Fierce Love: What We Can Learn about Epistemic Responsibility from Histories of AIDS Advocacy

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In the late 1980s and early 1990s, what drugs there were to treat the opportunistic infections that killed people living with AIDS were frequently not legal or were so expensive that they were in effect unobtainable, particularly for people living in poverty. In the Canadian context, being imprisoned, being racialized, being disabled, having unstable immigration status, having reduced family support, and living with HIV or AIDS were in the past (and are in the present) often entangled experiences. In this paper, I examine how direct-action activists addressed these cofactors in people's premature deaths. Their work changed the material conditions of people's lives in large part through changing the epistemic conditions that shaped how AIDS was known about and what it was. I use examples from the Toronto-based group AIDS ACTION NOW!'s campaigns, which produced the Canada's Emergency Drug Release Program and then Ontario's Trillium Drug Program, a program that even today provides access to medical treatments not otherwise available. I take this work as a grounded example of activism resulting in multilayered anti-oppression effects—but, interestingly, work that was not coherently grounded in an interlocking-oppressions or intersectional analysis.

The forms of medical activism I am interested in here powerfully express a non-reductionist and complex intersectional science and technology practice, bridging lay and professional medical contexts even when they are not politically unified and "pure" in their analysis. I draw on Lorraine Code's generative theory of the importance of "ecological thinking" as one way to practice what she calls "epistemic responsibility" to work in helping us think about the varied and complex early responses of activists in Canada to AIDS. Activists made wide-ranging, theoretically sophisticated, and socially significant interventions in how AIDS manifested in Canada. I am particularly interested in how their interventions manifested a kind of political work welcoming to unpredictable and emergent medical and social situations. I offer three preliminary insights from an ongoing research project investigating the history of AIDS activism in the Canadian context. I argue for: (1) the usefulness of Code's conception of the social imaginary for understanding how calcified social relations shape and limit the conditions for responsible knowing; (2) the importance of recognizing the communal and social nature of knowledge as a key piece of epistemic responsibility, which I articulate in terms of collective epistemic privilege; and (3) the possibility for practices of epistemic responsibility to create virtuous epistemic effects beyond what is known

(about) or intended by particular agents.

Social-political-epistemic interventions in the social imaginary

AIDS in Canada moved roughly two years behind its development as a crisis in the US. This meant that activists in the Canadian context were keenly aware of the medical and social practices being used across the border to manage the illness and, variously, the panic about it and the social worlds of the stigmatized people (the so-called "4-H" categories of homosexuals, Haitians, intravenous heroin users, and hemophiliacs) targeted as vectors of infection. They drew on this awareness in critiquing, for example, the Canadian government's refusal to test drug protocols (such as the use of aerosolized pentamidine to prevent *Pneumocystis* pneumonia [PCP]) that were already in use in the US. Activism to make specific medical treatments available in Canada meshed with sometimes quite audacious campaigns within the queer community to promote and eroticize safer sex practices. The work of early direct-action groups shifted the material and sensual contexts of people's lives, and in many respects fundamentally shaped AIDS policy decisions at provincial and federal levels.

Attending to how AIDS arose, manifested, and was managed in Canada offers a valuable case study of how the state has dealt with a socially charged epidemic. Because all epidemics have social and political aspects, understanding how social-movement actors engaged with and shaped the path of the AIDS epidemic in particular will offer lessons worth learning. A surprising number of these lessons concern the question of what it is, and was, to know the virus. Steven Epstein's foundational text *Impure Science: AIDS, Activism, and the Politics of Knowledge* illuminated how, as he wrote, we "understand the configuration of interests, beliefs, and practices that determine how we come to believe what we think we know about the epidemic" (Epstein 1998, 4). There is a generative ongoing discussion grounded in science and technology studies about this question of how we know medical and scientific objects of concern, which provides substantial traction for understanding how lay people shaped the scientific and medical understandings and embodied practices of AIDS.

