time this research emphases the grassroots work of Covid organising, and that no one is coming to save us, grappling with state abandonment in a time of crisis. For some of us this may have been a first lived experience of state neglect and for others this is yet another iteration of neglect. This work also encourages us to think outside of state institutions to what a Covid response would look like that centred disability justice and the building of life-affirming infrastructure for the age of pandemics and polycrisis. What might a response look like that centred all care for all people? That rejected the logics of scarcity, neoliberal evidencing, denial, and burden.

Six years into the Covid pandemic organisers are grappling with these many tensions. Additionally there are clear links with other forms of disability organising and perhaps we are treading similar paths to those in wider movements for disability rights and justice as well as attending to the specificities of navigating the novel experience of a global pandemic. Folks in this research project were organisers who have been disabled by Covid as well as those who have other forms of disability and clinical vulnerability. In the uk there has been a separating out of Covid organising and longer term disability organising, whereas in the us there are clearer overlaps. Future work could explore bridging these forms of organising in the uk to build and strengthen cross-disability movements. These differences are important to reflect on, especially in considering my role as the researcher and as someone who has only recently become differently, physically disabled.

I have tried to grapple with these tensions, while also writing in the brain fog of denialism and fatigue which has meant writing with all the possible critiques and denials of my work in mind. This has slowed the process, taking care to think through the best way to make this work land with folks as well as honouring the myriad ways the organisers I spoke to felt about navigating denialism, state abandonment and organising for collective liberation.

This report has not been easy to write, nor will it be a comfortable read. However I deeply hope folks can approach it with curiosity and tenderness to sit alongside us to reflect on the last 6 years and hear the call to attend more closely to the rupture of the Covid-19 pandemic, its ongoingness, what our current responses tell us about the capacities of our movements and how we can be guided by the folks doing this work to think about what we need to prototype and build for our current moment and futures.

INTRODUCTION

This report is about the Covid-19 pandemic, the denial of its ongoingness and how folks who are positioned as most vulnerable to the virus continue to organise to collectively respond to the current moment.

The research seeks to make sense of Covid-19 within a social justice framework questioning mainstream right wing political discourses of denialism. It aims to reflect on what 'normal' we have returned to, and the ways in which Covid denial has emboldened the very structures we are struggling against.

The research makes a significant contribution in understanding the ongoing nature of the pandemic as we enter into its sixth year, developing an analysis of the culture of denial and the impact of this on all of us and particularly those who are disproportionately impacted by Covid-19.

It aims to challenge *liberal fatalism* - the performative powerlessness of the state in responding to the Covid-19 crisis, which has absolved the government of any responsibility instead rooting ultimate responsibility on individuals and their choices. The research highlights the experiences of Covid safety organisers - disabled, immunocompromised, Covid-bereaved folks and their allies who refuse denial, fatalism, and individualism and work to create collective response-ability to Covid through mutual aid, education, advocacy and building community.

> "It aims to challenge *liberal fatalism* - the performative powerlessness of the state in responding to the Covid-19 crisis, which has absolved the government of any responsibility instead rooting ultimate responsibility on individuals and their choices."

This work centres the experiences and organising of these communities and what we can learn from them in building for our current moment. It asks us what it means that they have been marginalised within our movements and what Covid has taught us about the capacity and preparedness of our movements for organising in our current moment of polycrisis.

Background

Despite the pronouncements that the pandemic was 'over' by then us President Biden and uk Prime Minister Boris Johnson in 2021, the Covid-19 pandemic continues to be an ongoing mass death and disabling event. Covid-19 is a novel virus which in its acute phase causes a mild to severe respiratory illness. Since 2020 there have been 7 million deaths globally from the virus, 5 million of those deaths have happened since the pandemic was announced as 'over'.[2] These are conservative estimates, whereas the real figure may be between 19.1 and 36 million deaths.[3] These are incomprehensible numbers, and there have been few public acknowledgements or memorials to this colossal ongoing loss.

It is also becoming much clearer that beyond the initial illness the Covid-19 virus has long term impacts on all body systems - it is no longer understood to solely have an impact on the respiratory system but on the heart, immune system, gut, brain, kidneys, blood vessels and reproductive system.[4] This leads to increased risks of health problems like heart attack, stroke, accelerated ageing, immune system impairments, and new on-set diabetes. [5]

One professor described Covid as like 'throwing a bomb in the body'.[6] In the UK 1.9 million people have Long Covid, a prolonged and chronic continuation

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> Covid-19 disproportionately impacts those who are minoritised and structurally made vulnerable. In the first and second wave of the pandemic Black and brown folks were more likely to be admitted to hospital and more likely to die from Covid-19 infection.

of Covid and post-viral symptoms such as fatigue, brain fog and shortness of breath that impacts day to day living.[7]

Covid-19 disproportionately impacts those who are minoritised and structurally made vulnerable. In the first and second wave of the pandemic Black and brown folks were more likely to be admitted to hospital and more likely to die from Covid-19 infection.[8] The odds of having Long Covid are 46% higher for people from the most systemically under-resourced or 'deprived' areas in the uk compared to the least.[9] People with health conditions and older people are also most likely to be living with Long Covid.[10]

As we enter into the sixth year of the pandemic there has been a dizzying split in our realities - one world in which Covid is over and its impacts are denied and another in which folks grapple with this denial and how we develop networks of collective care in response to state abandonment in an ongoing pandemic. To begin to make sense of this the next section traces the early pandemic response in the uk, the move to the 'back to normal' and how historical and present neoliberal impulses have shaped and constrained the possibilities of the response to crisis - moving us very quickly from the initial responses centred in collectivity and mutuality towards state abandonment and individualised responsibility.

2020, crisis and neoliberal capitalism

In the early stages of the pandemic in 2020, among the fear, isolation, death and grief we collectively looked deep into the rupture the virus offered up, finding other possibilities as well as a mirror to the dysfunction and disorder of the 'normative'. We saw a 6% global drop in carbon emissions, that nature seemed to begin to breathe and sing again, that we quickly built mutual aid infrastructures with our neighbours and communities, that life carried on without endless consumption, that we could house all homeless people, stop evictions, provide benefits to protect people's health and let them stay home, and that we could build a global movement and support for Black lives and to defund the police in response to George Floyd's murder and the ongoing lynchings of Black people.[11]

This period of the pandemic illustrated at a global level that we could all choose and organise to live differently - that the normative and hegemonic economic and social structures were not inevitable and that we could choose to centre other ways of being in the world and in relationship with each other. The discourse was rife with proclamations of 'no back to normal' and a desire to listen to and be guided into a new way of living.

However, concomitantly since the very beginning of the pandemic there have been other conservative discourses at work that have primed us from the start to imagine and believe in a 'back to normal'. There were suggestions that Covid would be over within a couple of weeks; psychiatric research into mapping and creating assessments for 'Covid Anxiety Syndrome' in the spring of 2020;[12] The Great Barrington Declaration - put forward by the American Institute for Economic Research, a 'free market lobby group' best known for climate denial, which promoted the take up of herd immunity through natural infection as policy and the dropping of other precautions;[13] the formalisation of 'Prolonged Grief Disorder' in 2022;[14] and an emphasis on deaths from Covid as the deaths of those who would have died anyway - sick, disabled and elderly people - not healthy people with 'liveable' or rather 'productive' lives. This has been the priming for the 'sociological production of the end of the pandemic'.[15] Less than 2 years after the start of the pandemic Boris Johnson announced 19th July 2021 as 'Freedom day' in which all Covid precautions were dropped, and by September 2021 this had contributed to 40,000 hospital admissions and more than 4,000 deaths.[16] On 21st September 2021 Joe Biden announced the end of the pandemic, and by December 2021 between 400 and 450 Americans were dying a day from Covid.[17] These political decisions allowed for the unpicking of Covid precautions at the level of public health, as well as the repealing of earlier economic and health legislation that protected people's income, housing, and health - such as stopping evictions, furlough to help people stay at home, mandated sick leave for quarantine and isolation, and in the US context expanded Medicare protections. Through 'elite capture' big business and capital lobbied for an end to these protections - such as the reduction of the 10 day quarantine rule to 5 days and then to 0 - and successfully encouraged us to move from collective responsibility in a pandemic to individual responsibility and risk management.[18]

This movement from collective responsibility to individual reflects the wider neoliberal context of the last 40 years which has emphasised minimising state intervention and maximising capital and private enterprise. The UK saw some of the highest death rates from Covid in the initial years of the pandemic, having entered the pandemic with an intentionally underfunded healthcare system and a government that had failed, or rather refused to heed early warnings.[19] Originally a fully funded healthcare system offering free healthcare for all at the point of use, the NHS re-directed the war economy post-WWII towards strengthening public services. However since the 1970s and the election of Thatcher the NHS has become the focus of neoliberal extractive policies determined to privatise public services. Covid emerged within the context of 40 years of increasing privatisation - which has included outsourcing

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Zhang, Y., Witmer, L., Chinchilli, V. M., & Ba, D. M. (2022). Association of COVID-19 with diabetes: a systematic review and meta-analysis. *Scientific Reports*, 12(1). https://doi.org/10.1038/s41598-022-24185-7

6. Blum, D. (2024, July 5). This May Be the Most Overlooked Covid Symptom, *The New York Times*. https://www.nytimes.com/2024/07/05/well/covid-symptoms-stomach-pain-diarrhea.html.

7. Office for National Statistics. (2023, March 30). Prevalence of Ongoing Symptoms following Coronavirus (*COVID-19) Infection in the UK - Office for National Statistics*. Www.ons.gov.uk. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/30march2023

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> This movement from collective responsibility to individual reflects the wider neoliberal context of the last 40 years which has emphasised minimising state intervention and maximising capital and private enterprise.

NHS services to the private sector, private financing, cuts and underfunding, rationing services, migrant charging and including patient data in trade deals. The 2012 Health and Social Care Act made it compulsory for all NHS service contracts to be put out for tender - making it almost impossible for it to remain in public ownership - and also removed Government responsibility to provide NHS healthcare for us all.[20]

The ongoing privatisation of the NHS has allowed for the transference of public money to the private sector, particularly to government allies. This was made starkly clear during the initial phases of Covid when under emergency legislation contracts to private companies for personal protective equipment, pandemic related construction and testing and tracing systems were given without clear tendering processes. 58% of contracts were to those who were not on the approved suppliers list, and many successful applicants did not have reliable trading or credit history, or even medical expertise or experience.[21] This involved very significant amounts from the public purse, for example, £37 billion was given to private companies to develop the 'NHS Test and Trace' programme.[22] Of these contracts there have been concerns about the sheer level of misappropriation of funds and wastage - over half the money spent on PPE was wasted on unused or deficient products and of the PPE used the Health and Safety Executive were forced to lower their safety tests to allow lower grade PPE to be given to health workers.[23]

Proponents of privatisation argue that privatisation allows for 'healthy' competition which will raise the standards of a service or organisation and stimulate economic growth. However, from the example of Covid contracting it is clear that the process and intensification of privatisation in this period led to corruption, misappropriation of funds which in turn posed 'a significant risk to public health'.[24] Two-thirds of health care workers lacked access to appropriate PPE during the first lockdown, and there were racial disparities in who did and did not have access.[25] The House of Commons Public Accounts Committee report found that despite the 'unimaginable' costs of NHS Test and Trace, the programme made no measurable impact on the progression of the pandemic and failed twice in its aim to prevent further lockdowns.[26]

Health care quality and population health has been worsening since before the pandemic, with 10 plus years of austerity and since the implementation of the 2012 Health and Social Care Act.[27] Research has found that outsourcing has worsened health care, and that there is a significant relationship between increased outsourcing and treatable mortality - that increased privatisation has led to preventable deaths.[28]

Privatisation continues apace, with the abolishment of Public Health England (PHE) in 2020 and the introduction of the UK Health Security Agency (UKHSA) 'as a further step in the growth of a centralised and secretive state apparatus with the close engagement of private sector interests'.[29] The UKHSA's focus is on external threats like pandemics as well as economic growth, failing to address non-communicable disease and the lack of progress around life expectancy in the UK. This illustrates the ongoing detrimental effects of privatisation. This is also important to consider when reflecting on how health inequalities are central to the impact Covid has had on the population.

PHE was criticised for its inability to speak 'truth to power', however UKHSA and the new Office for Health Improvement and Disparities are even less independent from government.[30] There are concerns over their ability to structurally address health inequalities which have been further illuminated and impacted by Covid, and also how these agencies sit within a state framework of healthcare privatisation with their emphasis on economic growth and 'UK plc'.[31]

We can understand the pronunciations of 'back to normal' and 'Covid denialism' through the lens of economic growth, capital and the privatisation of health care - of the continual undermining of collective consciousness about collective responsibility and the responsibility of the state. The State response to the pandemic - from the very start has been shaped by 'racialised capitalist social relations', a necropolitical regime which has and continues to protect corporate and private interest.[32]

This is the way capitalism, particularly in the neoliberal period works - utilising crises to protect the interests of the State, private corporations and financial institutions and maintain the status quo at the expense of the working class and poorest people in the world.[33] The increase in public spending did not equate to a socialist shift, actually government and big business worked together to 'expand their control over society and augment profits at the expense of workers'.[34] The pandemic has deeply impacted health inequalities and reversed the progress on poverty reduction, with 120 million more people living in extreme poverty globally in 2020 than expected based on pre-Covid predictions. In the same year the richest people in America had increased their wealth by $339billion.

> We can understand the pronunciations of 'back to normal' and 'Covid denialism' through the lens of economic growth, capital and the privatisation of health care - of the continual undermining of collective consciousness about collective responsibility and the responsibility of the state.

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> It is a turning away from the response-ability of the collective, the state and unequal burdens of the virus on minoritised people and deprived communities. This is a far cry from early 2020 when a collective consciousness of the condition of breathlessness emerged in response to the murder of George Floyd, a time when death and sickness was no longer seen to be allocated to certain racialised (particularly Black) and minoritised bodies.

Under capitalism our response to crises centre the market, ensuring the status quo and engineering a 'back to normal' where capital reigns. There has been an ongoing political and economic campaign in which we have been engendered to forget what has happened over the last six years, and forced into a daily denial and erasure of the pandemic. This has been an active process of getting 'back to normal' to forget what we achieved socially, economically and politically during the initial stages of the pandemic - a redirection back into the neoliberal emphasis on individual responsibility and risk management, versus collective care and responsibility, and the state as a 'conduit' for economic growth and private enterprise.[35] This 'back to normal' campaign also turns us away from the neglect of the State, the misappropriation of public money and deepening inequality and poverty of the market response to the Covid crisis. It is an attempt to erase and deny what we learnt from the virus about the (dis)order of the world.

The 'shocking success' of eugenics and ableism around the pandemic illustrates a strengthening of the normative order and how violently we have been disciplined into this 'back to normal'.[36] It is a turning away from the response-ability of the collective, the state and unequal burdens of the virus on minoritised people and deprived communities. This is a far cry from early 2020 when a collective consciousness of the condition of breathlessness emerged in response to the murder of George Floyd, a time when death and sickness was no longer seen to be allocated to certain racialised (particularly Black) and minoritised bodies[37]. However the association of death with Blackness and otherness quickly re-emerged when it became clearer that the burden of Covid disproportionately fell on Black and racialised people, disabled people, working class people and those who lived in poverty; those who were disproportionately exposed in the workplace compared to the middle classes who could work from home; that it was people who lived in the places with highest rates of air pollution who had the highest rates of Covid deaths; and people who were already seen as not worthy of living - those seen as "better dead than disabled".[38] A return to 'normal' has emerged as the narrative that breathlessness followed the old patterns of the normative order, the norming that some are predisposed to social and premature death, and that the condition of racial capital is that some lives are worth more than others. This has developed despite continued waves of Covid, and increasing levels of disability and precarity due to the long term sequelae of Covid after initial infection. Underlying eugenicist ideology embedded within mainstream pandemic responses continue to frame this mass disabling event as happening to the 'Other', those moral failures who are already disabled and assigned to sickness, marking them as separate from normative bodyminds who assume their non-disability to be a permanent and moral state.

This 'back to normal' impulse draws us into complicity with the denial of crisis and ensuring the continued recentring of the normative - the state as a vehicle for economic growth and private profit. 'Back to normal' covers over the ways in which the state has abandoned all responsibility in an ongoing crisis and how this crisis has been utilised for extractive abandonment - to make profit from minoritised populations deemed as unwanted and surplus.

