Response to Joel Michael Reynolds, *The Life Worth Living: Disability, Pain, and Morality*

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I’d like to start with some thanks – [thank David Morris, Eva Feder Kittay, & co-respondent Licia Carlson]. And, of course, I’d like to thank Joel for writing this book, which contributes to the growing field of philosophy of disability alongside his many articles, co-edited volume on disability bioethics, and foundation and stewardship of the *Journal of Philosophy of Disability*. In his acknowledgments, he notes that this book was mostly written between 2014 and 2016, and that while it has been updated somewhat his next book will engage with more recent work in the field. I look forward to that and to seeing how his work continues and develops.

The Life Worth Living is particularly valuable for its phenomenological approach to disability and pain, which can serve to draw attention to their complexity and multifacetedness, and allows attention to the interweaving of components of experience—embodied, social, relational, and so on. It also points out the ways in which abilities are relational and contextual, and that we depend on a range of caring systems as part of our human being-in-the-world (14). The book's final chapter and conclusion highlight the role of community, relationship, and care in making "habitable worlds for all" (160). I really like the phrase, "habitable worlds for all," and will be coming back to it—it seems right to me as a way of expressing what we ought to be trying to create together.

In my comments, I'm going to focus on how we theorize about living with pain; this will mostly draw from chapter 2, "A Phenomenology of Chronic Pain." I'll then turn to the broader context of reading this book amidst an ongoing pandemic and climate crisis.

Pain and the Ableist Conflation

Reynolds's work—in this book and in his many articles—centres the idea of the "ableist conflation" as a way of accounting for how disability continues to be misunderstood and maligned, in philosophy, bioethics, medical education, public policy, and popular discourse. The ableist conflation, according to Reynolds, involves "the habit of thought wherein one conflates experiences of pain and suffering with experiences of disability" (4). Within the ableist conflation, conceptions of "*disability, harm, pain,* and *suffering* are all critically underdefined, as are the relations between them" (4). The ableist conflation moves from the claim that disability "necessarily involves a lack or deprivation of a natural good," which is conceived of as a harm, to saying that because disability causes this harm that it "comes along with or directly causes pain and suffering" (4).

Because of this conflation, philosophers, bioethicists, health care professionals, policymakers, and members of the public, tend to devalue disability and disabled lives, believing them to be lives of pain and suffering. Reynolds quotes an op ed by Stephen Pinker in 2015, referring to “death, suffering, or disability” interchangeably as “experiences no one wants, and obviously so” (10).

By pointing out the work of the ableist conflation, Reynolds is therefore able to argue that pain, suffering, and disability are not the same thing, and can be separated. Disability need not necessarily involve pain and/or suffering; rather than *meaning* pain or suffering, Reynolds argues that disability “is instead defined by the experience of being nonnormate” (13). Of course, being nonnormate in an ableist world is still *hard*, but that is different from conflating it as such with pain and suffering.

The idea of the ableist conflation, then, is a useful theoretical tool, and particularly useful in unpacking what gets called the “disability paradox”, in which nondisabled people often rate the quality of life of disabled people lower than disabled people do themselves (Albrecht and

Devlieger 1999), and the curative imaginary or ideology of cure, which posits that disability must always be fixed or cured (Kafer 2013; Clare 2017).

I agree that something like this at work with much ableist reasoning, and that if disability is defined as “the experience of being nonnormate” then it makes sense to note that it need not *necessarily* cause pain or suffering. Disability and pain as such are separate concepts; one does not entail the other.

However, when speaking of the lived experiences of people, I am wary of drawing too firm a line between lives with disability and lives with pain. At the end of chapter 4, after discussing theories and phenomenologies of both pain and disability, Reynolds notes that while disability in general is varied and mixed in its valence depending on context, chronic pain involves the kind of pain that is always negative; he writes: “Thus a main takeaway of the overall analysis undertaken so far is that to speak of disabilities that involve constitutive pain is to speak of categorically distinct forms of disability. Given that most disabilities do not involve constitutive pain, *constitutive pain marks an exception to conceptualizing disability as a whole*" (111).