However, to truly understand the epistemic and ethical role lay people—activists as well as friends and family members of people living with AIDS—had in shaping the ontologies of the virus itself, it is productive to focus more directly on the formation of "responsible knowing" as a form of life-giving epistemic-ethical practice. As Code writes, "It is clearly of paramount importance for community standards of responsible cognitive practice to prevail if members of epistemic communities are to be able to know well and to construct environments where they can live in enabling rather than oppressive circumstances" (Code 1991, 270). For people living with HIV and AIDS, life was quite literally at stake in the knowing

practices surrounding the disease.

Particularly in the first decade of AIDS, Canadian state policies focused predominantly on providing palliative care for people who were dying and preventing the spread of the disease. As one AIDS activist put it at a film showing about ACT UP New York: "There were a lot of people who would hold your hand while you were dying, but no one who was interested in keeping you alive!" To shift this situation required creative political action. More importantly, however, it required a shift in epistemic practice, such that new forms of scientific practice, and thus new ontologies, could arise. The social imaginary of AIDS as a death sentence, for which it was only possible to craft palliative responses, precluded policy, medical, and social practices premised on the possibility of living, and living well, with HIV and AIDS. As Code argues, the social imaginary in question matters profoundly:

> A social imaginary is social in the broadest sense; it is not merely about principles of conduct, although it is about those too; but it is about how such principles claim and maintain salience; about the scope and limits of human knowledge and the place of knowledge in the world; about the structural ordering of institutions of knowledge production; about intellectual and moral character ideals, subjectivity, and agency; about the kinds of habitat and living conditions that are within reach and/or worth striving for; about social-political-economic organization and just distributions of goods, privileges, power, and authority. (Code 2006, 30–31)

Changing the social imaginary in which HIV meant AIDS and AIDS meant death was necessary to produce the policy, institutional, practical, and medical conditions that would make it possible to live. The conditions for life with HIV and AIDS were both biochemical (was there medicine that could treat the syndrome) and social (was there a place to live, food, people who would touch you). Making these changes required in turn changing who was understood as a knowing subject, and reframing what would count as "good knowledge." As I'll argue in the next section, an individual knowing subject manifesting knowledge tested by the scientific standards of the day was not adequate to the epistemic and political context of AIDS.

Collective epistemic privilege

In the case of AIDS activism's work to transform the social imaginary, as in other situations of movement-produced theory and praxis, it is worth asking how social transformation involves knowledge. In this section I affirm one piece of what Lorraine Code articulates as epistemic responsibility. I argue that, indeed, epistemic responsibility is an important norm, vitally one that incorporates a non-individualist

approach to knowing. Code argues that it is "crucial that individuals be recognized as social beings, as members of communities with all the obligations membership entails, as much in intellectual as in moral activity. For such an epistemology . . . epistemic responsibility is a central virtue from which other virtues radiate" (Code 1987, 44). Code compellingly articulates an account of the necessary sociality underlying any knowledge practice, framing epistemic responsibility as constellating moral and intellectual virtues, and laying out an articulation of the broader context in which intellectual virtues associated with epistemic responsibility might be understood and practiced. Here I am focusing more narrowly on the implications of Code's discussion of epistemic responsibility as a communal activity.

My title characterizes activist work here as fierce love, echoing what some of my interviewees communicated about their orientation toward this work: unreasonably demanding, committed to possibilities beyond what is outlined by conventional reason, invested and situated. We need our love to be fierce in order to change the world. This is an epistemic and ontological orientation that takes a stand and has a stake, opening the possibilities for an orientation that Code calls epistemic responsibility. Rather than performing what Donna Haraway calls the "God Trick" of imagining that we can stand outside the relations of knowing in our knowledge practices, we understand ourselves as within and constituted by the social relations we attempt to know. We say: I know this because I care about this, I am invested in changing the world that I know in virtue of my placement in it. George Smith calls such changes in understanding "making the ontological shift," by which he means that our theory and practice does best when it starts from the understanding that we are placed within the world we are trying to understand; our understanding is an intimate part of transforming that world. Situated knowledges are, on this view, the only form of knowledge worthy of the title. And attending to how we knowers are differentially situated calls us to decide whose knowledge is best for the particular purposes we aim to enact.