The current research

Six years into the pandemic there is very little research into how communities and movements are navigating the ongoing harms of the pandemic, state abandonment and Covid denial. Much of the social scientific research on Covid has been focused on the initial emergency response of 2020 - 2021.

This research is interested in ongoing forms of grassroots and community based Covid safety organising in the uk - how organisers understand and respond to state abandonment and denial and how folks are building infrastructure to intervene in this crisis. This work also tells us about the capacity and preparedness of our movements for responding to the current moment of polycrisis and the ways in which the state is and will continue to abandon us amidst this.

Methodology

Method

Covid safer organisers were invited to participate in either group conversations with other organisers or a one-to-one conversation both facilitated by Stephanie Davis, Health Justice Researcher at HJL. The research was advertised through HJL's social media channels as well as Covid organising networks. The research centred folks who have been part of ongoing organising mutual aid, mask blocs or supporting disabled and covid-safer communities in the uk and Ireland.
As folks emailed to express their interest in the project they were sent information sheets and consent forms and given the opportunity to ask further questions or read through the information with Stephanie. This information ensured folks understood what was involved in the research, the process of the conversation, how their data would be drawn on, and their right to withdraw.

23 organisers signed up, with 17 joining one of three group conversations with 5-6 other organisers and 6 folks signed up for one-to-one conversations. Folks were a mix of disabled (by Long Covid and/or other disabilities), currently abled, immunocompromised, neurodivergent, carers, Covid bereaved

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29. Scally, G. (2021). A New Public Health Body for the UK. *British Medical Journal*, 373
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31. Scally, G. (2021). A New Public Health Body for the UK. *British Medical Journal*, 373
32. Knox, R. and Whyte, D. (2023). Vaccinating Capitalism: racialised value in the Covid-19 economy. *Mortality*, 28, 2, 329 - 345
33. Blakely, G. (2024). *Vulture Capitalism: Corporate Crimes, Backdoor Bailouts, and the Death of Freedom*. Bloomsbury: London
34. As above
35. Corcoran, M. S. (2021). Populism, Scandal Management, and State-Facilitated "Covid Corruption" in the United Kingdom. *Archives of Criminology*, 42, 2, 39 - 61
36. Osterweil, V. (2024, March 14). *Remembering As An Act of Revolt*. All Cats Are Beautiful. https://all-cats-are-beautiful.ghost.io/a-list-of-things-we-have-been-told-to-forget/
37. Hook, D. (2008). The 'real' of racializing embodiment. Journal of Community & Applied Social Psychology, 18, 2, 140 - 152
38. Carrington, D. (2020, April 7). *Air Pollution linked to far higher Covid-19 death rates, study finds*. The Guardian https://www.theguardian.com/environment/2020/apr/07/air-pollution-linked-to-far-higher-covid-19-death-rates-study-finds

people and allies. All were involved in local and national organising on Covid safety - from organising mask blocs and the distribution of masks, Covid tests and HEPA filter lending libraries to organising Covid-safer social and community events to undertaking advocacy and campaigning work.

The conversations took place online between March and April 2025 and were semi-structured. Organisers were asked questions on what was working in their Covid safety work, their needs, how the work could be broadened and strengthened, their questions and reflections on organising and what they might like to share with other organisers (both in and outside of Covid organising). In the group conversations access was emphasised - folks were invited to show up and participate in ways that were most accessible for them such as in bed, to type in the chat and stay off camera. At the end of the conversation people were provided with a debrief sheet as well as HJL's Aftercare menu. Folks in the group conversations noted how important it felt to be connected in the online space with other organisers and that this provided a boost to the often lonely work of Covid organising. The conversations were 2 hours long and folks were reimbursed £112.50 for the conversation time and one hour of preparation.

The conversations were audio recorded and then transcribed. Some folks asked for their contributions to be completely anonymised - where they took pseudonyms and all identifying information was removed from the data. Others were happy to have their full names included as well as identifying data about their organising.

Data was analysed using Thematic Analysis drawing on Braun and Clarke's (2006) paper. Group conversations and one-to-one conversations were coded one at a time before themes were developed across the full data set.

Ethics

At HJL we are exploring the different ways we can conceptualise and re-imagine ethics beyond the University. We aim to decentre the ways in which ethics is framed as about assessing institutional risk and as a form of measure of protection around insurance. As researchers at HJL we are thinking through what it means to be accountable to our communities and to do research in service of our movements.

This project did not seek ethical approval from a University process, instead it centred community knowledge. Three folks were invited to be 'community ethics reviewers'. Two were organising around Covid and a third was an independent academic on climate change. Reviewers were asked to read the ethics proposal and then to respond to a series of questions and prompts. These questions included usual ethical questions such as confidentiality, informed consent, and risks.

In addition reviewers were asked how far the proposed research respected the autonomy of individuals, groups, and communities and in what other ways the research's liberatory potential could be developed. They were prompted to consider how the research could be further developed to:

- Provide material relief or reduce harm to communities impacted by state abandonment.
- Ensure that those most impacted are reached.
- Encourage a participatory rather than passive inclusion in research.
- Centre action and impact that will be beneficial to communities of focus.

Folks were also asked for any further reflections on the focus of the research, its method, and areas for improvement.

The community reviewers gave rich and generous feedback that was then drawn on to further shape the research.

Limitations

The research is the first of its kind in the uk context. It was an exploratory project exploring Covid organising and how folks are responding to the specificities of the ongoing pandemic. In a larger project there could have been more of an exploration of wider disability organising and how Covid organising does or does not intersect with this work. However this might be more of an action point than a focus of research. The research question originally focused on what is happening in Covid organising in the uk, however a large part of the discussions in the group and one-to-one conversations explored the experience of navigating denial and making sense of the current conditions. The focus of the report is on both the conditions and how folks are responding to them. Covid organising is still relatively early on in its development and quite under-resourced, folks were responding to an ongoing emergency therefore the focus of the research was on reflecting this. However future research and action might further explore some of the tensions surrounding appeals to authority, different possibilities of organising in response to state abandonment and broader connections to disability movements in the uk.

CHAPTER 1

NAVIGATING COVID DENIAL





‘Where do you (the abled) go when you leave us behind? Is it worth it?’

Carrie Kaufman[39]

CHAPTER 1

This chapter explores the lived experience of navigating an ongoing pandemic in a ‘post-pandemic’ world, of how Covid denial impacts disabled, immuno-compromised, Covid bereaved people, and their allies. It considers how the Covid response in the uk was shaped by liberal fatalism that has been used to justify State inaction, and supported the return to ‘normal’ - a normal in service of capital, the economy and the political status quo. Denial is both politically and socially constructed, but also plays on a specifically Western response to collective traumas which are understood as impacting certain, surplus groups. Participants shared experiences of loneliness, abandonment and harassment, understanding the structural violence of the denial of Covid and its eugenicist roots as part of a wider analysis of the disappearing of disabled people, and the emboldening of fascism. This chapter considers how we might challenge Covid denial and eugenics in our movements and broader society.

Covid denial and liberal fatalism

Daisy: I think that there's a problem where you're up against the government who are saying "It's over". The NHS is ignoring the science from the COVID inquiry where it was discussed that Covid is airborne. And people respond by saying 'Well, my doctor doesn't wear a mask, therefore you're making it up', or 'If it was that bad the government would tell us'. And my response is 'Yes, but they're doing [it - ignoring Covid] because of the economy and all these reasons'...So it feels like a lot of people shouting things into the ether, only being heard by other people who already agree with them. And I don't know what the answer to that is, and whether it's kind of, eventually we're so loud that people start paying attention, or enough people get ill that they start paying attention to it, which is an awful thing.

As Daisy illustrates, over six years into the pandemic, it is clear that as a society we are living in a state of active denial of Covid and its continued impacts. Organisers talked at length of Covid denial - that Covid is now understood in the past tense, as something that cannot be named and must be spoken about euphemistically. Covid appears to have been 'forgotten', as something which is no longer relevant however this belies the active process of denial from the top-down.

Folks involved in this project were organising to build community for Covid cautious folks, challenge Covid denialism and address and intervene in the ongoing impacts of Covid. Participants included people with Long Covid, disabled and neurodivergent folks, Covid bereaved people as well as other activists who were drawing links between Covid, disability justice and other intersections. All pointed to the continued failures of the State and public health - from the initial emergency phase to the present. Denialism can be understood as shaped by these failures - however we can also understand these failures, and therefore denial itself as active political choices and policy that have allowed for what one participant, Grace, described as 'plausible deniability'.[40] As illustrated in the introduction, there has been so much to deny in the last six years - of corruption and the misappropriation of funds, the acceleration of privatisation, the impact of austerity on the NHS, and some of the highest death rates in Europe.

The early response to the pandemic has been described as one of the worst public health failures in uk history.[41] The uk saw some of the highest death rates from Covid in the initial years of the pandemic, having entered the pandemic with an intentionally underfunded healthcare system and a government that had failed, or rather refused to heed early warnings.[42] The uk was much slower in making decisions early in the pandemic which impacted further down the line - for example, delays in lockdown led to thousands of avoidable deaths; the uk refused to join with the EU to access personal protective equipment (PPE) which led to the later purchasing of PPE via private companies, many of whom were given tenders without reliable financial or trading history or medical expertise and who provided deficient PPE.[43] In 2016 the civil service ran a preparedness exercise for a pandemic and found that the NHS would be overwhelmed and predicted many of the things that would happen in 2020.[44]

Bacevic and McGoey[45] argue that the uk government embraced the 'uncertainty' of the early days of the pandemic as a political strategy in order *not* to act and justify *not* taking certain measures. They describe this as *liberal fatalism* which adopts unknowability and uncertainty as forms of insurance against political liability, where 'ignorance' becomes a 'justification for the absence of intervention'. This 'unknowing' allowed for justification of later interventions in the pandemic to be framed as due to the changing nature of the virus, rather than due to earlier government inaction. This response to the pandemic addressed two main aims - of 'maintaining political legitimacy and enabling the sustained flow of capital into specific sectors' - moving public money into the private sector.[46]

Liberal fatalism is a performative powerlessness, drawing back on the State's responsibility by emphasising unpredictability and 'rooting ultimate responsibility' on the individual and their poor decisions.[47] Liberal fatalism produces a 'politics of impossibility': closing down the range of possibilities for the collective and individuals while creating an 'ignorance alibi' for those in authority.[48]

It is easy to see how the position of liberal fatalism has shaped an ongoing performance of 'unknowability' which has produced current forms of Covid denial across society. Unknowing has been reproduced through the later phases of the pandemic through the purposeful dismantling of pandemic infrastructure so that the very basic understanding of being in an ongoing pandemic can be contested, refused and denied. For example, the removal of free testing and wastewater monitoring, the dropping of all precautions, and refuting evidence of new understandings of Covid (e.g. Infection Prevention and Control (IPC) and the government continue to maintain that Covid is not airborne but spread through droplets) means that the existence of Covid has become an 'unknown' - now it is a virus of the past, that cannot be named in the present. Misinformation and denial proliferates, the impact of the virus can be plausibly denied and responsibility is elided by the state, public health, healthcare, workplaces, and wider institutions.

"Liberal fatalism produces a 'politics of impossibility': closing down the range of possibilities for the collective and individuals while creating an 'ignorance alibi' for those in authority."

39. Kaufman, C. [@rosesarespread] (2022, January 24). 'I've been feeling a different depth of angry/sadness lately, as we witness another wave of outspoken eugenics from our government. Instragram. https://www.instagram.com/p/CZHmO3xrDOP/?igsh=Z-mplZGYwdnRuOG51 Retrieved November 17, 2025 from instagram.com
40. Ken Thomson, the Scottish National Party (SNP) Executive's former Director General for Strategy and External Affairs during the early phases of the pandemic, encouraged staff to delete pandemic related Whatsapp messages and described his middle names as 'Plausible Deniability' Walker, D. (2024, February 1). *Former Holyrood boss Ken 'Plausible Deniability' Thomson quits new role over Covid Inquiry row. The Scottish Daily Express.* https://www.scottishdaily-express.co.uk/news/politics/former-holy-rood-boss-ken-plausible-32022712
41. Sample, I. and Walker, P. (2021, October12). *COVID response 'one of UK's worst ever public health failures'.* The Guardian. https://www.theguardian.com/politics/2021/oct/12/covid-response-one-of-uks-worst-ever-public-health-failures
42. O'Sullivan, T. (2023). *The NHS is Slowly Dying of Privatisation*. Jacobin. https://jacobin.com/2023/03/uk-nhs-privatization-austerity-wages-deaths-health-care-demonstration; Corcoran, M. S. (2021). Populism, Scandal Management, and State-Facilitated "Covid Corruption" in the United Kingdom. Archives of Criminology, 42, 2, 39 - 61
43. Corcoran, 2021 as above; Bacevic, J. and McGoey, L. (2024). Liberal fatalism, Covid-19 and the politics of impossibility. *Economy and Society*, 53, 1, 163 - 182
44. Bacevic and McGoey, 2024 - as above
45. As above, p.166
46. As above, p.177
47. As above, p.177
48. McGoey, L. (2019). *The unknowers: How strategic ignorance rules the world*. Bloomsbury; Bacevic, J. and McGoey, L. (2024). Liberal fatalism, Covid-19 and the politics of impossibility. Economy and Society, 53, 1, 163 - 182

Rowan: One of the things we've been doing in the mask bloc that I think has been really successful is that Scotland is one of the few countries that still monitors wastewater and looks at virus presence in wastewater. So COVID, Flu, RSV, Norovirus is still monitored in wastewater in Scotland. It used to be monitored on a city by city basis, which was amazing, because you could literally look at [Name of Scottish city] specific wastewater numbers, and you could figure out the specific COVID risk or Flu risk in [Name of two Scottish cities] and in other central cities. They've now centralized the data which isn't as good, but it does still give a good, fairly accurate picture of when you're going into a COVID wave or a Flu wave or a Norovirus wave.

And one of the things we've been doing because that data is not particularly easy to access - it's on the NHS Lothian website, but it's buried under layers and layers of stuff, therefore it's not publicly available or understandable.

So as a mask bloc we've been making Instagram posts where we update people on wastewater numbers on a monthly basis just posting about that data, just reminding people, COVID is still around or Flu is still around, or COVID is quite low, but there's a lot of Flu around. Wearing a mask is beneficial for your health, and that's been really beneficial, I think, in lots of different ways. For people who maybe aren't as aware, it's raising awareness that COVID is still around, that Flu is still around, that it's still something to be avoided. And then also particularly for disabled people like myself, who are being extra cautious, it means that we can make risk informed choices about our behaviors, with things like scheduling a dentist appointment. I will do that when the wastewater numbers are low. So social media posting and sci-comms have been very helpful for us. I think also having sci-comm like training and background has been really beneficial for me.

Daisy and other organisers pointed to the difficulties of advocacy and education around Covid without clear data from the Government and public health. In Scotland activists like Rowan, still have access to reduced wastewater monitoring however this information has to be searched for and is hidden away making it inaccessible to the public. Wastewater (sewage) monitoring is used as an advanced warning system to detect levels of Covid-19 in the population, flagging levels of virus and potential transmission even before individuals become symptomatic or are asymptomatic. Rowan and other activists were doing the work of finding the hidden data around Covid and translating it for wider audiences online. Participants are battling the tide of denial and misinformation, but refuse the broader politics of the 'impossibility'of liberal fatalism - continuing under very difficult conditions to imagine and rehearse collective responsibility. This will be explored further in Chapter 3.

We must be cognisant of how the liberal fatalistic approach has seduced our movements into denying Covid, accepting the 'impossibility' of ongoing interventions around Covid, and letting Covid become the exception in our solidarity practices. We have been 'bombarded' with narratives of denial and back to normal to mask the ways in which the pandemic is ongoing and the structures that we fight against have 'adapted, entrenched themselves deeper, and capitalized on our growing numbness' - growing ever richer as we are further abandoned.[49]

Liberal fatalism must be named, understood and challenged, as this will continue to shape how the State and our institutions respond to the polycrisis - from climate change to genocide. As Beatrice Adler- Bolton[50] argues - 'What is Covid-19 if not a harbinger of things to come?'. Denial puts disproportionate burden on those most minoritised whilst temporarily insulating the most privileged, continuing to legitimise the political status quo and the flow of capital into certain sectors at the expense of the public purse.