I'll go over the distinctions Reynolds makes about kinds of pain in just a second, but I want to briefly stop and flag this: what does it mean, for our theorizing, to describe some forms of disability as "categorically distinct"? In Canada, conditions classified as "pain-related" are the most common type of disability (though most disabled people report having more than one type) (Statistics Canada, 2022). To argue that disability, qua deprivation, causes harm and pain (the ableist conflation) is different from noting that pain is a common experience for many disabled people. The question that I'm going to come back to is this: What does creating "habitable worlds for all" (160) mean when we consider the lives of disabled people living with pain? What does this mean for solidarity and our social and political priorities?

Features and Types of Pain

Let’s look at what Reynolds says about pain in order to understand its place in his account. In chapter 1, Reynolds surveys five theories of pain—religious[i], neurobiological, humanist, existential, and medical. He argues that these theories, despite their different domains and functions, all point to the same effect for pain: “to orient one toward not-being-in-pain” (34), that “the effect of pain is to allostatically regulate life: *pain is a command to reorient oneself*” (35).” While the beginning of the next chapter, a phenomenology of chronic pain, gestures to the limits of these theories, this account of pain as a command is not limited to these theories but forms part of the book’s argument as a whole. In the introduction, Reynolds uses it in making a fundamental distinction between pain and disability: “I argue that [pain] serves a single, overarching role at the level of lived experience: pain is a command to reorient oneself” (12), and then “Unlike experiences of pain, experiences of disability do not automatically issue regulative commands. At the broadest level, I argue that the meaning of disability is instead defined by the experience of being nonnormate” (13).

In chapter 2, Reynolds moves to a phenomenology of the lived experience of chronic pain, and outlines some of its general structures and features. In the very first paragraph of the chapter, he states that chronic pain includes forms of pain that, contrary to the theories of pain discussed in the previous chapter, are “fundamentally deregulative and disorienting” (37). The structures described in this chapter help to articulate this deregulation and disorientation.

The first structure is *foreboding* (44-46), in which “concern about the future as foreclosed and restricted becomes definitive of one’s relationship to it” (44). This shapes one’s sense of temporality and possibility, particularly in connection to worries about future limitations due to pain (45).

The second is *beholdenness* (46-47), in which there is a lack of control over one’s possibilities because “one is forever waiting, forever on call” and “forced to respond when called upon with regard to one’s bodymind” (46). Here, one feels as though one is “under the control of another power—pain—as well as the many, conflicting practices surrounding its control” (47).

The third is *bioreckoning* (47-49), which describes continually trying to monitor and account for one’s bodily state. As an example, Reynolds mentions Christine Miserandino’s “spoon theory” and its adoption by many chronically ill people (including their self-description as “spoonies”). It can also involve more technological versions of biomonitoring.

Finally, *disruption* (49-50) removes the regulative function of pain. With chronic pain, there is nothing specific to respond to, to reorient oneself around, which was key to the theories of pain discussed in chapter 1. Attempting to reorient oneself doesn’t guarantee any relief, which disrupts experience (50).

These four features are then woven together, altering even one’s sense of self, in affecting the ability to “regulate one’s activities and projects.” Reynolds writes that “Disruption feeds back into foreboding and beholdenness and also places extremely high demands on one’s ability to bioreckon. These demands are so high that one might give up, which is to say, lose hope that there is an account of the meaning of one’s life in pain” (50)

This analysis then feeds into the distinctions Reynolds makes between types of pain, which aim to clarify “the extent to which pain shapes one’s world” (55).

Component pain “enters into one’s prereflective and reflective awareness but is not definitive for one’s life projects” (51). It can impact our activities, but only for the short term; examples are tonsillectomy, pregnancy, amputation. As described later in the chapter, it is “an integral part of human life; it is the condition of the possibility of any model of flourishing” (56).