Attending to knowledge with this orientation is sometimes framed as respecting epistemic privilege; the people directly experiencing something are the ones whose knowledge claims we should take seriously. In political situations, this usually means attempting to hold responsibility toward those experiencing the negative effects of decisions about how the world should be. In responding to social relations of oppression and privilege, recognizing epistemic privilege then means to centre the lives and experiences of people experiencing vectors of vulnerability and harm. A bad but common effect of evoking an allegiance to epistemic privilege arising from an understanding of situated knowledge is that it individualizes the knowledge in question, with the practical result of an epistemic version of the "Oppression Olympics"—the idea that in order to respond to wrongs and harms we

ought to find the most oppressed person in the room and ask them what we should do.

Thinking about situated knowledge and epistemic privilege from an individualized point of view will almost certainly produce knowledge that is better than making decisions based on a supposedly neutral or general knower, since no such knower in fact exists. But understanding epistemic privilege as held by individuals also requires more than any one person should have to bear, with the familiar burdens of one person being asked to represent an entire group, or being forced to split-separate their identifications according to one particular political project. In the case of the AIDS activists I've been speaking with, such an approach resulted in challenging dynamics around who should have standing to make decisions. Should the locus of knowing be HIV-positive people? Queers? Intravenous drug users? People living in poverty? People in prison? People in Haitian communities affected by the stigma of being identified as propagating the epidemic? No one that I've spoken to described trying to find a single person who would be able to speak from all these different locations—that would be ridiculous—but the question of whose identity and understandings should guide a group's political work was clearly live. It's not always easy to determine who is "most affected" by oppression.

This is to say that the category of "who is most affected" is an unsettled category, shifting with context and urgency, depending on who is experiencing the group vulnerability to premature death. And as an unsettled category, political actors will have to continually and in unsatisfactory ways negotiate the relevant "we" they, or we, deploy in political work. In conversation once, Dean Spade called this form of negotiation an attention to "collective epistemic privilege." Collective epistemic privilege produces effects that resist multiple co-constituting forms of oppression; it has effects that track the co-constitution of multiple social relations of oppression and benefit. I understand collective epistemic privilege to begin from the central insight encoded in the idea of epistemic privilege simpliciter; the people most affected should, indeed, have standing to determine an organization's or campaign's direction. But the collectivity of this approach requires another aspect of love—the doggedness and care to work through complexity and impurity in our political work, to not settle or yearn for a clearly delimited "cut" around a relevant identity category, and to attend to the flourishing of a relevant group as well as individuals within it.

Activists succeeded in reconfiguring the political terrain of who needed to be understood as "good knowers" in relation to HIV and AIDS, employing what Code theorizes as non-individualist advocacy work intertwined with non-individualist knowing practices. In other words, they mobilized collective epistemic privilege and called medical and political decision-makers to account from that stance. This is a

common feature of advocacy and activist work. As Code writes, we ought to think about advocacy as a practice of

> establishing deliberative communities where inquiry becomes subject to public scrutiny devoted to evaluating agendas according to larger criteria of social-politically responsible epistemic practice. . . . Advocacy is thus both an epistemic and an ethico-political issue. Without advocacy, few of 'us' could claim sufficient credibility to challenge the combined force of the scientific paradigms and hegemonic social imaginaries sustaining the received politics of knowledge. (Code 2006, 194)

In the case of Canadian AIDS activism, advocacy forced the Canadian state to implement a previously mothballed Emergency Drug Release Program, create funding structures for drug access, include the voices and views of people living with HIV and AIDS on ethics review boards around these issues, and much more. Understanding the work these activists accomplished benefits from Code's analysis of epistemic responsibility; simultaneously, their work provides a productive illustration and affirmation of the importance of Code's work on the politics of epistemic location, on how, and how well, we know.