Covid Denial, Collective Trauma and Surplus Populations

Understanding liberal fatalism and its politics of impossibility at the macro level helps us to contextualise the ways we have been shaped at the micro level in our communities and relationships in how we have responded to Covid. Folks pointed to the failures of the state, but they were also deeply disturbed by the ways in which denial was reproduced within Leftist movements, communities and interpersonal relationships. They were shocked by the ways in which society had moved so quickly from 'all in this together' to a 'back to normal' which abandoned the most marginalised.

Denial was understood by participants as both politically/socially constructed and produced as well as a psychological response to the trauma of the pandemic. As well as a political tool, denial is also a protective defense mechanism. Trauma can 'hijack' our imaginations and defend against a reality that is overwhelming.[51] The pandemic is a once-in-a-life-time rupture and an ongoing mass death and disabling event - it is difficult to comprehend the scale of death and suffering, of at least 232,112 deaths from Covid in the uk, 7 million worldwide, of the continuing risks of the virus for long term health, increasing rates of Long Covid in children and adults, to face our own mortality. A more dissociative, and culturally/politically accepted, response to this trauma is to deny the reality and emphasise our own individualism, invulnerability and attempt to overcome our human frailty.[52] Through this we denigrate and other those who have been positioned as more vulnerable to the virus, distancing ourselves from the inherent vulnerability of our own fleshy and finite body-minds - whether we are currently abled or not.

More creative, imaginative and restorative approaches to the trauma of the pandemic were illustrated by the earlier 'all in this together' response, - the desire to collectively create a different world through the rupture of Covid.[53] However this response was quickly usurped by the forces of capital which urged a 'back to normal' and a denial of Covid.

49. Adler-Bolton, B. (2024, September 25). *Structural Violence and the Pandemic: An Update on Our Collective Reality.* Substack.com; Blind Archive. https://blindarchive.substack.com/p/structural-violence-and-the-pandemic
50. As above
51. Kalsched, D. (2021). Intersections of personal vs. collective trauma during the Covid-19 pandemic: The hijacking of the human imagination. *Journal of Analytical Psychology*, 66, 3, 443 - 462
52. As above
53. As above

It is important to understand the collective response of denial as shaped by our political and social context. Liberation psychology considers how oppression and particularly colonialism and its legacies, coloniality, have powerful psychological effects whether these are consciously recognised or not. Oppression produces forms of social amnesia - of society's 'repression of remembrance of its own past' which encourages dissociation, bystanding and supports the status quo. We can understand the move towards denial as part of longer term collective psychological defenses shaped by histories of colonialism in which we have become adept at turning away from suffering and denying structural violence - where 'violence and inequity have become normalized, a kind of amnesia sets in among the privileged that is part of the pathology of collective trauma'.[54] Depth psychology encourages us to listen in and apprentice to these symptoms so that we might grapple with the grief of the pandemic and allow us to engage with its chronicity and a changing world. As yet there have been no widespread public reckonings with the grief of the last six years, or mourning for those who have died and continue to die outside of the bereaved families. Peter Shabad suggested that psychological symptoms are memorials to our lonely suffering, perhaps we might understand part of Covid denial as a memorial to our sufferings that prevents us from collectively reckoning and engaging in the present.

For organisers there was a lot of pain around this denial. One participant, Niki, a member of a Mask Bloc, lamented that the pandemic has 'inured' many to a 'callous' turning away from suffering and the sense that some lives may need to be sacrificed for the convenience of others. Although we must understand denial as part of a much broader and longer term collective response to oppression and understand how the logics of capital, coloniality and whiteness circulate within Covid denialism and what 'normal' we have hurriedly returned back to.

Niki: We should be moving towards being able to recognize social issues before, as Fran said, the most vulnerable people lose their lives. Unfortunately, we're really moving in a direction of accepting that a lot of people are gonna die for our convenience. And so in terms of having to meet people, where they're at and kind of explain the basics, oftentimes, the basics you need to explain to people is you should care about people, you should give a fuck about other people, and that's just an especially difficult one, because it's such a fundamental thing. It's very easy to say, oh, things are bad now when they were better in a mythical previous age. But I definitely feel like the pandemic really inured people, made them very callous around that in a very distinct way.

> Denial keeps us deadened, disconnected, dissociated but safe and comfortable from the uncertainties of life at the end of the world.

> It is the deaths and further disablement of certain populations deemed *surplus*, those positioned as both eugenic and financial drains on society - disabled, poor, and racialised groups - that are deemed a reasonable sacrifice for a return to 'normal'.

It is the deaths and further disablement of certain populations deemed *surplus*, those positioned as both eugenic and financial drains on society - disabled, poor, and racialised groups[55] - that are deemed a reasonable sacrifice for a return to 'normal'. These are populations that are deemed burdens while they are also made 'productive' and 'profitable' through both 'organised abandonment'[56] and "extractive abandonment" - through which private care, healthcare and surveillance industries make money through their abandonment. These groups are also deliberately and disproportionately under-resourced making them more vulnerable to ill health and then made the target of these industries.[57] As discussed in the introduction, healthcare and welfare systems have been the target of neoliberal extractive policies over the last 40 years which has led to the rapid privatisation of public resources. The Covid-19 crisis has been utilised as a vehicle to further this agenda which further evidences extractive abandonment - making profit from the crisis and from those deemed burdensome and unproductive.

It is *racial capitalism* that socially determines our vulnerabilities to the virus and to ill health. Class, race, and other social inequities shape our conditions and contribute to classed and racial health inequities.[58] Racial capitalism influences health outcomes, risk factors for ill health and limits access to resources that might support and protect health.[59] Racial capitalism is disabling. And it is in service of this system that we have submitted to returning to 'normal' - a normal of stark inequity and a normalisation of death and disablement.

The levels of death and continued suffering are 'produced by a system that views death as an acceptable outcome in the preservation of capital'.[60] Adler-Bolton[61] points to the positioning of the deaths of disabled and immunocompromised people as 'deaths pulled from the future' - of Covid simply hastening the deaths of those who were going to die anyway. Research also suggests that when the racial disparities of the pandemic became clearer this reduced the fear of Covid-19 and reduced support for Covid-19 safety measures among white people.[62] These deaths are seen as an inevitability and a certainty among the uncertainty of the pandemic, hiding the ways in which vulnerability to the virus is *'socially determined'* and facilitated by ongoing forms of structural violence which position certain populations as surplus and disposable.[63]

The pandemic response has emphasised certain populations as both eugenic and financial burdens - as weak links, as Dr Anthony Fauci (former Chief Medical Officer to the President of the United States) described as those who will simply 'fall by the wayside' - but that life must go on.[64] There is an economic

54. Watkins, M. and Shulman, H. (2008). *Toward Psychologies of Liberation*. Palgrave Macmillan
55. Adler-Bolton, B. and Vierkant, A. (2022). *Health Communism: A Surplus Manifesto.* Verso
56. Gilmore, R.W. and Gilmore,C. (2016) Beyond Bratton. In C. Heatherton and J.T. Camp (Eds.). Policing the Planet: Why the Policing Crisis led to Black Lives Matter (pp.173 - 200). Verso Books
57. As above
58. Laster Pirtle, W. N. (2020). Racial Capitalism: A Fundamental Cause of Novel Coronavirus (COVID-19) Pandemic Inequities in the United States. *Health Education & Behavior*, 47(4), 109019812092294. https://doi.org/10.1177/1090198120922942
59. As above
60. Adler-Bolton, B. (2024, September 25). *Structural Violence and the Pandemic: An Update on Our Collective Reality.* Substack.com; Blind Archive. https://blindarchive.substack.com/p/structural-violence-and-the-pandemic
61. As above, footnote 52
62. Skinner-Dorkenoo, A. L., Sarmal, A., Rogbeer, K., André, C., Patel, B., & Cha, L. (2022). Highlighting COVID-19 racial disparities can reduce support for safety precautions among White U.S. residents. *Social Science & Medicine*, 114951. https://doi.org/10.1016/j.socscimed.2022.114951
63. Adler-Bolton, B. (2022, January 3). *"Deaths Pulled From the Future."* Substack.com; Blind Archive. https://blindarchive.substack.com/p/deaths-pulled-from-the-future

weighing up of if it would be really worthwhile to care for these groups. In their book Health Communism, Adler-Bolton and Vierkant[65] argue that this framework has been foundational to the modern state and its institutions - and any centring of the surplus would be a threat to capital. This makes the political forces of denial and forgetting of the earlier phases of the pandemic more understandable - in 2020 the rupture of Covid led to broad based support and belief in the possibility of another world - of mutual aid, ending evictions, defunding the police, of a more popular than ever movement for Black Lives Matter; the glimmer of possibility of another world which would centre those at the margins.[66]

> Beatrice Adler-Bolton argued that we must ask "what is normal in a system that readily sacrifices most of us to sustain itself?" and why have we been so seduced by a return to this 'normalcy'.

However, as we accelerate through and towards polycrisis, the 'neoliberal market economy promotes a forgetting of the past and the constant replacement of the old with the new', of the dissociative filling of our time and attention towards the new lest we look back or feel inwards or turn towards the 'unalterably' other.[67] Denial keeps us deadened, disconnected, dissociated but safe and comfortable from the uncertainties of life at the end of the world, keeping us disconnected from each other and what we had imagined possible at the start of the pandemic.[68] Denial does not keep us responsive to our changing conditions or responsible to our communities, it keeps us stuck in defensiveness. We must then move towards both *witnessing* and *action* - shifting from the dissociation of denial towards mourning who and what no longer exists post-2020, and facing the present of the ongoing pandemic in solidarity with those deemed disposable and surplus.

Centring those deemed 'surplus' must be an integral part of our struggles, rejecting the normalisation of mass death and disablement - rather than reproducing the system that creates these conditions, Beatrice Adler-Bolton argued that we must ask "what is normal in a system that readily sacrifices most of us to sustain itself?" and why have we been so seduced by a return to this 'normalcy'.[69]

Imagining a new normal

Andrea Barrett: Yeah, I think the idea that people just need to be presented with the information is a slightly naive one. People need a way into considering a radical, different perspective. It's not just facts about a virus. It's having a new narrative that explains the cognitive dissonance of the last few years and an openness to taking on a new story that is going to be inherently more uncomfortable than the one they currently have. And so the task of education isn't just presenting new information, it's making it as comfortable as possible so that a person can sort of release their resistance to even be open to it, because there's a reason why COVID denialism is the norm, because facing it requires a comfortableness with discomfort that most of us only have out of necessity.

As Andrea notes, there must be a radical shift in perspective and an openness to the discomfort of the current moment. It is a form of disabled wisdom and skill to be comfortable with discomfort, and this wisdom must be listened to. This is an example of Kalsched's[70] call to respond to the trauma of Covid through our imagination in more creative and positive ways - resisting the hijacking of our imaginations by dissociation, denial and capital. Disabled people and their comrades are creating worlds of possibility and templates for surviving the end of the world, navigating the dizzying split between a reality in which Covid exists and a reality where Covid is denied.

It is through discomfort, facing grief and death in the pandemic that we are offered possibilities for living in the present - to break out of denial, the normative of the 'back to normal' - we are called 'to bear responsibility and to open possibilities for freedom'.[71] This opens space for who we need to be for our current times and changed and changing conditions - supporting possibilities for new forms of being at the end of the world and challenging the structural violence of capitalism.

Kalsched argues that to face Covid we must face the shadow of death and our fleshy, finite lives. We must build the ability to have an imagination for death and our own human beingness - our interdependence, vulnerability and frailty. This would enable us to collectively grieve and respond into a politics of possibility. Disabled people are canaries in the coalmine, and, as Alice Wong[72] says, we are 'modern-day oracles' leading the way in facing our current crisis - as Andrea notes, it is disabled people who have a comfortableness with discomfort out of necessity and survival to imagine other worlds. However, disabled folks cannot be left to bear the burden of this work alone - the continued attacks on welfare, austerity and the ongoing pandemic make for brutal, violent and exhausting conditions which erode our capacity for imagination and force us into survival mode.

These times require bravery, an ability to unflinchingly face our present - to look to ourselves and each other to bear responsibility, to reject collusion

64. Wong, A. (2024, January 17). *COVID Isn't Going Anywhere. Masking Up Could Save My Life*. Teen Vogue. https://www.teenvogue.com/story/covid-isnt-going-anywhere-masking-up-could-save-my-life; Adler-Bolton, B. (2022, January 3). *"Deaths Pulled From the Future."* Substack.com; Blind Archive. https://blindarchive.substack.com/p/deaths-pulled-from-the-future
65. Adler-Bolton, B. and Vierkant, A. (2022). *Health Communism: A Surplus Manifesto*. Verso
66. Osterweil, V. (2024, March 14). *Remembering As An Act of Revolt*. Collective of Anarchist Writers. https://www.cawshinythings.com/a-list-of-things-we-have-been-told-to-forget/ ; Adler-Bolton, B. (2022, January 3). *"Deaths Pulled From the Future."* Substack.com; Blind Archive. https://blindarchive.substack.com/p/deaths-pulled-from-the-future
67. Watkins, M. and Shulman, H. (2008). *Toward Psychologies of Liberation*. Palgrave Macmillan, p.120; p.115
68. Osterweil, V. (2024, March 14). *Remembering As An Act of Revolt*. Collective of Anarchist Writers. https://www.cawshinythings.com/a-list-of-things-we-have-been-told-to-forget/
69. Adler-Bolton, B. (2024, September 25). *Structural Violence and the Pandemic: An Update on Our Collective Reality*. Substack.com; Blind Archive. https://blindarchive.substack.com/p/structural-violence-and-the-pandemic para, 23
70. Kalsched, D. (2021). Intersections of personal vs. collective trauma during the Covid-19 pandemic: The hijacking of the human imagination. *Journal of Analytical Psychology*, 66, 3, 443 - 462
71. Watkins, M. and Shulman, H. (2008). *Toward Psychologies of Liberation*. Palgrave Macmillan, p.129
72. Wong, A. (2020, March 18). *Disabled Oracles and the Coronavirus*. Disability Visibility Project. https://disabilityvisibilityproject.com/2020/03/18/coronavirus/

with liberal fatalism, with the sacrifice of the surplus for capital and to be in solidarity with disabled and immunocompromised communities, recognising how both Covid and the structures which determine our vulnerability to ill health and disease harm us all.

Disappearing of disabled and immunocompromised people Loneliness and abandonment

Covid safer organisers and activists can lead the way in how we can respond to Covid, however Covid denialism has pushed many out of public space and our movements. Covid denialism has meant the withdrawal of all Covid protections and a denial of the actual virus in daily life, this has meant for many of the participants that they have been pushed out of public life - for some lockdown didn't end or they have had to return to a type of lockdown due to the inaccessibility of public space. Participants all shared feelings of having been abandoned - by wider society, our movements, medical professionals, and by friends, family and community who deemed Covid safety too burdensome.

> Keith Jennings: By its very nature, living in a COVID conscious way is isolating and can make for a very lonely existence.

Covid conscious, disabled and immunocompromised people experience deep isolation, often feeling lonely and isolated from the wider world. Due to Covid denial participants found it deeply difficult having to navigate a different reality from the rest of the world. Movement spaces had become inaccessible for disabled people, including those with Long Covid, due to the lack of Covid precautions.

Folks shared the ways in which Covid denial undermined their close relationships - Berg shared how their close friend would 'roll her eyes' at being asked to take a Covid test before meeting. Organisers experienced their requests around Covid safety as being seen as burdensome and something that would either be very begrudgingly accepted or ignored. These were points of tension, and asking about masking, testing, and air ventilation was challenging for participants as it challenged denial.

> "For some lockdown didn't end or they have had to return to a type of lockdown due to the inaccessibility of public space."

These experiences highlight the ways in which ableism and eugenicist thinking permeate our intimate relationships, even those relationships formed within Leftist contexts that centre ideas of community and caring for one another. This parallels broader responses to disability, chronic illness and access in the left and in movement spaces. Solidarity is central to leftist movements, however there is a sluggishness around continued solidarity in regards to Covid. There is a collusion with and a reproduction of the surplus vs worker binary even in our most radical spaces that sees disabled people as a burden and undeserving of solidarity. This collusion needs to be interrogated, to reflect on the ways in which the current systems we struggle against recoup us into ableist ideas of deservingness, scarcity, worth, value and productivity and how these are reproduced in our movements for liberation. Covid denial frays our relationships and community bonds, colluding with the 'exclusion of the surplus from the body politic' and their abandonment.[73] This disrupts the radical possibilities of solidarity between workers and surplus and the challenge this would present to capital, a turning away from the radical possibilities imagined at the start of the pandemic.