Constitutive pain, on the other hand, is “pain that substantively and definitively enters into one’s life projects” (52). This pain takes two forms; suffering, in which one has “unpleasant sensations that inform or orient one’s long-term projects” but it is still possible to be distracted away from it, and constitutive suffering, in which one has “constant unpleasant sensations that fundamentally orient one’s long-term projects and one’s sense of self” (53). This latter form of suffering, exemplified by PTSD and chronic pain, involves cases where suffering has become part of everyday experience, sense of self, and “acts as a foundation of one’s being in the world” (54).

Consuming pain is the third variety of pain, and can involve “extreme suffering,” in which one has “constant or recurring unpleasant sensations so intense that one’s experience primarily or solely consists of them” (54). Reynolds gives as example the suffering expressed in the poetry of Jane Cave (1754-1812), writing about what were likely regularly recurring migraine headaches. Torture, inflicted by others, is also a form of consuming pain (55).

Reynolds's work to unpack and distinguish between kinds of pain and the structures and phenomena associated with pain is worthwhile, given the frequency by which "pain" is invoked uncritically in ethical and political theories as something like "the bad thing we try to reduce or avoid." Indeed, Reynolds points to this use in ethical theories at the end of the chapter.

He states that while ethical and political theories generally aim at the avoidance or minimization of pain, this should not apply to component pain, but rather constitutive and consuming pain (56). This means that lives associated with constitutive or consuming pain are "potential targets," because, as Reynolds writes, "Lives of constitutive and consuming pain aren't just lives less worth or not worth living for ethical and political theories—they are lives the absence of which marks a truly just society" (57). Reynolds is therefore concerned to make sure that this categorization of lives is not skewed by the ableist conflation, which "leads people to assume that many, if not most, disabilities involve constitutive or even consuming pain, which is not the case" (57). These sentences from the end of chapter 2 then serve to set up a strong contrast with how Reynolds understands disability.

Two Threads

I see two threads running through the book. One is to develop a philosophical rebuttal to the vile idea that one would "rather be dead than disabled" (153-4); this rebuttal involves a robust defense of disabled lives as worth living. This thread leans heavily on the idea of the ableist conflation to pry disability *away* from pain and suffering in order to argue for the value of disabled lives (and against *fearing* disability). On this thread, the account of pain, and the distinctions made about kinds of pain, are used to argue that most disabilities do not involve constitutive or consuming pain (or their ensuing suffering), and so lives lived with them are worthwhile. This move comes at the cost of seeming to endorse the idea that ethical and political theories are *correctly* in the business of determining which lives are worth living (and it’s just that most have been wrong about where to set the line).

The other thread, which I also be a central concern of the book, concerns the work and importance of making “habitable worlds for all,” emphasizing the role of care and relationship. This version is less invested in prying disability away from pain and more on emphasizing the social and relational contexts that enable us and help make access and thus create possibility. As Reynolds writes, “ability is a question of access: it is a question not of how one is as an individual but of the interaction, interanimation, and interrelationship between oneself and everything around one” (158). The work of making “habitable worlds for all” doesn’t stop at a clearly demarcated line, nor do I take it to exclude those who live with chronic pain. I don’t think that exclusion is the aim of the book – there is a reference to the enabling of pain management technologies later in the book within the context of a discussion of access (158) – but it is implied in the way that distinctions between types of pain are used and the statement at the end of chapter 4 that constitutive and consuming pain don't characterize most disabilities.