Propagating ecologically attuned epistemic-scientific processes

Let's start by considering a particular transformation of knowledge, and then the formation of that knowledge into transformed institutions: the Emergency Drug Release Program, or EDRP. George Smith, mentioned above, was an important but too often forgotten scholar-activist, centrally responsible for much of the early activist response to HIV and AIDS in the Canadian context. A sociologist attuned to the politics and practices of knowledge production, he contributed enormously to the formation of the Toronto activist group AIDS ACTION NOW! (including the imperative that every political group should have a name that you could also shout as a demand at a protest). Smith investigated what was wrong with the management of the AIDS epidemic in Ontario—what the collective responsibility and opportunities for critical intervention, in Code's sense, were. He says that "the study's most important finding about the management of the AIDS epidemic, from the standpoint of people living with AIDS or HIV infection, is the lack of an infrastructure to manage the delivery of new, experimental treatments. These findings have directed the work of AIDS ACTION NOW! in designing and in putting in place just such an infrastructure" (Smith 46). George Smith is here using the sense of "having a standpoint" that Dorothy Smith has articulated as an important part of feminist methodology: beginning from the experience of those most affected by the social relations under investigation.

Glen Brown, a long-term Toronto activist, explained AIDS ACTION NOW!'s discovery of the EDRP:

> It was a hidden mechanism that they could've been using for years and just hadn't bothered despite all the pressure, and then after enough pressure they finally figured out they actually had this mechanism to allow people access to drugs that were not yet fully licensed if there was a 'catastrophic' illness. . . . In subsequent years, and probably still today the name of the program has changed, but it is still a program that is accessed. And now not just by people living with HIV and AIDS, but people with other catastrophic illnesses, this little mechanism that was previously hidden. . . . It's saved many lives. (Brown 2014, 15)

Making the EDRP an activist target, then, required investigating the hidden policy infrastructure shaping medical practice. AAN!'s work changed enactment of policy, starting with knowing that the policy existed and understanding what its implications were, and then transforming the biochemical and social possibilities for legal drug access for people living with new or catastrophic illnesses. This was partially a matter of relentless confrontation. As Tim McCaskell remembers:

> There was already an institution in place whose job it was to do just what we wanted it to do, but they wouldn't do it, for no apparent reason. Because it was a federal department and there was an election . . . that fall, every time Mulroney came to town we were there with the AIDS ACTION NOW! banner. We managed to get some really good media coverage of [Toronto doctor] Michael Hulton phoning the EDRP and asking for a drug for a patient, and the guy from the EDRP on the other end of the line, swearing at him and telling him to leave him alone. "I told you that before, we won't do it." Finally, he just said, "Fuck off," or whatever. It was very bad press for the EDRP and for the Mulroney government. So, as soon as they got re-elected, the first thing that the new Minister of Health did was to announce that the EDRP would be open for a number of experimental AIDS drugs, and then it got expanded. (McCaskell 2014, 14)

As McCaskell describes, part of the work AAN! took up involved embarrassing the government in power, raising the political stakes of inaction just before election time. At the same time, they were transforming the social imaginary. This may be hard to remember, because what HIV and AIDS means for people with access to drugs in the era of highly active retrovirals has already transformed. At the time, though, even to show that there were drugs that would help keep people alive

longer, and that those drugs were being withheld because of an extant but unused policy for accessing them, constituted a shift in the social imaginary both of the disease and of the supposedly beneficent Canadian health system.

In her discussion of Apotex, a pharmaceutical company that brought a suit against whistle-blowing doctor Olivieri for revealing that a drug lauded for helping with a condition also had bad health effects, Code discusses the collective responsibility for advocacy-based transformation of scientific practice. She writes:

> Apotex is not solely answerable for the Olivieri affair: it is a symptom, not the disease. The social practices and institutions that make its funding style possible demand ongoing social-political intervention, committed to democratic, ecologically attuned epistemic-scientific process whose purposes include honouring the responsibilities capable of contributing to viable, habitable community. (Code 2006, 275)

The campaign around the EDRP shows how activists made social-political interventions in response to particular social practices and institutions using what Code beautifully frames as an ecologically attuned epistemic-scientific process. Practicing collective forms of knowing in advocacy work attuned to social and medical realities manifests transformational epistemic responsibility. As Code writes, "Ecological thinking works with a conception of materially constituted and situated subjectivity for which place, embodied locatedness, and discursive interdependence are conditions for the very possibility of knowledge and action. It ushers in a renewed conception of responsible deliberative-negotiative citizenship, as responsible in its knowing as in its doing" (Code 206, 20). In the EDRP work, activists cleared space for a more democratic, ecologically attuned epistemic-scientific process.