Harassment

Participants also experienced extreme and explicit harassment for wearing masks in public and organising Covid safer events. This harassment intersected with other forms of minoritisation - Riya, a Covid safer organiser and young person of colour had had their mask physically ripped from their face. Greta, a Covid safety organiser, and her organising group received intersecting queerphobic and ableist harassment and threats, where they had to recruit security to ensure their safety at a Covid safer event they had organised. These extreme forms of harassment, threats and physical violence are at the sharp end of how disabled people are being hounded out of public life for challenging Covid denial and trying to survive the ongoing pandemic.

> Greta: So we've gotten a few comments on our most recent social media post on it, like threatening to show up to our events. So today we had a meeting, and we're hiring a security organization that specifically does queer and anti racism security. So hopefully we can hire them to be there through this...
>
> Stephanie: How were people framing that threat? Like, you shouldn't be doing COVID safety events, or like?
>
> Greta: we got, and I'm very sorry for what I'm about to say, but one person reposted saying, 'the AIDS victims are organizing again'... we got someone saying, 'but can I show up with a really bad chest infection?' So many other ones. People saying that, like, oh, one person said, 'My dad died, and I think this is dramatic.'
>
> So that was one, and then the one that, like, I put in my article in undergrad, was once someone saying, 'What makes you think you deserve to live?' direct quote.

73. Adler-Bolton, B. and Vierkant, A. (2022). *Health Communism: A Surplus Manifesto.* Verso p.76

> Riya: Now I can attest it's really bad I've been physically assaulted so many times, had my mask ripped off me. I think especially being like a young brown person, people do not like that. I feel like people think that you're taking away their rights by wearing a mask yourself.

These forms of hate illuminate the structural violence of Covid denial and eugenicist policy, as well as the politicization of Covid mitigations that evoke such strong reactions from others. The politicisation of masking is also strengthened by the incoming Crime and Policing Bill which will ban masks at protests, although with a legal exemption for health - however this defence would only be able to be used after arrest.[74] Participants noted that in different locations across the uk police already ask people to remove their masks at protests, or forcibly remove them.

> "This harassment highlights how the surplus are positioned as burdensome and dehumanised - 'what makes you think you deserve to live?' is chilling in exemplifying the surplus as a eugenic burden."

Organisers talked about how much strength and confidence they had to have to continue to mask in public, and that for minoritised people this was a barrier to continued masking. This harassment highlights how the surplus are positioned as burdensome and dehumanised - 'what makes you think you deserve to live?' is chilling in exemplifying the surplus as a eugenic burden. The intersection of this harassment with visible disability, racialisation, sexuality and trans identity shows how Covid denial intersects with and is reproduced through other forms of oppression - and as we will reflect later in this chapter how liberal fatalism, Covid denial and eugenicist policy have helped to embolden fascism.

Folks also experienced being positioned as 'mad' for their Covid safety - being called 'crazy', and having to manage how they are perceived - trying their best to seem as 'reasonable' as possible. This illustrates the level of Covid denial and how difficult it is for organisers to navigate this. In therapeutic spaces Covid cautious individuals also experienced being framed as 'anxious' and requiring exposure therapy to learn to live without Covid mitigations.

> Daisy: That is a huge problem for people in that a lot of therapists think it's anxiety, and they're encouraging people, to just gradually start going out without your mask on. Just hang around with these people without your mask on.

This framing of covid cautious people as overly anxious and 'mad' started early in the pandemic with psychiatric research into mapping and creating assessments for 'Covid Anxiety Syndrome' in the spring of 2020;[75] illustrating how we were primed from the start of the pandemic to return 'back to normal' as quickly as possible.

There is a strong structural and cultural investment in denial and participants experienced being pushed out of public space, harassment and denigration. This in itself is maddening, and one discussion among participants focused on Ignaz Semmelweis and drew links between him and Covid safer organisers.

> Participant24: Semmelweis let me get it right. He was, just Google it so that I get the story absolutely right. They were a Hungarian obstetrician. He discovered the infectious character of something, and advocated rigorously for cleanliness and the use of antiseptics by doctors examining patients. He was sectioned eventually, and he had a horrible end, because the culture around him would not accept this reality which he was advocating for. So, yeah, think so. I think that has to happen. It has to be rejected first, and then eventually it becomes common knowledge and accepted.

Semmelweis was an obstetrician in the mid-1800s who discovered that the spread of disease could be reduced through handwashing by medical staff, however this challenged the scientific consensus of the day and his work was critiqued and rejected. He was eventually put into an asylum and died two weeks later. Among Covid safer communities Semmelweis seems to have become a patron of sorts which illuminates the scale of gaslighting and denial and what it means to be working at odds with mainstream (mis)understanding and denial of Covid-19. Sanism is another way in which disabled people are undermined and can be dismissed. It must also be recognised that participants noted that many Covid cautious organisers are neurodivergent - that there is the wisdom of neurodivergence and the ability to recognise patterns where others do not, a willingness to question our social realities as well as commitments to social justice. Again, through this, disabled people can be understood as 'modern-day oracles' with wisdom that needs to be embraced not dismissed.[76]

Disappearing

Participant X, a Covid safer activist, developed an abolitionist analysis of this denial, abandonment, gaslighting and harassment as a form of disappearing disabled people. They drew on Alice Wong's analysis of Covid denial and mask bans in the US as a form of new ugly laws - X described these as 'socialised ugly laws' wherein the social pressure to collude with denialism, alongside harassment and hate experienced by disabled and multiply marginalised folks trying to survive the pandemic force folks out of public life. Ugly laws were forms of legislation in the US in the late 1800s that aimed to stop poor and disabled people being in public space - particularly those who appeared

74. *The UK Government's plan to ban face coverings at protests - Liberty*. (2025, April 23). Liberty. https://www.libertyhumanrights.org.uk/issue/the-uk-governments-plans-to-ban-face-coverings-at-protests/; Mortimer, J. (2025, June 3). *Police to Get Powers to Ban Masks at Protests as Starmer's Government Accused of "Copy and Pasting" Conservative Plans*. Byline Times. https://bylinetimes.com/2025/06/03/police-to-get-powers-to-ban-masks-at-protests-as-starmers-government-accused-of-copy-and-pasting-conservative-plans/

75. Nikčević, A. V., & Spada, M. M. (2020). The COVID-19 anxiety syndrome scale: Development and psychometric properties. *Psychiatry Research*, 292, 113322. https://doi.org/10.1016/j.psychres.2020.113322

76. Wong, A. (2020, March 18). *Disabled Oracles and the Coronavirus*. Disability Visibility Project. https://disabilityvisibilityproject.com/2020/03/18/coronavirus/

to be 'unsightly'. These laws disproportionately impacted people by 'race, gender, immigration status, and sexuality'.[77] These laws were influenced by segregation and eugenics. Wong presents the mask bans currently spreading across the US as new forms of the ugly laws, that can be understood to perform the carceral function of disappearing disabled people.

> Participant X: I just remember someone talking about referring to COVID and COVID abandonment as a form of socialized ugly laws. And I think that's a very important link to make, because in terms of disability, a massive function of carceral systems throughout history has been to, disappear disabled people, and that's basically the same thing that is happening to immunocompromised people. It's just the fact that it's not. Actually the state? Well, it is the state doing it, but it's also the communities who claim to be anti state, who are then co-signing it and doing it themselves as well.

Although we do not currently have mask bans in the uk, Participant X describes the abandonment and harassment of Covid cautious disabled people as a force of 'disappearing' and a form of 'socialized' ugly laws enabled by the carceral state and reinforced through its wholesale endorsement across broader society. They critique the return to 'normal' as investment in the very systems our movements claim to challenge. The carceral state will always use 'health and disablement as weapons', particularly to target surplus populations.[78] Disablement and 'maiming is a source of value extraction from populations that would otherwise be disposable'.[79]

Eugenics and fascism

Participants understood the harassment and disappearing of disabled people as part of the eugenics of the pandemic response, and made links between this response and the further attacks on disabled people through welfare state violence. The pandemic and the liberal fatalism of the pandemic response, as well as the failure of a broad-based Leftist challenge to this has allowed for eugenicist policy to proliferate.

Participants understood the linkages between eugenics and fascism, pointing to how the acceptability of Covid denial and eugenics has enabled and ushered in an era of emboldened fascist politics.

> Daisy: The link between the flu pandemic in 1918 and fascism. And when people were originally saying that, I was like, 'really?', but now I can, you can totally see, the links and that timeline.

The 1918 flu pandemic killed at least 50 million people around the world, emboldening eugenicist ideas of needing to sacrifice the vulnerable for the good of the 'healthy' population - the idea that some lives are worth less than others.[80] This is a fascist ideology at its root, and some studies suggest that the flu pandemic and the responses to it may have influenced the rise of fascism in the 1920s and 1930s.[81]

> "The 1918 flu pandemic killed at least 50 million people around the world, emboldening eugenicist ideas of needing to sacrifice the vulnerable for the good of the 'healthy' population - the idea that some lives are worth less than others."

Participants drew parallels between that historical period and our current moment - where eugenicist ideas about the value of certain lives over others, of the health supremacism of Covid-19 'only' affecting the vulnerable have become mainstream and accepted opinion. The liberal fatalism of the uk state response has encouraged a focus on the responsibility of the individual alone to navigate the pandemic, positioning death and disablement as an individual failing - a failure of the choices made and of the moral failure of being 'vulnerable' - ignoring the political choices and structural inequality that make us more vulnerable. To be asked 'What makes you think you deserve to live?' highlights the embedding of eugenicist thought in the everyday, and of how disabled people trying to survive the pandemic are positioned as burdens. This is starkly highlighted by what Selina Nwulu describes as the 'sleeping scandal'[82] of non-consensual 'do not resuscitate' (DNR) orders in the first and second wave of the pandemic in the uk. In some NHS trusts there were blanket DNR orders for patients with Covid based solely on their age or disability.[83] Similarly, in March 2020 services for people with learning disabilities received letters to tell them that their clients would be ineligible for hospital treatment if they caught Covid. Adults with learning disabilities were over-represented by at least 3.1 times in deaths from Covid.[84]

Conclusion

At the beginning of the Covid-19 pandemic in 2020 there was hope that another world was possible - Covid violently illuminated the longstanding structural inequalities and violence of our society and it felt as though there was broader support than ever to reckon with this. However, very quickly we returned to 'normal' - and a state of denial which encouraged us to forget Covid and forget what we had hoped was possible in those early phases. This denial was politically engineered through the liberal fatalism of the Conservative government, who wanted to ensure their continued political legitimacy, status quo and keep the economy moving - in particular to continue the huge transfer of money from the public purse to the private sector.

Covid denial has been seductive, and the tendencies shaped by histories and presents of oppression - to turn away from suffering, particularly if it is the suffering of those deemed 'surplus'. It is the logics of capital, coloniality, whiteness that circulate in Covid denial and the rhetoric of back to normal -

77. Wong, A. (2024, January 17). *COVID Isn't Going Anywhere. Masking Up Could Save My Life. Teen Vogue*. https://www.teenvogue.com/story/covid-isnt-going-anywhere-masking-up-could-save-my-life;
78. Tastrom, K. (2024). A People's Guide to Abolition and Disability Justice. PM Press
79. Puar, J. K. (2017). *The Right to Maim*. Duke University Press. https://doi.org/10.1215/9780822372530
80. Lurie, S. (2024, November 18). *History shows that pandemics lead to fascism*. Rabble.ca. https://rabble.ca/health/history-shows-that-pandemics-lead-to-fascism/
81. Galofré-Vilà, G., McKee, M., Bor, J., Meissner, C. M., & Stuckler, D. (2021). A lesson from history? Worsening mortality and the rise of the Nazi Party in 1930s Germany. *Public Health*, 195, 18–21. https://doi.org/10.1016/j.puhe.2021.03.022
82. Nwulu, S. (2025). Black Climates. Chatto & Windus.
83. Reed, J. (2024, October 10). *NHS trust put in place do-not-resuscitate rule, Covid inquiry told*. BBC News. https://www.bbc.co.uk/news/articles/cd98vpxgp7ko
84. *Covid-19 Inquiry Told of Do-Not-Resuscitate Communication To People With Learning Disabilities | Disability Rights UK*. (2025). Disabilityrightsuk.org. https://www.disabilityrightsuk.org/news/covid-19-inquiry-told-do-not-resuscitate-communication-people-learning-disabilities?srsltid=AfmBOooahH

and it is in service to these that we have returned to a normal which sacrifices 'surplus' populations - the disabled, poor, racialised.

What does it do to us to respond to both collective trauma and liberal fatalism in this way? What does it mean for us if we have been seduced by this back to normal - a normalisation of mass death and disability, a normal that 'readily sacrifices most of us to sustain itself?' That submits to the logics of eugenics - that some lives are worth more than others?

Colluding with the denial may be comfortable but it keeps us from being responsive to the current moment or from being responsible to our communities. We must then move towards witnessing and action and centring the surplus, rather than reproducing the system that creates conditions of mass disablement and death.

Disabled, immunocompromised, Covid bereaved folks and their allies are navigating the dizzying split between the world of Covid denial and the world in which Covid exists. They lead the way in facing the discomfort and grief of our changed and changing world, leaning into a politics of possibility and rehearsing actual collective care in ways that do not deny the pandemic. Our movements and wider society must challenge the abandonment of disabled and surplus groups, building solidarity and reckoning with how the liberal fatalist response to Covid and Covid denial has emboldened the very structures we are struggling against. We must understand the intersections of our struggles, that we must fight against the normalization of 'unrelenting mass death and disablement' on all fronts.

CHAPTER 2

COVID DENIAL AND THE MATERIAL CONDITIONS OF THE 'POST-PANDEMIC'

In Chapter 1 we considered the political and social context of Covid and Covid denial, how liberal fatalism has shaped the pandemic response in the uk and how this has forced disabled people out of public life, and has worked to further 'disappear' disabled people. In this chapter we explore the second theme and consider how this political and social context shapes the systemic, material conditions of life post-2020 in an ongoing pandemic, how this undermines disabled and immunocompromised people's basic participation in society[85] and the ways in which the people I spoke to are attempting to challenge this exclusion.

Organisers were working in different arenas but focused on healthcare, workplaces, and education and the role of public health, trade unions, and government and councils. Folks were also building their own covid cautious communities and mutual aid networks in response to these conditions - this will be covered in Chapter 3.

Public health

[Regarding the topic that masking and Covid organising is more organised in the us]

Participant X: It does just seem a bit more normalized. And I kind of wonder why that is. And part of me wonders...I think in America, because of their healthcare system, they have quite a different understanding of health plus capitalism. Whereas I think here in this country, for a lot of people on the left, their understanding of disability and capitalism doesn't really go beyond the need to fund the NHS. And I wonder whether that's an element of it, because when you're just focusing on getting more money in the NHS you then overlook the fact that, okay, the NHS can be fully funded, and doctors are still going to be extremely ableist and one of the main groups enacting that.

As discussed in Chapter 1, the uk Covid response has been described as one of the worst public health 'failures' in uk history.[86] This failure continues to shape all other facets of life in the ongoing pandemic - in healthcare, our places of work and in education. However, there are tensions around positioning this as 'failure' versus questioning the role of the state and public health.

As Participant X notes, healthcare and by extension public health are not benevolent systems but are institutions that enact harm. In the us context, organisers may more clearly understand the dynamics of power within healthcare under capitalism. However in the uk there can be a tendency for the NHS and the welfare state to be looked at through nostalgic and rose-tinted lenses, they are symbols of national pride and understood as benevolent institutions. As the Deaths by Welfare research at HJL has highlighted, this can make it difficult to reckon with the ways in which harm has been 'baked' into these systems and that harm is a feature, not a bug.[87] Since their inception these institutions have been sites of control, surveillance, and harm and work to delineate between deservingness and undeservingness, citizen and non-citizen along classed, racialised and disability lines. We might then understand the 'failure' of public health and the NHS response to the Covid-19 pandemic as working in alignment with these binaries - of who is deserving and who is undeserving, who is productive, and who is burden, reinforcing the worker - surplus distinction. Back-to-normal and Covid denial is an investment and boldening of these binaries, and the narrative of the burdensome. As China Mills points out, these stories about the burdensome are utilised to dismantle welfare and divert resources away from the most marginalised. Disabled people have been marked as 'impediments'[88] to the ending of the pandemic, the acceptance of harm against disabled folks and the positioning of disabled people as 'outliers'[89] has been utilised to dismantle the few public health mitigations we once had such as free testing, sick pay for quarantine, and free access to vaccines.[90] We could understand this is an acceptance of the harms enacted by public health, in service to the normative or default ways of being - and the discarding of those deemed surplus.