I worry that the first thread, in its efforts to neatly separate pain and disability for the sake of refuting the ableist conflation, takes focus away from the imperatives and social imagination of the second thread. Given the histories of ableism (and racism) in theory (especially bioethics!) and practice, I worry about tasking ethical and political theories with making determinations about what lives are worth living, full stop. But even aside from this generalized concern, I worry that carving out constitutive and consuming pain as exceptions in discussion of disability creates or maintains a hierarchy in forms of disabled life.[ii] This hierarchy then serves to make some disabled people worse off, and appear disposable; a particularly pressing concern in the context of Canada's MAID practices.[iii]

If we shift focus away from the first thread and toward the second, however, Reynolds's account of the structures of pain can serve to generate renewed and redirected ethical and political theorizing about creating and sustaining habitable worlds that include lives lived with chronic pain, that see these lives in continuity with disabled lives generally.

Pain, habit, relation, and habitable worlds

The theories of pain discussed in chapter 1 lead to the command to reorient oneself. The description of component pain in chapter 2 seems largely centered around temporary forms of pain that have definite and discernable causes. Chronic pain, on the other hand, doesn’t allow for that reorientation; it is described in terms of the disruption of one’s habits and expectations. But what if it became the basis of a new set of habits? What if accepting, and working around, its ebbs and flows became a new embodied orientation?

For example, bioreckoning is described in negative terms as being “before a continual tribunal,” but it might also contribute to self-knowledge and the cultivation of new and different habits of navigating amidst pain and fatigue, as evident in the community adoption and development of “spoons” language and shared wisdom around rest. Leah Lakshmi Piepzna-Samarasinha describes something like bioreckoning in terms of disabled knowledge and skill:

> “Disabled people know about resting because when your body literally has an hour of spoons a day and you have no choice but to rest, you might as well learn how to organize from a space of resting a lot. How we learn what one-spoon organizing looks like, and also, how to have fun on a serious fourteen-dollars-for-extras-a-month budget while we do it” (Piepzna-Samarasinha 2022, 307).

This shift in habits doesn’t imply a regained mastery over the body (even within careful deployment of spoons, sometimes pain is just going to do its thing), but does form a new orientation, not toward normalcy but different ways of making a life.

In this vein, it would be interesting to expand and complicate the account of distraction. Reynolds mentions distraction in the context of clarifying the relation of pain and suffering; as he writes:

> “despite suffering, a person could become temporarily distracted or even experience happiness. Distraction functions to pull one out of one’s suffering even if one maintains the same ultimate relationship to pain before, during, and after that distraction. If one understands distraction as this fleeting, temporary forgetting of suffering, it is not surprising that distraction can function both through innocuous examples (laughter, music, good company, etc.) and through noxious ones (e.g. self-cutting, substance abuse)” (53).

Distraction, then, happens within the context of ongoing pain. But if we think of a life with chronic pain as developing a different orientation, then it is important to recognize the existential significance of these moments. We do not expect particular pleasures to last forever, and that many of the things that matter most in life are deeply ephemeral is a key insight of many philosophies and artistic works. Someone with chronic pain who is having a good time knows that the good time will end (and that their pain may mean the good time must end sooner than it might have otherwise); to deliberately use some of one's spoons for something gives it a particular weight. As such, it would be good to develop stronger language than "distraction," without suggesting that the pain has ceased. Framing these experiences solely in terms of distraction supposes that their primary object is the forgetting or displacement of pain, rather than being good in and of themselves.

Consider *I wanna be with you everywhere* (IWBWYE), a disability gathering and series of performances and readings in April 2019 in New York, described Piepzna-Samarasinha in their most recent book. The website for IWBWYE states that “Programs and events will unfold across each evening, but there’s also going to be a major sense of ease” (Piepzna-Samarasinha 2022, 189).

As Piepzna-Samarasinha describes,

> “The show also featured stuff you don’t see every day or, let’s be real, ever: five rows of ‘creative adaptive device’ seating in the front, right in front of giant featherbeds called Buffies people with pain (including yours truly) were lying on to watch the show… a sensory-friendly room designed by and for neurodivergent people with a ton of free ear defenders, pillowforts in the corners where you could recline on bean bags draped with curtains, coloring books, and someone’s seashell collection” (184)[iv]

The inclusion of access for people with pain, amongst other arrangements, is part of what enabled IWBWYE to be “pure disabled joy” (194).