The EDRP expansion came out of hard, confrontational work by activists; it was not something politicians figured out and offered out of the goodness of their hearts. Because most politicians at the time didn't know anything about the life conditions and needs of people living with HIV and AIDS; lacking that knowledge, they failed to think hard and imaginatively about what could be done. As with so many things, that hard, imaginative work had to be done by people directly affected by multiple vectors of vulnerability, strength, and resistance. Of course, winning this fight did not solve everything; once drugs could be released through the program there were still substantial barriers between people living with HIV and AIDS and meaningful social and medical support—after AAN! won EDRP, they turned to fight for drug affordability and access, which I'll say a bit about next. This campaign to permit quicker release of experimental or off-label use of existing drugs also shows us, then, the importance of incremental wins that can provide the foundation for

future, further, wins. I discuss this further in the following section.

Emergent material effects of practicing epistemic responsibility

Doing and knowing are intertwined. Putting the Emergency Drug Release Program to work on AIDS as a catastrophic illness shifted the terrain of possibilities, opening the possibility for understanding HIV and AIDS as something other than a death sentence. This work transformed the social imaginary, and that transformation had material effects—drugs were available that could keep people alive when particular opportunistic infections struck. But then there arose the situation in which there were some drugs available, thanks to winning the Emergency Drug Release Program, but they were too expensive to access. As Brent Southin says:

> I remember a lot of stuff later in the '90s around Trillium of course, but, because that was one of my big issues from day one. They kept saying, "Let's get all these drugs," and I kept saying, "But they cost tens of thousands of dollars," so . . . . (Southin 2014, 9)

Because the drug costs were so high and many of the drugs were experimental or not on the coverage lists, even if people had jobs that carried drug benefits, they could not afford them. So people living with HIV and AIDS were often forced to quit jobs if they had them, spend any savings they had (and of course a lot of people had neither jobs nor savings) and go on social assistance, because then they could have some access to coverage for medical needs.

To address this situation, AAN! shifted its focus from the national campaign that won EDRP access, governed at the federal level, to a provincial campaign, because coverage for health care is funded and managed at the provincial level. Part of the organizing work in Ontario involved interventions with politicians just before a Conservative government came into power. In our interview with him, Southin told us a story about going to a provincial political convention of the more left-leaning party then in power. This kind of more conventional political participation was not part of the regular work AIDS ACTION NOW! Did—most people in the organization weren't members of political parties. Southin, however, was a member of the NDP in addition to being a member of AAN!, so he had a pass to the provincial convention in the lead-up to the elections. The plan had been to coordinate a protest with AIDS activists in Hamilton, a small city outside of Toronto—but no one from the local area showed up. Southin narrated:

> So, there's three of us—Greg, me, and one other. So, I said, "Well, let's go in," and I had a pass. But if they stopped you at the door because you don't

have a pass, you were stopped! So, in the end, I got in. They stopped Greg. Many people had to stop Greg. He was pretty angry. [*laughter*] Because he didn't have a pass, and it was like, "Okay, he's really friendly." (Southin 2014, 9)

In the end, though, Southin went in to the convention alone. Southin is a fairly soft-spoken and quiet person, who nevertheless single-handedly disrupted the Ontario Premier's speech, refusing to allow the convention to proceed until the question of funding for expensive drugs was addressed. In talking with our research project, he phrased this intervention with characteristic understatement:

> So, I interrupt Bob Rae's speech and then he met with us— Greg and myself and with Ruth Greer, who was the health minister at the time. And they again said, "Oh no, we can only do it later maybe." And then we said, "Well, on World AIDS Day we're going to burn you in effigy if you don't do it by then." This was like, in November. The day before World AIDS Day, they announced Trillium, the drug plan. People who worked in his office said that was why. They had no intention of doing it. (Southin 2014, 9)

The threat to burn the Ontario Premier in effigy had some weight, because AAN! had shortly before burned an effigy of the Minister of Health to protest his handling of the AIDS crisis.