> "Since their inception these institutions have been sites of control, surveillance, and harm and work to delineate between deservingness and undeservingness, citizen and non-citizen along classed, racialised and disability lines."

We can also re-think this 'failure' of public health as a 'success' from the standpoint of private enterprise as discussed in the introduction. Public health has succeeded in its continued extractive abandonment from surplus populations, as well as supporting the economic growth of UK plc and orienting the population towards the minimisation of the pandemic and the minimisation of the harms of the last 6 years.

This public health response to Covid has crystallized into ongoing uncertainty, ignorance and denial around the virus through which the State has amplified all ambiguities of Covid and undermined scientific consensus and evidence that does not align with 'back to normal'. Organisers pointed out the lack of clear and accessible information and that misinformation comes from the top-down through the refuting of scientific evidence. For example, Sioux points to the need to challenge the official guidance of uk Infection Protection and Control (IPC) that Covid is not airborne but spread through droplets as this conflicts with broader scientific consensus that highlights the significance of airborne spread. The majority of experts at the Covid Inquiry agreeing that this is the primary mode of spread.[91]

Sioux Vosper: We need the IPC [Infection Prevention Control] guidance to change, I think, and that's when the NHS and when people will get on board. People are just using it as an excuse that, well, the guidance is that 'we don't need to wear masks' and 'we don't need to do anything' and 'it's not airborne, it's droplets'. But CATA - I don't know if any of you saw that, the COVID Airborne Transmission Alliance really blew that out of the water. They were so good at the inquiry, and they're really on board with anything to do with COVID, they are a group of doctors and consultants.

Organisers were navigating the tension of how to respond to the intensity of denial, of drawing on scientific evidence to appeal to wider authorities alongside the grief of state abandonment and neglect - and that evidence of the harms enacted by the State and by the virus may not equate to change within these systems.

In the earlier phases of the pandemic the uk's covid response was focused on public approval and shaping public perceptions of the science rather than being 'guided by the science'.[92] At this stage the government was commissioning opinion surveys on public understanding of the virus and approval for

85. Clinically Vulnerable Families. (2025, March 2). *"Learning to Live with Covid" Didn't Result in Any Learning*. CV Families. https://www.clinicallyvulnerable.org/post/learning-to-live-with-covid-didn-t-result-in-any-learning
86. Sample, I. and Walker, P. (2021, October12). *COVID response 'one of UK's worst ever public health failures'.* The Guardian. https://www.theguardian.com/politics/2021/oct/12/covid-response-one-of-uks-worst-ever-public-health-failures
87. Mills, C. (2024, September 10). *Understanding Welfare State Violence - Healing Justice Ldn*. Healing Justice Ldn. https://healingjusticeldn.org/methodology/calling-some-people-a-burden-provides-a-cover-story-for-welfare-state-violence/
88. Yong, E. (2025). Foreword: Into the Pandemic's Disability Hinterlands. In M. Mills, H. Kornstein, F. Ginsburg, and R. Rapp (Eds.) How to Be Disabled in a Pandemic. New York University Press. (pp.vii - xi)
89. As above
90. As above
91. McConway, A. M. (2025, February 6). *'Airborne' seems to be the hardest word*. North West Bylines. https://northwestbylines.co.uk/news/health/airborne-seems-to-be-the-hardest-word/
92. Bacevic, J. and McGoey, L. (2024). Liberal fatalism, Covid-19 and the politics of impossibility. *Economy and Society*, 53, 1, 163 - 182

certain interventions. The uk pandemic response was shaped by an emphasis on sustaining political legitimacy for the Conservative government, and to 'maintain the networks of economic and political patronage' in the crisis.[93] Understanding the state as aiming to maintain itself and facilitate profit for uk plc challenges us to consider the desire to draw on scientific evidence and pleas towards authority, an authority that is only interested in those deemed surplus as far as they can be extracted from.

> Understanding the state as aiming to maintain itself and facilitate profit for uk plc challenges us to consider the desire to draw on scientific evidence and pleas towards authority, an authority that is only interested in those deemed surplus as far as they can be extracted from.

Drawing on liberal fatalism, the state has engendered a politics of uncertainty which allows for denial as discussed in Chapter 1, and also engenders a politics of impossibility - closing down the collective possibilities of responding to Covid, of a powerlessness to respond to the pandemic while continuing an 'ignorance alibi' for political elites.[94] This shapes the 'normal' we have returned to, in which Covid is denied and creates risky and dangerous material conditions for us all, disproportionately impacting those deemed 'surplus'.

Organisers highlighted the need to challenge public health, however understood the investment in the 'ignorance alibi'. Several folks highlighted the parallels between the early days of the HIV epidemic and Covid - of government inaction and public health disregard, particularly because of who is disproportionately impacted by both HIV and Covid.

> Polly Jennings: I was just going to say it does go back to public health information. People. From my conversations 99% of people have no idea what airborne spread actually means, or what it looks like, or what the impact of it is. I say to people, it [the Covid virus] moves like cigarette smoke. If I'm standing on the other side of the room and you're smoking and I can smell it, that's it, you're getting an infection.

Organisers like Polly highlighted the difficulty of advocating about Covid within this context of misinformation and of public health disregard. There is a need for clear, accessible health information and clarity on how to manage Covid in lieu of state abandonment. This will be explored further in Chapter 3 - where Covid activists are organising to continue an ongoing grassroots response. There is a need for the building of community based public health infrastructure that addresses the importance of clean air, in the same ways we have infrastructure for clean water. There is a tension between top down and bottom up approaches to public health and infrastructure, and participants pointed to the need for both approaches - and that communities need to support each other in responding to this crisis as we continue to be abandoned by the State - a state that for many of us never cared for and has actively targeted as 'burdensome' and surplus.[95]

> Fran: So really the question then becomes, how do you change the material realities of the most affected - how does that actually work in practice? Because you have that trickle down approach where you're lobbying politicians, you're trying to change policy, you're trying to enforce all of these structural changes. But we know that these structural changes obviously flow from the top down and intend to reach the most affected and the most vulnerable last, so, how can we interrupt that movement and actually work in a disruptive way, in a new way that actually preserves dignity and encourages the idea that these are the lives that matter just as much as people who would be positively impacted by policy first. And that looks like actually looking at the people who don't have the resources to protect themselves from the next pandemic, or the one that we're currently in at the moment.

As Fran, a Covid and mutual aid organiser, points out lobbying for structural and policy change can mean that change can reach the 'most affected and the most vulnerable last'. They point to the need for a scissor movement - of both lobbying and grassroots action and solidarity to address the material realities of those most impacted by Covid (and recognising how Covid impacts us all).

A common critique in Leftist communities of Covid activists is that Covid is a structural problem that needs to be addressed at a structural level, however this fails to recognise the eugenicist violence and motivations of a state which 'let the bodies pile high' and the urgent need for a politics of solidarity at the grassroots - that can call the State and its institutions to account as well as building our own infrastructures.

This also ignores the accelerating privatization of the NHS and public health, which has been given a boost by the liberal fatalism of Covid denial and the pandemic response. The abolishment of Public Health England (PHE) for its failures at the beginning of the pandemic led to the creation of the UK Health Security Agency (UKHSA) and the Office for Health Improvement and Disparities (OHD). PHE was criticised for its inability to speak 'truth to power', however UKHSA and the new Office for Health Improvement and Disparities are even less independent from government.[96] Scally[97] describes UKHSA 'as a further step in the growth of a centralised and secretive state apparatus with the close engagement of private sector interests'. There are concerns over both organisations' abilities to structurally address health inequalities which have been further illuminated and impacted by Covid, and also how these

93. As above
94. McGoey, L. (2019). *The unknowers: How strategic ignorance rules the world*. Bloomsbury
95. Mills, C.(2025, September 18). *Deaths by Welfare - Healing Justice Ldn*. Healing Justice Ldn. https://healingjusticeldn.org/methodology/deaths-by-welfare/; Adler-Bolton, B. and Vierkant, A. (2022). *Health Communism: A Surplus Manifesto*. Verso
96. Hunter, D.J., Littlejohn, P. and Weale, A. (2022). Reforming the Public Health System in England. *The Lancet*, 7, 9, p.799
97. Scally, G. (2021). A New Public Health Body for the UK. *BMJ*, 373 p.1

agencies sit within a state framework of healthcare privatisation with their emphasis on economic growth and 'UK plc'.[98]

We must struggle against privatisation and the structural violence of public health, healthcare and Covid denial *and* build our own infrastructures for these times, that can intervene in and shape our material conditions for the better.

Covid and accessing healthcare

The uk public health stance shapes our material realities - all facets of life where Covid denial is the norm. In these next three sections I consider organisers' experiences in navigating safe access to healthcare, work and education which are shaped by public health failure, liberal fatalism and Covid denial.

Organisers described being abandoned by the medical system, and that there is a lack of knowledge or a forgetting and denial of Covid within the NHS. Infection control is focused on MRSA and norovirus, but following the IPC stance and guidance there is little focus on airborne infection control. The people I spoke with noted pockets of good practice, however much that had been in place in the early phases of the pandemic had been erased. Folks struggled with accessing medical care while being put at risk of being infected by Covid.

> Riya: I think coming from a healthcare perspective, I think even within healthcare circles, it's knowledge that just isn't present. And I'm genuinely the only person I see masking in the entire hospital in a day - being there for 10-12 hours. I might see an older lady, occasionally, another member of staff, but it's always the blue surgical masks. I think there's just not knowledge on what good masking is. So I'd like to say that it's just healthcare knowledge isn't as widespread as it should be. But I think even within healthcare communities, people just don't know.

> Daisy: And infection control seems to be more around MRSA, norovirus, that kind of thing rather than airborne [infection control]. From what we can tell as well, we were told [by hospitals] 'this is our standard', and some of it blatantly isn't being stuck to from our various trips to hospitals as patients.

Following public health messaging, organisers found that in accessing NHS healthcare and working within healthcare there was a lack of understanding of Covid, but also a disparity between expected standards and how healthcare operated in the day to day. Folks were concerned with the risk of Covid infection when going to hospital or the doctors. Research in the uk and Canada has found that hospital acquired Covid infections can drive transmission

> The costs are seen to outweigh the benefits of 'back to normal', especially as Covid has been framed as an issue only for the 'vulnerable', the surplus who are seen as already both eugenic and financial burdens on the state.

of infection in the community.[99] Between 2020 and 2022 at least 70,000 people admitted to hospital in the uk caught Covid in hospital after being admitted for other reasons such as cancer treatment, accidents, and for operations and of this number at least 14,000 died.[100] A 2023 article in the Journal of the American Medical Association asked if it was still 'worth' preventing the spread of Covid in hospitals particularly considering the financial cost.[101]

Liberal fatalism, covid denial and public health guidance has created a laissez-faire approach to airborne infection control in hospitals - that it is impossible to stop transmission, despite significant infection control for other contagious diseases such as MRSA and norovirus. There is a seeming acceptability that a hospital can be a place where people might catch a life-changing illness - even at their most vulnerable and when seeking care. As Julia Doubleday notes, 'come in for heart surgery, leave with a heart-damaging virus. What a business model!'.[102] The emphasis is on the individual to protect themselves, burdening disabled and those positioned as high-risk people with navigating forced exposure in healthcare and therefore restricting access.[103]

As highlighted in the Journal of the American Medical Association and as discussed in Chapter 1, there is a weighing up of the economic costs of preventing Covid in healthcare - of the costs of implementing improved air ventilation, air purification, testing and tracing, separate wards for positive and negative patients, and high quality masking. The costs are seen to outweigh the benefits of 'back to normal', especially as Covid has been framed as an issue only for the 'vulnerable', the surplus who are seen as already both eugenic and financial burdens on the state. If hospitals began to incorporate more stringent Covid infection controls this would disrupt Covid denial - and that Covid has continuing risks for both sick and disabled folks as well as those who are currently healthy or non-disabled.[104]

98. Scally, G. (2021). A New Public Health Body for the UK. *BMJ*, 373 p.1
99. Wilson, N.J., Grima, A.A., Eunyoung Lee, C. and Fisman, D.N. (2025). Healthcare Associated Covid-19 in Ontario, Canada: Relative Mortality and Contribution to Community Epidemic Growth. Medrxiv doi: https://doi.org/10.1101/2025.07.28.25332157; Cooper, B. S., Evans, S., Jafari, Y., Pham, T. M., Mo, Y., Lim, C., Pritchard, M. G., Pople, D., Hall, V., Stimson, J., Eyre, D. W., Read, J. M., Donnelly, C. A., Horby, P., Watson, C., Funk, S., Robotham, J. V., & Knight, G. M. (2023). The burden and dynamics of hospital-acquired SARS-CoV-2 in England. *Nature*, 1–7. https://doi.org/10.1038/s41586-023-06634-z
100. Williams, K. (2023, March 13). *"We need to do better" - over 14,000 people died with Covid after catching it in hospital.* Daily Mirror. https://www.mirror.co.uk/news/uk-news/we-need-better-over-14000-28046576
101. Klompas, M., Baker, M. A., & Rhee, C. (2023). Is Nosocomial SARS-CoV-2 Still Worth Preventing? *JAMA Network Open*, 6(11), e2344704. https://doi.org/10.1001/jamanetworkopen.2023.44704
102. Doubleday, J. (2023, August 23). *Hospitals are killing patients because they don't feel like doing infection control.* The Gauntlet. https://www.thegauntlet.news/p/hospitals-are-killing-patients-because?hide_intro_popup=true
103. Gordon, J. (2023, November 13). A Limited Analysis. [A comment on the webpage *Is Nosocomial SARS-COV-2 Still Worth Preventing?*]. Jama Network. https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2811653
104. See above

Covid and education

Similarly immunocompromised and disabled families and children find that they cannot access school without forced exposure to Covid. Parents and Covid organisers are attempting to intervene to encourage schools to buy HEPA filters, as studies have found air purifiers can significantly reduce airborne transmission of Covid-19 in classrooms.[105]

However as in healthcare there is a resistance and lack of understanding of Covid, shaped by current public health guidance and Covid denial. Immunosuppressed, immunocompromised and disabled children are being failed, as well as currently abled children. As of March 2024, 111,816 children aged 3 to 17 were living with Long Covid in England and Scotland.[106]

Andrea Barrett: What motivates me is that when I went to school in the early 2000s there was so much more accessibility for immunosuppressed kids than there have been the last few years. I'm part of lots of different online groups for different types of immunosuppression based on different conditions throughout the years. And I think children who are immunosuppressed are being failed.

Daisy: We wanted to contact schools to ask around, because I'm aware a lot of them have CO2 monitors. And is anyone using them? Are they using them in projects with the kids? Are they taking readings? What's the ventilation like? We wanted to get that kind of information on what's happening. Because it would be lovely if they could do education around schools and go, 'Hey, this is going to save you money in the long run, if you're constantly having to get supply teachers in, because your teacher is off sick, if your kids are off sick,'. The messaging seems to be, kids are away from school, and it's truanting, but a lot of kids are off sick. We're trying to find a way to educate the schools and suggest some of the things they could do.

Andrea Barrett highlights the worsening of public health standards and the reversal of progress for immunocompromised children in schools. As Daisy notes, the focus is on children being in school and concerns about truanting over understanding the impacts of Covid on children. In 2021 as children returned to school the uk repealed preventative strategies despite their continuation in other countries.[107] The government launched a national communications campaign from 2022 to 2024 to increase school attendance and encourage families to send their children to school when ill, currently children can go to school with 'mild' Covid infections or if someone in their household has Covid.[108]

> "42% of clinically vulnerable families had been told to consider withdrawing from school, this is called 'off-rolling' and is illegal as it can be used to improve attendance and attainment figures for schools."

> "Covid disproportionately impacts the most marginalised children - those who are clinically vulnerable, have special educational needs and disabilities, are from poorer areas, and are racially minoritised."

This has been particularly difficult on families with clinical vulnerabilities, those who are racially minoritised, those who live in multi-generational households and children with special educational needs and disabilities (SEND).[109] These families have been understandably reluctant to send their children into schools with few or no Covid mitigations and have been concerned about the impact on the health of their children and family members. In some cases schools have pressured families at higher risk of Covid to either send their child to school or de-register, with some families fined, prosecuted or referred to social services.[110] 42% of clinically vulnerable families had been told to consider withdrawing from school, this is called 'off-rolling' and is illegal as it can be used to improve attendance and attainment figures for schools.[111] There is some concern that the pandemic has been utilised for the off-rolling of SEND students within the marketised, league table focused education system.[112] Some students are seen as worth less within this system, and students who 'enhance' the metrics are prioritised.