The temporary nature of this arrangement doesn’t make it less worthwhile. As Piepzna-Samarasinha writes, “In this pandemic, 2022, moment of crip time that is so often inside the walls of our homes, so fearful and surrounded by people who want to kill us, I am grateful to have experienced those four days of big disabled maximalist possibility” (195).[v]

These moments of pleasure are existentially meaningful in opening up possibility, of different visions of freedom. Again, this can be a different kind of orientation, in which the possibility – in fact probability – of bodily disruption is already taken into account.

This kind of orientation is expressed in disability culture in discussions of “crip time” which can involve grief and loss as well as a non-normate attunement. As Ellen Samuels writes:

> For *crip time is broken time*. It requires us to break in our bodies and minds to new rhythms, new patterns of thinking and feeling and moving through the world. It forces us to take breaks, even when we don't want to, even when we want to keep going, to move ahead. It insists that we listen to our bodyminds *so* closely, *so* attentively, in a culture that tells us to divide the two and push the body away from us while also pushing it beyond its limits. Crip time means listening to the broken languages of our bodies, translating them, honoring their words. (Samuels 2017).

Meanwhile J. Logan Smilges's recent *Crip Negativity* argues that "it is only by feeling our bad crip feelings collectively, as well as cripply, that we can begin to demand all that we need to thrive" (Smilges 2023, 37). My purpose here is not to minimize or romanticize the effects or experience of pain by pointing to faux-feel-good-style silver linings, but to reintroduce a space of possibility to the phenomenological analysis of pain provided in chapter 2, which largely emphasizes the *constriction* of possibility[vi] and loss of freedom.

Much of this space of possibility is connected to community and relationality, and the shared work of creating access. This isn’t a surprise given Reynolds’s arguments in the second half of the book as well as the overall trajectory of disability theory and disability organizing, but this dimension isn’t explored very much in the chapters on pain. Whereas later in the book Reynolds highlights the relational aspects of disability, the analysis of pain and its meaning in chapter 2 seems focused around the individual; the only others who show up in this phenomenological account in any detail are medical professionals to whom one must explain oneself. This intense focus on the self is highlighted by the characterization of pain Reynolds quotes: “Prescientifically, pain is that mode of being in which the body becomes the center of one’s life-world” (44).

Given the discussion later in the book that emphasizes relationship, this seems a missed opportunity. In analyzing journal entries when she was in university and dealing with chronic pain, Alyson Patsavas states that most of her entries focused “more on feeling alone with the pain than on the severity of the pain itself” (Patsavas 2014, 213). She describes, then, the significance of finding someone else that understood: “Finding someone in my dorm who also experienced daily pain helped me recognize, for the first time, a broader community. I could connect with someone who did not need an explanation for the pain. I could imagine others experiencing pain. I could imagine pain beyond just my bodily experience” (Patsavas 2014, 213). She concludes by emphasizing the situated nature of experiences of pain, in terms of access to care as well as relationship (Patsavas 2014, 216).

Theorizing lives lived with pain primarily in terms of restriction, and as an exception to most disabled lives, can occlude the ways that building relationship in and through pain can open up new kinds of existential possibility, through things like the feeling of being seen and validated in one’s pain, as well as shared creative problem-solving, access-creating, and culture-building amongst people who know what it’s like.

When we go back through the phenomenological analysis in chapter 2, we can also note how much of the experiences described are shaped by relational, social, political, and economic circumstances. For instance, in foreboding, part of the problem described is that one’s experiences and testimony are disregarded and minimized (45). As Reynolds notes, this intensifies fear for one’s future and the possibility of any kind of relief (45). A changed regime around pain medication, a more accessible health care system, greater possibilities for part-time and remote work, and better education about pain and chronic illness for health care professionals –

these are examples of things that would significantly transform how people's testimony is received and so their fears for the future.