Glen Brown was a co-chair of AIDS Action Now! during the negotiations for the Trillium drug plan, which even today provides access to drugs for people who cannot afford them. He said:

> If there wasn't this plan, there was a lot of people who had high drug costs, so they had to go on welfare. It was the only way, which didn't really make any sense for anybody. At one point, they put forward a plan that they could afford this thing if they started charging seniors, if they started putting seniors on . . . deductible plans. And so we got a call from the Ontario Federation of Labour saying, "What the fuck are you doing?" And we said, "No, we're not supporting that. We will not agree to a plan that starts taxing seniors for this". And so they backed up on that. And then they began talking about what a deductible strategy would look like. At that point, our demand was fairly clear that we didn't want anything that was just an HIV plan, that it had to be for anybody who had a catastrophic illness. As it turns out, the plan was even a little better than that because it's not based on any illness category at all. (Brown 2014, 22)

He situated winning the drug access program as it manifested in the provincial election:

> Of the platform that we put together and then they adopted, that was the last one that we were able to achieve. And in fact we achieved [it] in the very dying days of the Rae government. Bob Rae now speaks so proudly of that accomplishment, but he would not have done it if we had not beaten the crap out of him for months and months and months and months and months.

In talking to people about the fight for funding for drug access, I have been very moved by this moment in which AAN! refused the plan to make catastrophic drug funding available only to people living with HIV or AIDS. The activists doing this work were under tremendous pressure, with a number of central people in the organizing group dying simply because they could not afford drugs that would very likely have kept them alive. In this context, holding out for a plan that was not AIDS-specific is remarkable, creating a really important option for people to access the medicine they need without going on social assistance or checking into the hospital. This had immediate and ongoing effects for people at every stratum in Ontario, but it had a disproportionately big effect for racialized, disabled, and working poor people.

I have been thinking about this campaign—and much of the AIDS activist history I am learning about in doing this project—in terms of Ruth Gilmore's definition of racism: she defines it as "the state-sanctioned and/or legal production and exploitation of group-differentiated vulnerabilities to premature death, in distinct yet densely interconnected political geographies" (Gilmore, 28). I reflect on Gilmore's argument about this approach to the social determinants of life and death in relation to what in feminist academic spaces we usually think about as intersectional analysis. I more often use the language of "interlocking oppressions analysis," or "intermeshing analysis," drawing more explicitly on the ways Black and women of colour feminists talked about how social relations mutually create oppression and benefit in the years before we had a Kimberlé Crenshaw article to cite in academic spaces.

Terminology aside, this particular campaign for what became the Trillium drug program has intersectional effects that Gilmore's work helps us understand. This campaign's effects include quite profound benefit for people experiencing multiple vectors of vulnerability—we can celebrate it from the point of view of an interlocking oppressions analysis. But, although I am still early in the process of tracing how AIDS activism happened in this country, it is very clear to me that not everyone in AAN! shared such an analysis. There were profound conflicts about class, race, gender, sexuality, nationality and immigration status, and disability

within the political milieu of the AAN!, and the people central to making Trillium drug funding happen were not always on what I would identify as the right side of debates about these issues. Their intentions didn't express an intersectional analysis. And yet because they correctly identified a social relation calcified in a textually mediated ruling relation, to take up some of George Smith's and Dorothy Smith's language for this approach, they were able to make a political change with profoundly anti-oppressive effects.

To understand this fact is to reject the idea that each individual working on a given political project needs to have political righteousness, or to even be totally correct in our analysis (individually or as a group) in order to make changes that are actually in line with a politics expressing an understanding of how oppressions and benefits interlock and co-produce an unjust world. Instead, when we resist the group-differentiated vulnerability to premature death of some people (in this case, people living with AIDS) and resist closing down the space of identification, we might produce effects beyond what we know. That is, because these social relations cannot exist in isolation, when we change the practice of one site of living, we also change the others. The fact that we can do political work with profound effects on the co-produced social relations of oppression and harm such as racialization, class, ability, and sexuality affirms again the usefulness of conceiving of epistemic responsibility in relation to collective epistemic privilege; a multiply constituted epistemic centre of gravity for our political decision making might produce more adequate political work.