There is unequal access to education[113] and people I spoke with found it difficult to interact with schools, councils and government in advocating for Covid mitigations. Participants were faced with blocks and resistance more broadly while finding lone individuals within organisations who were supportive. The costs of air purifiers were a prohibitive factor alongside a lack of understanding of Covid, despite the health and economic benefits of reduced sickness for children and teachers - and despite concerns about rising sickness and absence levels. This is as those in teaching and education have been found to have the highest likelihood of experiencing Long Covid symptoms.[114] Covid disproportionately impacts the most marginalised children - those who are clinically vulnerable, have special educational needs and disabilities, are from poorer areas, and are racially minoritised.[115] Since the start of the pandemic there has been a concerted effort by the state and the media to downplay the impact of Covid on all children.[116] The lack of Covid mitigations in schools disproportionately burdens these children and their families, and creates a barrier to education. This may have also led to exclusionary practices like off-rolling which exclude children identified as surplus and less 'worth while' than those who can 'contribute' to school metrics.

105. Curtius, J., Granzin, M., & Schrod, J. (2021). Testing mobile air purifiers in a school classroom: Reducing the airborne transmission risk for SARS-CoV-2. *Aerosol Science and Technology*, 1–18. https://doi.org/10.1080/02786826.2021.1877257
106. Office for National Statistics. (2024, April 24). *Self-reported coronavirus (COVID-19) infections and associated symptoms, England and Scotland*. Ons.gov.uk; Office for National Statistics. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/selfreportedcoronaviruscovid19infectionsanddassociatedsymptomsenglandandscotland/november2023tomarch2024#long-covid
107. Pagel, C. (2021, August 20). *Schools—a gaping hole in the English covid strategy - The BMJ*. The BMJ. https://blogs.bmj.com/bmj/2021/08/20/christina-pagel-schools-a-gaping-hole-in-the-english-covid-strategy/
108. Department for Education.. (2024, January 8). *Major national drive to improve school attendance*. GOV.UK. https://www.gov.uk/government/news/major-national-drive-to-improve-school-attendance; NHS. (2022, March 2). *Is My Child Too Ill for school?* Nhs.uk. https://www.nhs.uk/live-well/is-my-child-too-ill-for-school/
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110. As above
111. Long Covid Kids. (2022, October 11). *Ghost Children. Completing the Jigsaw with Covid19 infections and Long Covid in children. Long Covid Kids. https://www.longcovidkids.org/post/ghost-children-completing-the-jigsaw-with-covid19-infections-and-long-covid-in-children#viewer-2dhpj*
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114. Theocharis Kromydas, Evangelia Demou, Edge, R., Gittins, M., Srinivasa Vittal Katikireddi, Pearce, N., Martie van Tongeren, Wilkinson, J., & Rhodes, S. (2025). *130 Long-COVID by occupation and industry in the UK using the ONS coronavirus infection survey. Does sars-cov-2 infection matter?* A58.1-A58. https://doi.org/10.1136/oemed-2024-epicohabstracts.130
115. Wenham, L. J., Din, I., & Eaves, L. (2021). 'I no longer trust our son's school': Parents Resisting the Return to Face-to-Face Teaching. *Forum*, 63(2), 74-88. https://doi.org/10.3898/forum.2021.63.2.07; Greenhalgh, T., Manoj Sivan, Perlowski, A., &

Covid and the workplace

Organisers shared experiences of not being protected in the workplace, and the need to hold employers to account. However, the current Health and Safety Executive (HSE) guidance does not expect most employers to consider Covid-19 in their risk assessments or to have any mitigation measures in place.[117] Participants pointed to health and safety law and the equalities act as possible avenues to challenge the lack of mitigations in the workplace, as well as the possibilities of litigation. Long Covid Doctors 4 Action (LCD4A) and Long Covid Educators for Justice (LCEJ) are two groups seeking compensation for occupational exposure to Covid-19 and for better protection from airborne viruses in the workplace - through personal protective equipment (PPE), ventilation and air filtering. Trade Unions are fighting for Covid to be recognised as an occupational disease as there is growing evidence that suggests workplaces are a significant source of infection.[118] The Trade Union Congress found that 20% of workers with Long Covid had seen a significant negative impact on their job security, including having to leave their job.[119] Covid is a labour issue and has a disproportionate impact on some workers, for example in some sectors women and Black people have experienced more exposures to the virus due to the type of work, the contracts they are on, lack of availability of PPE, and because of systemic racism and sexism. This has meant higher rates of infection, death and Long Covid.[120]

> "Trade Unions are fighting for Covid to be recognised as an occupational disease as there is growing evidence that suggests workplaces are a significant source of infection."

Polly Jennings: This is my story of how I had to leave my job because they couldn't protect me. You know, at the end of the day, some of that is me, some of that is them, and we have to hold our employers to account. We've got health and safety law. They're not following it. And, yeah, the unions have dropped the ball, and we have to pick them up on that too. We've got the equalities act, we are supposed to be protected by these things, and that's not happening. And I know there's been a lot of pushback in terms of legal challenges, and that's brilliant, and there's some that are starting to come through now, and there's some that are getting pushed back. But I think unfortunately, that's the way as well, that we're going to have to have some litigation. We have to make it real for people. It's got to hit their bottom line. If an employer feels that an employee is going to sue because they're not safe at work, they're going to do something. That's how we're going to have to do it, one employer at a time, like that, I think, unfortunately, yeah, on all fronts at the same time.

Berg: And I also have another answer, another interpretation of the question of what is working in my COVID safety work, which is that I've gotten literal work out of it, which I think is quite rare, and that is through my union. I managed to because the chair of my branch for [Name of University] is relatively COVID aware, and was very good during lockdown, less so now, but still. So I went to the branch, and I was initially just asking them about reviving some of the projects they were working on during lockdown, which was to put pressure on the university as an employer to improve air quality and other things. And she said, 'Hey, we have a spare slot for a health and safety officer half a day a week. Why don't you do it and just focus on COVID stuff?' And so I said, 'Okay, great'. So, I've been doing that officially. Well, I have to do other union stuff as well, so I can never spend half a day a week on it. But it is quite impressive that they managed to set aside some paid time. So now I'm spending all of that time getting data, or not getting data from the university about air quality and ventilation and other safety measures, and going to meetings and health and safety meetings, putting motions in to request certain things from the university. Mixed success, but still it's quite interesting that unions can potentially prioritize it in a way that other, maybe many other organizations, can't do.

Folks found that unions could be supportive spaces - for example, Unite Union London and Eastern Branch sponsored the 2024 Together Against Covid conference which brought together Covid activists organising around a range of issues. Some organisers such as Berg found their unions to be supportive of undertaking work to pressure workplaces into improving air quality. Wilf Sullivan, former TUC Race Equality Officer has argued that unions failed in some ways in the early phases of the pandemic by submitting to the notion of 'individual risk' vs 'environmental risk' which has pushed disabled and vulnerable people out of the workplace - leaving those disproportionately burdened to navigate the pandemic without broader infrastructure or support, belying the fact that Covid-19 is a risk to all.[121] For example, clinically vulnerable people have been forced out of jobs and denied reasonable adjustments to work remotely or have their safety considered.[122] The people I spoke with overall found unions to be places which were helpful in encouraging an institutional response to Covid, however folks are fighting against the tide of public health misinformation and denial. Sioux Vosper also highlighted voluntary campaigns such as the Covid Pledge which encourage businesses to take continued Covid-19 mitigations, risk assessments and worker benefits to allow for self-isolation.

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120. North West Trade Union Covid Action Group (2024). *North West Long Covid-19 Charter*. https://gmhazards.org.uk/wp-content/uploads/2024/07/Long-Covid-Charter-online-version-5-1.pdf

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Conclusion

Liberal fatalism and Covid denial shape the material conditions of our lives forcing repeated exposure to Covid, endless re-infection, illness, disablement and death, and restricting access to public life - to safely access healthcare, work, and education. This is a form of systemic exclusion and discrimination of those deemed 'surplus' - disabled, immunocompromised, poor, racially minoritised children and adults.

> Covid-19 intersects with disability justice, labour rights, housing, healthcare, children's rights, racial justice, gender justice, queer justice, class struggle - as discussed in Chapter 1 and illuminated further here Covid is intersectional and disproportionately impacts those who are already minoritised in multiple ways.

Covid-19 intersects with disability justice, labour rights, housing, healthcare, children's rights, racial justice, gender justice, queer justice, class struggle - as discussed in Chapter 1 and illuminated further here Covid is intersectional and disproportionately impacts those who are already minoritised in multiple ways. Denial and structural conditions socially determine vulnerability to the virus, facilitated by ongoing forms of structural violence which position certain populations as surplus and disposable.[123] The folks I spoke with felt that disabled, immunocompromised and covid cautious people were being pushed out of public life - with access to healthcare, education, work and community spaces becoming increasingly and rapidly inaccessible.

Across healthcare, education, and workplaces the surplus are seen as eugenic and financial burdens - the costs of Covid mitigations and welfare are deemed not worthwhile, and as disruptive to the return to a 'normal' in service of capital and its economy. This has created dangerous and risky material conditions for disabled and immunocompromised people as well as for everyone else.

The positioning of Covid as impacting 'only' the vulnerable hardens the boundaries between worker and surplus, belying the fact that Covid impacts us all and is in itself disabling - that unsafe healthcare, workplaces, schools burden us all. We must question a system that 'readily sacrifices most of us to sustain itself',[124] and understand that we are all being sacrificed in service of capital. Covid denial and the devaluation of disabled (those disabled or differently disabled by Covid and those who have not) and immunocompromised people must be challenged and resisted, connecting with and attending to the differences and connections to wider disabled people's movements and how disabled people have been and continue to be abandoned more broadly. Those who are currently abled and less impacted by Covid must be courageous and join with those deemed surplus to demand 'all care for all people'[125] - that the 'caustic, statistical valuation of life',[126] of who is and is not worth caring for should be rejected. We must understand the need for collective struggle against Covid, eugenics and ableism - uniting our intersecting struggles and understanding Covid and the positioning of the surplus as central in our work.

Public health must be reclaimed - supporting the development of community public health infrastructure and people's science so that our communities and movements can build care infrastructures that can include all as we continue to be abandoned by the state as we accelerate through and towards polycrises. Drawing on a healing justice framework we must tend to the collective trauma of the pandemic and how these conditions have impacted our movements and communities - what does denialism, eugenics and ableism do to our ability to be together and imagine otherwise?[127] How might we create emergent processes that can address the violence of our times and create models of collective care that can challenge the harms of the state, healthcare and public health?[128] Those who work to organise for structural and institutional change can no longer avoid Covid, and must understand solidarity with the surplus means challenging the forms of ongoing exclusion through Covid denial and liberal fatalism. This calls for a 'radical abundance of care'[129] which rejects eugenicist ideas of 'worth' and of 'back to normal' in the service of capital.

> Those who work to organise for structural and institutional change can no longer avoid Covid, and must understand solidarity with the surplus means challenging the forms of ongoing exclusion through Covid denial and liberal fatalism. This calls for a 'radical abundance of care' which rejects eugenicist ideas of 'worth' and of 'back to normal' in the service of capital.

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125. Adler-Bolton, B. and Vierkant, A. (2022, p.14). *Health Communism: A Surplus Manifesto.* Verso
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CHAPTER 3

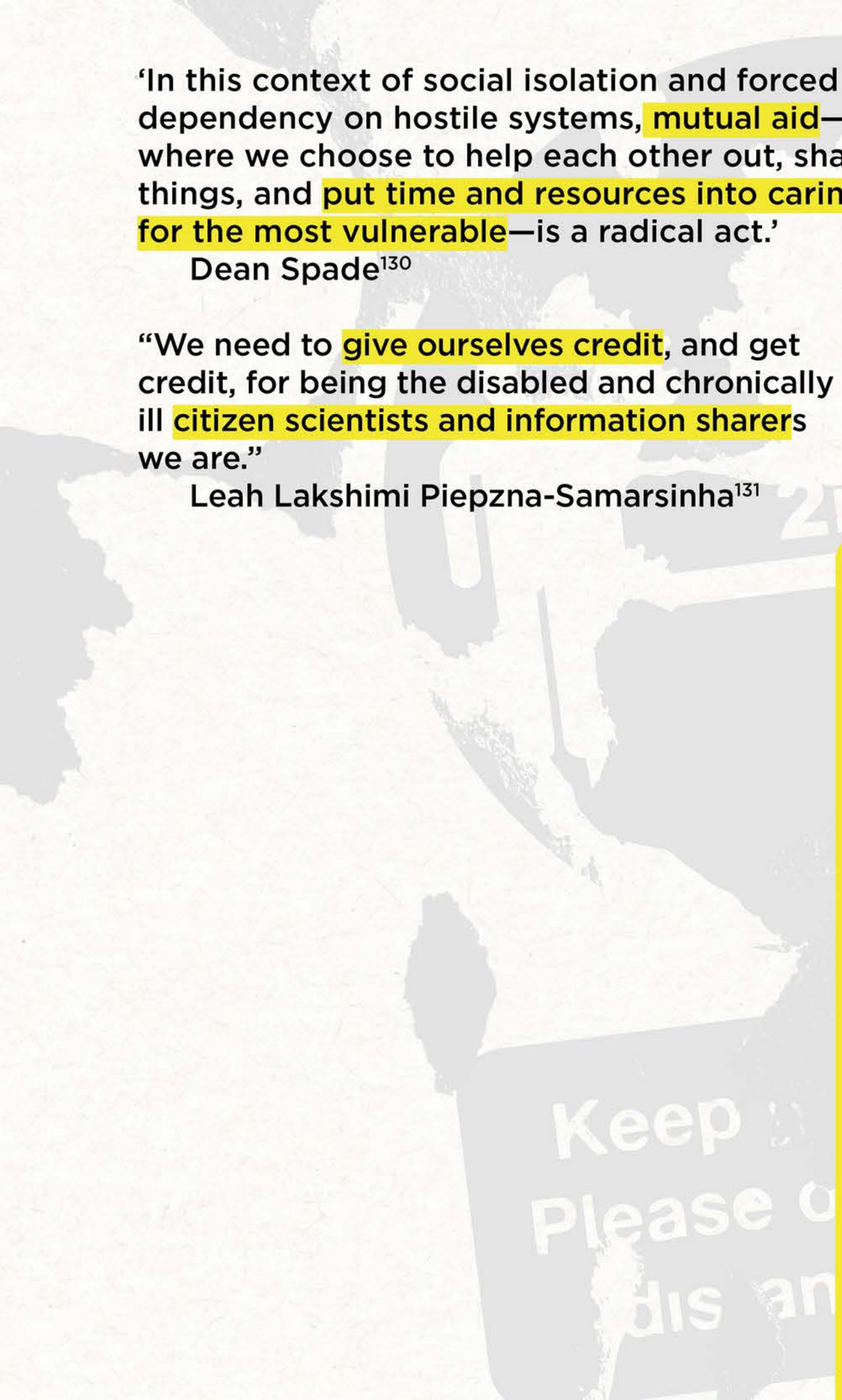
MUTUAL AID AND COMMUNITY BUILDING

‘In this context of social isolation and forced dependency on hostile systems, mutual aid—where we choose to help each other out, share things, and put time and resources into caring for the most vulnerable—is a radical act.’

Dean Spade[130]

“We need to give ourselves credit, and get credit, for being the disabled and chronically ill citizen scientists and information sharers we are.”

Leah Lakshimi Piepzna-Samarsinha[131]



In this chapter, having explored the current political social context of Covid denial in Chapter 1 and the material impacts of this denial in Chapter 2, we will explore the how Covid cautious communities, disabled and immunocompromised folks organise mutual aid in the ongoing pandemic, building covid infrastructure as public health falls by the way side, and build community to create networks of care.

Mutual aid

In 2020, as the pandemic developed there was an explosion of mutual aid and community initiatives as we grappled with the novel virus, lockdown, and social distancing - informal modes of helping each other with groceries, medical supplies and checking in on each other in isolation and for those working through the pandemic. Much of that then drifted slowly away as we began to return to a 'back to normal', however Covid organisers have continued to develop mutual aid strategies and organisations challenging the denial of Covid and creating community based infrastructure as public health continues to abandon us.