In bioreckoning, continued vigilance is not only needed in terms of keeping track of one's own spoons, but also to justify and prove one's pain is real to disbelieving and/or gatekeeping others (49). These features are described as part of the structure of chronic pain, but can also be subject to resistance, activism, re-education, and so forth. The shared experience of 'spoonies,' for instance, opens up spaces for solidarity, being 'seen,' and pragmatic agency.

Meanwhile, the very embodied aspects of beholdenness – where "One's body vehemently 'calls in,' and one must respond" (46) – can be made more liveable through addressing our social and lived environment. In my own research on people's experiences with gut issues, I found that social and relational factors like having a "safe friend" to help navigate a space, offer a drive, or be blunt to about one's gut needs, as well as environmental factors like safe food and accessible bathrooms, strongly affected a person's sense of freedom and agency (Dryden 2021, 2022). I like the account of beholdenness generally (and will probably use it in future work on gut issues, because yes, the body there does *quite* vehemently 'call in'), but understanding its significance and interrelation with disruption requires attention to social and relational context.

Addressing this social and relational context doesn't do away with pain, but is part of the project of making worlds habitable, much like the giant featherbeds at IWBWYE.[vii] As Reynolds writes in the conclusion, "We will always have people who through various events in life end up in bodies and minds that work in different and unexpected ways. … Worlds worth living are built by and through caring systems made for all sorts of people" (159. The role of our ethical and political theorizing, then, should be less to do with minimizing constitutive and consuming pain themselves (which may not be possible), but taking on this project for all.

Pain in continuity

We can put pain into continuity with other aspects of disabled life and disability culture through attention to the interweaving of often-unpredictable constraint and reframed forms of possibility that characterize living with pain. I'll briefly mention two, climate change and COVID-19. I have two purposes here: one, to suggest how the structures Reynolds uses for pain could be extended further into different contexts for further phenomenological study, and two, to emphasize what's gained by thinking of pain in continuity with disability.

So, climate change. Like Reynolds's characterization of pain, the phenomena of climate change are "deregulative and disorienting." I'm thinking of things like having to flee one's home; having to cope with intense temperatures one's body is not accustomed to; avoiding constant smoke; losing a sense of the regularity and timing of seasons. Possibilities seem constricted, and our short- and long- term projects may become untenable. This calls for a different kind of orientation than a normative one that assumes business as usual.

Disability activists and scholars have been pointing out the contributions disabled people can make in the ongoing climate crisis for some time; a recent example is an article by Julia Watts Belser for *Truthout*, who notes that:

> "…disability has also taught me that limits can be generative. Disabled people know precarity intimately. But we also know something about how to find beauty and claim pleasure, even when we ache. Disability is a masterclass in adaptation, an invitation to work creatively within constraint. There's a good life here, grounded by limits. In these days of intensifying climate disruption, that's wisdom our world desperately needs (Belser 2023)."

The experiences of living with chronic pain are entirely relevant here, in terms of living with something that is not going to get better, while still carving out moments of meaning in making a life. The structures of pain Reynolds describes – foreboding (concern for the future as foreclosed), beholdenness (feeling out of control), bioreckoning (accounting for one's bodily state amidst new and unpredictable climate events), and disruption (disruption!) – are at play here, in ways that call for solidarity and working together against the pressures to ignore or deny. The question isn't whether lives lived through a climate crisis are worthwhile, but how we can help build worlds for ourselves amidst it.

My second example is the ongoing COVID-19 pandemic. Here, we might consider structures as responses to the pandemic in general (such as the bioreckoning that might be involved in calculating risk, measuring CO2 levels to determine safety, etc), as well as in the experiences of those with long COVID (for which chronic pain is a frequent symptom), where the degree of uncertainty about the course of the disease as well as the unavailability of treatment can contribute to foreboding and beholdenness. Disruption is, of course, amply present throughout.