> Mutual aid addresses crises that have been created or often made worse by the wider, hostile systems, as has been outlined in Chapters 1 and 2 the Covid pandemic has been intensified by the forces of liberal fatalism and racial capitalism which shore up long-standing systemic inequalities.

Mutual aid is 'collective coordination to meet each other's needs, usually from an awareness that the systems we have in place are not going to meet them'.[132] Mutual aid addresses crises that have been created or often made worse by the wider, hostile systems, as has been outlined in Chapters 1 and 2 the Covid pandemic has been intensified by the forces of liberal fatalism and racial capitalism which shore up long-standing systemic inequalities. Covid is a 'racialized, biopolitical class war'[133] and mutual aid is thus 'survival work' - we can only survive through the practice of collective care and interdependence challenging the liberal individualism of the 'you do you' response to the pandemic.[134]

Rowan: So I joined the mask bloc in 2024...So there's a core sort of organizing that we've been doing, primarily focusing on the distribution of masks, so making sure we can from a mutual aid perspective, distribute masks to people in need. We do that. We also support local events with providing, supplying masks, distributing masks, educating people. We've had a couple of events that we've attended where we've had stalls, where we've distributed masks and zines and resources about COVID, and spoken to people in the community in [Name of Scottish city] about COVID and clean air, and just sort of got the message out there.

Bear: [in response to a question about the values of their mask bloc] So it's an important thing to be doing, to be meeting people's needs in both the organizing work and in the receiving end of the organizing work. We make sure that when people come in with a request, there's no judgment or anything like that. There's just like directly, 'what can we do for you? How can we collaborate? What other information might you need?'...[Regarding values] There's, like, mutual aid, intersectionality, care and, like, connection building, I think would be the four big ones that have come up for sure.

Greta: We're working on building capacity for sharing things like, for example, we were just donated a Plus Life, which is great. We were like, 'We cannot hoard this 29 days out of the month'. So we have to figure out who we're going to share it with, and how we're going to work out sharing it and all that. Because it just seemed very unethical to just keep it for ourselves. Because we're out here saying everyone deserves help, but then we're not going to share that.... So yeah, we're working on sharing that.

The organisers that were a part of this project were involved in mask blocs which are mutual aid organisations providing free masks and educational resources to their local communities as well as lending libraries for HEPA filters. Greta's organising group had been donated a Plus Life - a medical grade covid test unit that they were working on sharing within their community. A Plus Life test offers results that are comparable to PCR tests that used to be widely available at Covid testing sites and through the NHS, these are much more accurate than lateral flow tests that are now the only widely available tests for Covid - offering clarity around sickness particularly for those who are at higher risk.

The blocs aim to attend to people's material needs - to share and distribute resources across local communities, not to hoard supplies. Mutual aid is not charity, as Bear notes mask blocs respond to individual requests for support without judgement - centring care and interdependence. There are no eligibility criteria to access a mask bloc. Organisers also shared supplies at protests and at encampments for Palestine, and have begun to build 'mask hubs' - places in communities where folks can access masks without having to go through the mask bloc, such as libraries and community centres. This work requires the longer work of building relationships - both with other organisations and in supporting folks accessing mask blocs.

130. Spade, D. (2020, p.7). Mutual Aid: Building Solidarity During this Crisis (and the next). Verso
131. Lakshmi Piepzna-Samarasinha, L. (2022, p.57). *The Future is Disabled: Prophecies, Love Notes and Mourning Songs.* Arsenal Pulp Press
132. Spade, D. (2020, p.7). Mutual Aid: Building Solidarity During this Crisis (and the next). Verso
133. Hebert, P. & Colón, E.R. (2020, p.264) Slow Burn, Humid Pitch: Cultivating Care While Livin' La COVIDa Loca. *NACLA Report on the Americas*, 52:3, 260-267, DOI:10.1080/10714839.2020.1809079
134. Spade, D. (2020, p.31). Mutual Aid: Building Solidarity During this Crisis (and the next). Verso; Kornstein, H. and Lim Rogers, E. (2025). When Postviral Goes Viral Myalgic Encephalomyelitis, Long COVID, and Pandemic Déjà Vu. In M. Mills, H. Kornstein, F. Ginsburg, and R. Rapp (Eds.) How to Be Disabled in a Pandemic. New York University Press. (pp.191 - 213); Hebert, P. & Colón, E.R. (2020, p.264) Slow Burn, Humid Pitch: Cultivating Care While Livin' La COVIDa Loca. *NACLA Report on the Americas*, 52:3, 260-267, DOI:10.1080/10714839.2020.1809079

Educating about Covid

Folks in mask blocs were not just distributing masks but sharing resources and building relationships to share information about Covid, challenging Covid denial and misinformation. Daisy's mask bloc was working with a local University on research on Long Covid and inequality and were going to create resources for the research. The mask bloc had also created resources on Covid and pregnancy for healthcare staff in response to a request from a pregnant person who was trying to advocate for themselves in accessing healthcare.

Organisers reflected a lot on the best way to educate about Covid and encourage people to take up continued mitigation efforts - noting that information alone does not always help people to understand. This seems to be a strong communications challenge for mask blocs and organisers, and an issue that was constantly reflected on during the research. Mask blocs drew on a range of different strategies from sci-comms - sharing health information including science around the impact of Covid, how Covid spreads, how face masks work, other mitigation strategies and data about changing levels of Covid infection in local areas; 'possibility modelling'[135] - social media posts normalizing mask wearing and Covid mitigations; to taking more relational approaches to talking about Covid at an emotional level. Bear shared how their mask bloc reflected regularly on how to bridge the gaps of misinformation in ways that would resonate with folks beyond the sharing of information resources. Mutual aid is participatory and a key part of this work is developing an analysis of lived experiences and responding to ongoing challenges - as Bear shares, a curiosity and reflexivity on the work. Bear also noted in their personal life the importance of listening closely and connecting on an emotional level in educating about Covid - exploring the unmet needs of folks learning about Covid.

Bear: A big value for me personally, and that I think the mask bloc is doing quite well, is curiosity, like, 'why are we doing things? Why are people not responsive to COVID safety information and the data that's out there? How can we bridge the gaps of misinformation?' Which I think would, you know, be representative of things like, 'Oh, we don't want a mask hub to just have masks' like people might not know how to use them or why to even use them. So bridging that gap of like, having conversations with people has been quite important as well. And I think mostly is the pooling of resources and trying to figure out where and when they're most needed has been quite good.

In my own personal life, I have found that oftentimes people just don't know how to associate it with something that they already know. So I found it very helpful to talk about and be upfront and clear about loved ones experiences with long COVID or experiences with other infectious diseases, airborne diseases, etc, where, if you really come down to it, all of us know, possibly someone who's impacted by an illness or by a disability. It doesn't take long to actually figure out a connection, but people don't put the connection together, and most of the time, people, I found, want to be heard as to why they don't think COVID is serious, or why they don't think vaccines work or something.

And I found that a lot of the time, some conversations I've had that have been quite hard hitting has been figuring out where the gap was missing, or where, the previous unmet need has been, and being like, 'Oh, I'm sorry you were let down by, this person in the medical sphere'. Or, 'I'm sorry you've, like, been led to believe that this need doesn't matter'... I was once unaware or like, ignorant about many of the things around COVID myself. And it was because nobody had actually bothered to sit down and be like, 'Oh, do you remember this person from a couple years ago that you met that had this situation going on, think if that was you, or think if that was someone you loved - that is still happening to people all around the country and the globe'. So, yeah, it's been an interesting one to try and relate personally to the wider...I think a lot of people struggle with that. A lot of us do. That being said, not all of my conversations around COVID have been very fruitful, and I still think I have a lot to learn on how to approach these things.

There was sometimes uncertainty about how to proceed around Covid education. On the one hand many folks were holding the urgent need for solidarity around Covid for disabled and immunocompromised folks - indeed the majority of people who participated in the project were disabled, immunocompromised, had Long Covid or were supporting loved ones navigating this. However on the other hand from a 'public health' perspective folks also described the need to meet people where they are at, taking harm reduction approaches through the use of sci-comms and relational approaches to behaviour change and Covid mitigations. Harm reduction approaches encourage the reduction of risk over zero tolerance messaging - not aiming for perfection in Covid mitigation strategies.[136] Right wing responses to the pandemic have emphasised the threat to 'freedom' of Covid mitigations, and harm reduction messages have been found to invoke less of a perceived threat to freedom than other messages.[137]

> Harm reduction approaches encourage the reduction of risk over zero tolerance messaging - not aiming for perfection in Covid mitigation strategies

However, the more 'harm reduction' approach could be a source of tension as Participant X noted how the norm of a lack of Covid mitigations in wider movement spaces lended itself to the tendency to celebrate bare minimum

135. Lakshmi Piepzna-Samarasinha, L. (2022, p.61). *The Future is Disabled: Prophecies, Love Notes and Mourning Songs*. Arsenal Pulp Press
136. Kemp, D., King, A., Upshaw, S.J., Mackert, M., and Jensen, J.D. (2021). Applying harm reduction to Covid-19 prevention: The influence of moderation messages and risk infographics. *Patient Education and Counseling*, 105, 269 - 275
137. As above

and half-hearted approaches, such as 'masks encouraged' spaces where there was very little take up of masking or 'access friction'[138] was relied upon to argue against any mitigations instead of as an opening to dialogue on radical access to navigate differing access needs and centre the most marginalised from Covid.

Organisers were holding the tension of the need for collective responsibility and resisting individualism of the pandemic response, alongside the need for individual change. Organisers understood and reflected on how misinformation also intersects with understandable mistrust of healthcare and the state, particularly for marginalised folks and uncertainty of how to navigate this especially as marginalised people are also disproportionately impacted by Covid both in its acute phase and long term.

Mask blocs and Covid organisers collectively hold these myriad needs and challenges while understanding the exhaustion, frustration and hurt of disabled people doing this work and holding grace and compassion in doing the sometimes slower change work of education and challenging misinformation and denial with partner organisations and individuals - navigating the collective trauma of the pandemic and the differing responses to the trauma.

Mask blocs are not just spaces for the distribution of resources but a space through which organisers develop analysis and make sense of lived experiences, strategising to create capacity for change. Organisers were grappling with developing political education - how to support our movements and communities to resist the sidelining of Covid as an issue only for the 'vulnerable', that Covid should not be ghettoised into simply 'access' information for disabled folks but centralised as a concern for all. Folks are trying to resist the normalisation of mass sickness and the deterioration of our health and understand, as reflected on in Chapter 1, that we are on the edge of a needed, new paradigm shift in understanding the importance of clean air and the need for wider infrastructure to support this.

Participant X: I feel like having sustained information, sustained conversations is probably an important piece of it. I mean about [people understanding] the risks of repeat COVID infections. And so long COVID does come under that umbrella, but being very clear that it's not just long COVID, but I think a big part of it is understanding how infection works. So understanding that COVID is airborne, understanding why it's important to mask, even if you don't have symptoms, how asymptomatic infections are super common. I think a big one is just educating people about the fact that lateral flows are like 20% or 25% effective. And you know, understanding that it moves like smoke...So stuff like that, and yeah, and I think refusing to normalize the amount of sickness that is happening. And just trying to get people to see connections between what they're already seeing, and what is happening. Because everyone knows someone, who's had their health deteriorate in the past five years, and it's kind of like, the longer time, the more time passes, the easier and easier it is to just blame that on aging.

Berg: Before sewage systems came in, or, a kind of governmental water system came in, and I forget what the illnesses were that were spreading all over in Victorian cities, but it feels like we're at that moment now, and about, air? Yeah, Cholera. For example, I remember watching a documentary with the penny lick ice cream truck that would go around the neighborhoods, and people paid a penny to have a lick from the ice cream, and they would just reuse the same bowl. It feels like that's where we are right now in terms of air and individual actions are not going to do very much about that. We need,, an overhaul of our societal infrastructure, of how we think about air, just as much as a person judging someone else for having a go at the penny lick 150 years ago, like someone judging someone for not wearing a mask now is, kind of beside the point, and what needs to happen is just a humanity, our society, or humanity in general, but our society, in the immediate term to start expecting more in terms of air quality and air infrastructure.

Organisers were grappling with building infrastructure - collectivising responsibility for clean air and our health; as well as the need for individual actions that support clean air. Berg highlights the need for a paradigm shift, that while individual actions are helpful in the interim, the importance of clean air, air quality and air infrastructure illuminates our interconnectedness and entanglement with each other and the need for larger systemic change. Organisers are at the critical edge of pushing the learnings from the pandemic forward, instead of denying them - of a shift towards understanding our interconnectedness through our shared air, that one cannot be an individual separate from others, the impact of airborne disease, resisting the normalisation of sickness, and the need for clean air infrastructure.

"Organisers are at the critical edge of pushing the learnings from the pandemic forward, instead of denying them - of a shift towards understanding our interconnectedness through our shared air, that one cannot be an individual separate from others, the impact of airborne disease, resisting the normalisation of sickness, and the need for clean air infrastructure."

138. Mills, M., Kornstein, H., Ginsberg, F. and Rapp, R. (2025, p.20). Introduction: How to be Disabled in a Pandemic. In M. Mills, H. Kornstein, F. Ginsburg, and R. Rapp (Eds.) How to Be Disabled in a Pandemic. New York University Press. (pp.1 - 44)

Building infrastructure

Chloe: Yeah, I think there's a need to shift the dial or the Overton Window, whatever you want to call it, you need presence, right which takes money, it takes budget, and it takes marketing, narrative, skills and expertise, and obviously the time and energy to do all of that. And I think there are so many different ways in which we're failing, as a society, to address COVID safety.

Sioux Vosper: We're all connected yet we didn't know that we were connected till we came on this call. Like, I'm in the WhatsApp group with you, Grace, and Berg you knew about the conference. It's like, wow....I didn't know about Breathe Easy. So I will be spreading the word about that. That's really good. Thank you so much Stephanie, it really is. Yeah, it's inspirational, isn't it? Really what makes you want to keep going? Keep plodding on. Cos you've got to have hope. We've got to keep at it. We've got to, you know, might feel like we're walking in treacle or hitting our heads against a brick wall, but there's people doing really good things.

Bonita: A lot of our fundraising for the [Palestine] encampments came from other disabled people, and obviously, a lot of disabled people don't have a high income. And they are giving a few pounds here and there, obviously they're really struggling. And that's not okay. And a lot of it was self funded by us as well.

Also I burnt out from communicating with encampments. So prevention of burnout in this work is really important, because we need to keep growing. And we're all, a lot of us are, not all of us, but a lot of us are sick and disabled as well.

Organisers were building Covid and mutual aid infrastructure from the ground up with very few resources, grounded in disabled creativity to imagine and practice surviving the 'improbable present'.[139] However, folks resisted the 'neoliberal logic' of 'making do' and were clear that further work and support was needed for strengthening this work.[140] As Dean Spade[141] argues we need to strengthen our mutual aid networks to continue to respond to the pandemic, the polycrises and to help us transform the ways we live together at the end of the world.

To be able to build stronger infrastructure folks recognised the need for much further resourcing of Covid organising. Mask blocs and other covid safety organisations rely solely on fundraising - with donations often primarily coming from within Covid safer communities which tend to be majority disabled and low income. Bonita's work is also often self-funded, supporting Covid mitigations in the encampments for Palestine. The burden of this work falls on the shoulders of those who are already sick and disabled in a current landscape which is becoming more and more difficult for disabled folks to survive. Working in under-resourced ways meant that many organisers did not know about similar work or other mask blocs, and really highlighted the need for a network and directorate of Covid organising in the uk. Resources are needed to build the capacity of these disparate groups to connect, learn from one another and strategize to strengthen this work. As Chloe noted this work requires a range of skills and capacities which require budgets. There is a need for wider support, to explore the potentialities of funding through philanthropy or other established organisations, however Covid denial positions this work as niche - it is difficult to do this work without funding and without wider 'credibility' that other institutions or groups might bring. At the same time other organisers were wary of the compromises to grassroots work that comes with funding, especially on a topic like Covid.

> "The burden of this work falls on the shoulders of those who are already sick and disabled in a current landscape which is becoming more and more difficult for disabled folks to survive."

Building Covid infrastructure was also important to support working together to mitigate the difficulties of doing this work and challenging Covid denial. Sioux describes this work as sometimes feeling like you are 'walking in treacle or hitting our heads against a brick wall', but connecting with others through the research and potentially through a broader network might mitigate against this, recognising the importance of preventing burnout.

In addition to this work organisers also reflected on the need for data to evidence the importance of clean air and the impact of Covid organising. As discussed in Chapter 1, the lack of infrastructure to monitor Covid infection rates such as wastewater monitoring and free testing has aided in the denial of the pandemic as ongoing, and makes it more difficult for organisers to evidence their work. Folks suggested campaigning for the re-uptake of wastewater monitoring and the ability to report positive Covid tests to the NHS to support this work, alongside research to evidence the impact of clean air interventions.

However, others noted that research evidencing the impact of toxic air and the use of HEPA filters has already been undertaken - it is widespread Covid denial that makes it difficult to communicate and find acceptability for these findings. Additionally, as discussed earlier in this chapter there is a gap between presenting information about Covid and challenging Covid denial and changing behaviour. Organisers pointed to the need for further research on how to communicate about Covid, as well as building a directorate of Covid resources to challenge misinformation.

139. Lakshmi Piepzna-Samarasinha, L. (2022, p.34). *The Future is Disabled: Prophecies, Love Notes and Mourning Songs*. Arsenal Pulp Press
140. Mills, M., Kornstein, H., Ginsberg, F. and Rapp, R. (2025, p.17). Introduction: How to be Disabled in a Pandemic. In M. Mills, H. Kornstein, F. Ginsburg, and R. Rapp (Eds.) How to Be Disabled in a Pandemic. New York University Press. (pp.1 - 44)
141. Spade, D. (2020). Mutual Aid: Building Solidarity During this Crisis (and the next). Verso

Collaboration

Through strengthening Covid safety infrastructure organisers can then build the capacity of existing and developing blocs and organisations to broaden this work - building collective power.

Folks emphasised the importance of collaborative work - of how disconnected groups could be from one another, alongside the importance of working with established institutions like trade unions to strengthen Covid safety in their work - for example, linking it with broader campaigns on worker's rights. The organisation Long Covid Kids had extensively worked in collaboration with other third sector organisations, charities and MPs to extend the reach of their work. As with Covid education this involves slower relational work to develop connections and allies across different sectors, to further bolster this work.

Stephanie: How could the work be broadened and strengthened?

Andrea Barrett: I was thinking of how there's a missed opportunity in the UK of joining forces with disability activists. And I think that it's because in the UK, compared to other places, I think that there's a devolving of those that are generally disability rights activists and those that are COVID activists. In the US, I see there is like almost one and the same group, to some extent there's a greater intersectional awareness, and in some ways they have more rights there, although, of course, they're being challenged these days. But in the UK, since the start of the pandemic, there's been a devolving between disability rights and COVID safety.

Additional comment from Andrea Nov 2025: the disability benefit cuts protests in the Summer of 2025 was the first time I've seen a collaboration between disability rights activists in the UK and covid activists. Namely; face masks were recommended, required and distributed for those attending these protests by Crips Against Cuts groups, and covid safety was centred by many adjacent groups supporting protests, that had decentred it in prior years. The decentring previously was, in my opinion, due to disability being associated with covid via exceptions to wearing face masks in 2020, rather than a reason for mitigations. But since mid 2025 I've seen UK media coverage around disability feature more face masks, and normalise the positive association more, rather than the inverse.

Key to this collaboration work was developing a stronger connection between broader disability activism in the uk and covid activism. In the us, from the start of the pandemic there has seemed to be a clear overlap - that covid organising has been intrinsic to disability movements, however Andrea noted how in the uk there has been a separation between the two. Although many Covid organisers are disabled, broader disability activism in the uk has not focused as closely on Covid and Covid organising involves a large number of people who have been more recently disabled by Covid - although not all. Andrea points to the need for more connections to bridge this gap - to ensure there is learning from each other and the long term work of disability activists in the uk. This would also situate Covid denial and the pandemic response within the broader problems of ableism and eugenics, and specifically in regards to Long Covid address decades of disregard and neglect of chronic illnesses.[142] There are many connections to be made between these forms of organising, of navigating denial and disregard and systems of health and public health built around the disbelief of disabled people. ME [Myalgic Encephalomyelitis] activists have pointed to the structural changes that governments could have put in place decades ago that would have supported folks in this pandemic.[143] This is an area of further development and action. There does seem to be emerging possibilities of cross-disability organising through the Crips Against Cuts campaign which is bringing together some disability and Covid organising in new forms.

Fran: How do we take a more frontline approach, as many have said here, meet people where they are. That means really trying to strike deep with individuals that we come across, following up on certain people's progress. Do they need anything? Not just distributing a mask, but actually, because a lot of the folks, and again, a couple of people mentioned this, who are cautious, are already disabled and are cautious because they've already been disabled. So how are they managing their disability? How can we care for them in the long term and not just drop off a mask, drop off a test, and be like, 'okay, good work team. Let's go home'.

So it's a human centered approach. It's one rooted in social justice. It's one rooted in a lot of justice organizing by BIPOC [Black, Indigenous, People of Colour] communities, and we think it's necessary to disrupt in this way. And of course, alongside folks who do have those resources and who are doing that work from a policy point of view, trying to get cleaner air in schools etc, which is absolutely essential as well.

> "M.E [Myalgic Encephalomyelitis] activists have pointed to the structural changes that governments could have put in place decades ago that would have supported folks in this pandemic."

Additionally, traditionally mutual aid does not typically focus on a single issue alone. Fran's mask bloc work is guided by BIPOC organising strategies which take a more holistic approach which aim to attend to broader material needs beyond just Covid. This raises the issue of the fracturing and separating

142. Kornstein, H. and Lim Rogers, E. (2025). When Postviral Goes Viral Myalgic Encephalomyelitis, Long COVID, and Pandemic Déjà Vu. In M. Mills, H. Kornstein, F. Ginsburg, and R. Rapp (Eds.) How to Be Disabled in a Pandemic. New York University Press. (pp.191 - 213)
143. As above

of Covid organising from wider movement in the uk. Folks in this project grappled with the questions of trying to do Covid work in existing movement spaces vs developing specific Covid focused organising - finding that movement spaces were often not conducive to this work, making more progress working with Covid cautious comrades. However, collaboration across movement spaces was desired and folks reflected regularly on how to improve the impact of this work within other leftist organising and community spaces. Collaboration is needed in the face of overlapping and intersecting polycrises, as Bear noted that not every request to their mask bloc was for masks for Covid but also in response to decreases in air quality due to demolition work in their Scottish city. Mutual aid is integral to our movements, as Covid mutual aid illustrates to navigate our changed and changing conditions, to survive ever increasing hostile systems and to bring people together and into our movements.

Building community

Participant X: If people are organizing [Covid safer] social events, that can seem frivolous to some people, but I think, a lot of disabled people, chronically ill people, high risk people, people who take Covid precautions, etc, are very, very isolated. And if mutual aid is about fulfilling people's basic needs, I think that human connection is one of those needs. And so that's kind of how I would frame that side of things.

Stephanie: So did you say that some people might see that as frivolous? I missed what the word was.

Participant X: Yeah, frivolous. I think to someone who leads a normal life. If someone was organising a social event and then they tried to frame that as organising or mutual aid, then I think a lot of people would kind of struggle to see it in that light. But if you're someone who literally goes for months at a time without being in the same room as another human being, then it can be.

> "Even if folks want to organise, the basics of material resources and human connection are needed to create capacity for organising - and for many folks because of the level of isolation they have been experiencing they need space to connect."

Andrea Barrett: If you don't have the basics, like housing, that is supporting health rather than making it worse, or a solid social network, like friends and people that you can go to for emotional support and vice versa, then I think people struggle to organize.

And I think this explains the people who join the groups that are kind of there for campaigning, but then they join it for social reasons, because I was chatting with a few different campaigners, one of them about a year ago. I remember them being a bit frustrated because they were trying to recruit volunteers to help with tasks, but everyone just wanted to chitchat in the group.

But I suppose that speaks to a need for social needs to be met, that people need to have a certain level of connection in their life before you're able to give back, because otherwise, there's that starvation pattern. I've been in meetings, early meetings, with people, and you can tell they're very isolated, because they can't always stay on topic with practical things. Because we need that, being able to have that connection and those social needs met before you can go on to practical things.

Mutual aid is not just about attending to material needs, but also fulfilling people's basic needs such as human connection. Building Covid safer community was central to organisers' work, and as Participant X describes, this is just as central to mutual aid as distributing resources although they were conscious that in comparison to abled, normative modes of leftist organising this might be deemed 'frivolous'. As discussed in Chapter 1, many disabled and immunocompromised folks experience isolation and loneliness as public and community spaces become less and less accessible due to Covid denial. Many of the organisers run online social spaces as well as in person events with strong Covid protocols to create spaces of connection and belonging. Folks reflected on the importance of community spaces where Covid safety measures are understood and their need for mitigations are not judged.

As Andrea and several others noted, folks can often come to organising spaces to find places of connection and belonging and organisers were conscious of creating community spaces that people could participate in and not feel they had to be involved in mutual aid distribution or campaign work. As Andrea reflected, even if folks want to organise, the basics of material resources and human connection are needed to create capacity for organising - and for many folks because of the level of isolation they have been experiencing they need space to connect.

This touches on the emotional support required for folks continuing to navigate Covid and for those doing mutual aid and Covid safer work. Organisers recognised Covid as an ongoing collective trauma that continues to be denied and remains unprocessed. For both organisers and those 'still Coviding' community spaces offered the potential of processing this, however there wasn't always the capacity alongside the day to day work of organising a mask bloc. There is a need for space to process this collective trauma.

Rowan: And I think something else that really resonated with me, maybe people have touched on it already, was the emotional side of COVID organizing, which is navigating the fact that for everybody, regardless of whether they're COVID cautious or not, it is and was a collective trauma event and how do we, a lot of the denialism is rooted in that collective trauma and in the lack of processing, and the lack of space for processing that trauma and supporting people through that trauma, and denial is the easiest method to follow for that so....

How do we tackle that collective unprocessed grief and trauma that everybody lives with, but that I think COVID conscious people and people who do organizing like ourselves are maybe more aware of, and a lot of people who don't have that awareness aren't even aware that that's a trauma that they have experienced and that they're living with....

There's a big emotional side of things that we sometimes don't have the capacity to process or talk about when we're managing all of the practical day to day. Like, oh, we need to fundraise. We need to send out this email. But we've had discussions about it in our mask bloc. So we're interested in doing more in the future.

Helen Gomez: I'm going to give a little shout out at this point for next steps, being focusing on the self, because there's just some incredible amount of self advocacy, that's needed here. Like it's huge. I don't think anyone underestimates that, especially not in this group. Definitely don't underestimate it. No one underestimates how difficult it is.

I've definitely found it hard to go into spaces and just make the demand for the space that I deserve to take up and make the demand whilst very, very expertly and carefully tuning my voice to the correct pitch and controlling my emotions and being very open and welcoming to lack of knowledge, blah, blah, whatever.

I think that there has to be an incredible amount of work done on bolstering up through community. I really, at the moment, need immediate local - this [the focus group] is class, erm this is brilliant. And I definitely need some local community, some people in Northern Ireland who know the specific difficulties of the culture here. When people who really don't like to stand out in lots of senses, and there's traumas and levels of things that are interacting here, I think that require, that are maybe quite exceptional to the region, but not to deviate from my point. Just like people having a collective sense of like identity, in people with long COVID. And people who have disabilities, of different things, that different disabilities that require clean air.

Additionally, Helen and others noted the importance of Covid community spaces - including the temporary space of this project - to support one another in the everyday self-advocacy work of navigating a 'post-Covid' world. It takes an inordinate amount of effort and confidence to advocate for mitigations, to take up space, and to perform sanist ideas of 'reasonableness' as a disabled person challenging Covid denial - folks noted having to monitor their voice, tone, emotions to ensure they appeared rational and non-threatening, and non-confrontational. This also intersects with other forms of marginalisation and contexts - as discussed in Chapter 1 race, visible disability, trans identity, body size, but also as Helen highlights here the impact of differing socio-political contexts also plays a part in the difficulties of navigating Covid. Having Covid safer community and knowing you are not alone in this was incredibly powerful for folks, such is the experience of isolation and loneliness.

Covid cautious community also provides a space for 'crip doulaing'.[144] A doula is someone who supports a person through childbirth, a 'crip doula' is a disabled person supporting another person who is newly disabled, has become differently disabled, 'of dreaming a new disabled life/world into being'.[145] Rowan reflected on how those who were disabled before the pandemic have supported folks newly disabled by the pandemic, who have in turn supported and 'doulaed' more recent waves of newly disabled folks.

The difficulties of surviving the ongoing pandemic - staying safe[r], isolation, managing disability/becoming (differently) disabled, processing ongoing collective trauma, and having confidence to self-advocate as a disabled person can take a huge toll. Building Covid safer community challenges the individualism of the pandemic response, providing a buffer and making space for the collective to shoulder some of these difficulties. These are forms of rehearsing collective care, building connection and solidarity. In some ways we could also argue that Covid organising and mutual aid is in itself a form of crip doulaing itself, of dreaming and birthing a disabled life world into being amid the ongoing pandemic.

Conclusion

The Covid organisers in this project focus on mutual aid, education, advocacy and self-advocacy and community building to collectivise surviving hostile systems and the ongoing pandemic. This work is creating possibilities of other ways of being that challenge the defaulting to the 'back to normal', recognising the increasing need to build infrastructure and networks within our communities and movements that can tend to our material and social, emotional needs as both the polycrises and our abandonment continue to speed up. Organisers are fighting for a disabled future, this requires wider collaboration and scaling up within our movements and communities. The enforced silo-ing of Covid organising needs to be challenged, with wider movements for liberation welcoming and collaborating with this work to support the scaling up of this infrastructure and to enable broader mutual aid systems to flourish which recognise the ongoing pandemic.

144. Lakshmi Piepzna-Samarasinha, L. (2022, p.24). *The Future is Disabled: Prophecies, Love Notes and Mourning Songs*. Arsenal Pulp Press
145. As above

CONCLUSION & REFLECTIVE POINTS

This report has aimed to turn a lens onto the phenomenon of Covid denial, the ongoing nature of the pandemic and illuminate how disabled folks and Covid safer organisers are responding to these changing conditions as the state continues its organised and extractive abandonment.

It has troubled the investment in the 'back to normal' of 'post-pandemic' life, exploring the ways in which this response has emboldened the structures we are struggling against. It considers how our movements have been seduced by this back to normal, the very systems our movements claim to challenge and how Covid denial constrains the possibilities of solidarity with marginalised communities and those deemed surplus.

The research asks what does Covid-safer organising tell us about our capacity and preparedness for organising in these times. What does it mean that Covid organising has been sidelined within our movements?

Health justice is central in our movements against capitalism - centring those deemed surplus and interrogating and challenging the ways in which we are re-couped into binaries of worker-surplus and how eugenicist ideas of burden, deservingness, scarcity, and productivity permeate our notions of care and solidarity.

The research centres the work of Covid organisers in the uk as a guide towards moving from denial to engaged witnessing and action. Their work illustrates the possibilities of responding to our changing conditions and the importance of building and prototyping collective care, interdependence and grassroots infrastructures of public health and mutual aid. These organisers point to the capacities our movements need to meet the current moment and the polycrises that face us.

Tensions to navigate as we move forward together:

- How can we be curious about how denialism (in relation to Covid as well as denial as right wing impulse in our broader culture) has shaped culture and organising?
- What is whispering or calling for you to turn towards in your organising? What is left unnamed or unspoken?
- How does denial keep us safe? What does denial keep us from?
- What does 'back to normal' feel like six years into the pandemic? How does this 'normal' shape your life, organising, work, relationships? What is the place of normal in our organising?
- How can we understand the interlinkages of our struggles and how Covid has emboldened the structures we are trying to challenge?
- How can we be in solidarity with those deemed surplus? How do we develop solidarities amongst those deemed surplus?
- How do we build solidarity between different experiences of disability, and between those who are more recently disabled by Covid and those who are disabled in other ways?
- How could we challenge the tendency to want to evidence harm to authority? What does it mean that this work is an appeal to our movements to understand harm?
- What are the material and social needs for folks in our communities to have the capacity to organise?
- What does Covid-safer organising tell us about our capacity and preparedness for organising in these times?
- What does the Covid response tell us about organised and extractive abandonment and how the state will respond to present and future (poly)crises?
- How can Covid-safer organising and disability justice be centred in our movements? How can we build life-affirming health infrastructure that can respond to our changing times?