Efforts to smooth over disruption for the general public, however, sharpen the question of which lives are worth preserving. The policies and statements of government and media have largely sequestered off “the vulnerable” and suggested that the deaths of disabled and chronically ill people are acceptable in the ongoing push to ‘normal.’ [viii] In the last couple years, even a number of disability organizations (not to mention academic conferences like this one) have moved away from COVID-19 precautions, making events inaccessible for many chronically ill and immunocompromised people. This is ironic given that COVID-19 is itself a mass disabling event, as the number of people dealing with long COVID increases.

In contrast, efforts guided by disability justice and Sins Invalid’s principle of “no body or mind can be left behind,” have developed practices around information-sharing, mutual aid, shared guidance about ventilation, nasal sprays, procuring masks, etc. Like responses to climate change, this work reflects an orientation (in Belser's words) to "work creatively within constraint." Again, considering continuities between the disorienting features of pain and other aspects of disabled life prompts work around shared access that emphasizes creating "habitable worlds for all" over the imposition of a "normal" that would leave many behind.

Conclusion

Reynolds's work on the ableist conflation works to target the fear that many have of disability. He then uses his analysis of the contextual and relational nature of abilities to argue that "*care creates worlds*" (159). This is an important message in an economic and political context that so often heightens vulnerability by isolating us from each other and from access to care. The book is an important contribution and I look forward to seeing how

Reynolds and others continue to build on what he has done here.

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[i] In an endnote, Reynolds briefly explores whether his description of pain in this tradition would also work for Eastern religious

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traditions. It would be fascinating to explore this further, but I'm not knowledgeable enough to do that here.

[ii] Patsavas (2014) documents the societal and media messaging around chronic pain that characterizes it as "a fate worse than death" (203).

[iii] A quick side note I probably won't have time for at SPEP but is relevant to this point: even while arguing for the general availability of assisted suicide for all suicidal people in his recent book *Undoing Suicidism*, Alexandre Baril points out that the current laws around MAID in Canada are ableist and saneist in their assumptions about who ought to be able to access it (Baril 2023, 198). Quoting Alyson Patsavas, he criticizes discourses that "frame pain as a problem that renders life unworthy of living" (Patsavas 2014, 208, quoted in Baril 2023, 198).

[iv] Also travel arrangements (192)

[v] Full quotation: "In this pandemic, 2022, moment of crip time that is so often inside the walls of our homes, so fearful and surrounded by people who want to kill us, I am grateful to have experienced those four days of big disabled maximalist possibility. I hold the memory close of the last night, where someone put on Fleetwood Mac, and the whole damn crowd sang and signed along, with such wistful fierce crip yearning: I wanna be with you everywhere… Because that's all I/we want, isn't it? To be with

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each other, our crip kin, everywhere everywhere everywhere. To have disabled art joy and eat pierogies lounging on an accessible giant bed, to be dancing in our bodies. To make and know a disabled freedom portal of disabled joy and cripworld pleasure and possibility, to the place where everything can be different" (195).

[vi] "The ableist conflation assumes … that the very conditions of the possibility of living with a disability are fundamentally constricted possibilities and that the pains one experiences are not mere components of a life" (57).

[vii] "We're operating from the point of view of access intimacy. Access isn't an individual's need, but a common capacity shared between us all." https://performancespacenewyork.org/shows/i-wanna-be-with-you-everywhere/

[viii] For example, in January 2022, then-director of the CDC, Rochelle Walensky, responded to a question about the effects of the vaccines and living with the virus by saying: "The overwhelming number of deaths — over 75 percent — occurred in people who had at least four comorbidities, so really these are people who were unwell to begin with — and, yes, really encouraging news in the context of Omicron" (Dickinson 2022).