So, what produces these kinds of effects? At least in the interviews I've done so far, though very few people say this explicitly, it seems to be that there was sometimes substantial conflict around what was only sometimes talked about as interlocking oppressions analysis—where resources were allocated, how priorities were set, and how AAN! interfaced with other groups. Some of this had to do with who would hold primary decision making power; in AAN! that conversation centred around the importance of having HIV-positive people in the roles of chair or co-chair of the steering committee, which made the core political decisions for AAN! And this was sometimes contentious and difficult. In many of the AIDS activitst groups we've been talking with, this question of who would lead the group was centred on serostatus; positive people were understood in many AIDS activist groups as holding epistemic privilege. Renee du Plessis articulated this well in framing how she got involved in AAN!:

> And so that is one of the reasons I got into AIDS ACTION NOW!—but why do you stay, you know, or make any sort of commitment? Really it had to do with, for me, these were the people who were the most affected in a very immediate way, from what I was reading and seeing. And they had organized

themselves and they were articulating the possible solutions. And so I thought, "That's great, because I don't want to be articulating and I don't want to be creating." I like the idea of the people most affected taking leadership and defining what my support would be. And that's how it's always been, whether it's in First Nations work or women's work, I have always seen it as being, "Who's the most affected by the particular problem that the group is representing?" (du Plessis 2014, 2)

However, as Du Plessis told us,

> The challenges were that the group that was the most affected was not exclusively well educated, with a multitude of resources. Gay men also included poor men and First Nations men and immigrant men, you know. And then it started also getting to be where I became more and more aware of criticism that lesbians were holding, and that women in general were holding, both to the organization and what they were doing and their presumptions on who was actually the most affected. (2014, 5)

She described hearing more and more criticism of the organizing practice of AAN!, and reflecting on them.

> And so just hearing various people who were in one way or another respected and yet they were really challenged by this group that they felt was putting a stranglehold onto what the direction should be and how we presented things. By the time I became aware of their criticisms, I was also feeling, "Why are we so limited in focus. I thought the group was for *all* people who were struggling with AIDS, not just this narrow group." . . . I remember a conversation with one of the leaders, who just point blank said, "Well, I'm the one who's dying, not you." I was made to feel, because my involvement was not . . . because I wasn't dying or my health wasn't affected directly that I didn't have any legitimacy. It was troubling for me, because those people not at the table were also dying. And so I was just very troubled and feeling very conflicted for a while because I was giving my energy to something that I felt wrongly excluded legitimate claims. (du Plessis 2014, 8)

Du Plessis was not alone in being troubled about the scope of what claims were taken up; in Toronto, it is clear that there was substantial debate and deliberation about epistemic standing for setting political priorities. There were various smaller groups and organizations, many of which spun off and continue to have a life of their own—COMBAT (Community Organizations Mutually Battling AIDS Together),

Black CAP (Black Coalition for AIDS Prevention), PASAN (Prisoners with AIDS Support Action Network), Voices of Positive Women, and other organizations grounded in politically rooted identity formations. And there were other people who had organized with AAN! who left the organization at some of the sites of friction coded as "identity conflicts."

And yet, out of this process, we have the example of Trillium funding for drugs. Partially for pragmatic reasons about coalitional political work with other "disease groups," as they were called, but also perhaps for other reasons, AIDS activists refused the easier deal that would have secured funding for AIDS drugs only. The intersectional effects of their standing in solidarity with others in their present and in aspirational solidarity with people needing drug access in the future is significant. At the same time, as one person told us in the interview after asking us to turn off the camera, there were solidarity duties that people felt—when AAN! was asked to approve a version of Trillium drug funding just for people experiencing AIDS, one reason that they may not have done it is that they were working with other groups. When I asked Glen Brown about which other groups could have been explicitly part of the conversation about drug access, he said:

> I think epilepsy would've been one of them. Diabetes probably—the Canadian Diabetes Association. There were other groups. So, once we actually got the commitment to develop this thing and there were more people that were on the table saying, "What does it look like?" then there were other illness groups, I hate to use that phrase, at the table. It wasn't just us. But we were still the cranky ones.
> Alexis Shotwell: Right. The cranky powerful ones.
> Gary Kinsman: The cranky ones get things done.
> Glen Brown: We had an anniversary gathering at, I guess, the twentieth year. And I phoned Ruth Greer, who was the Minister of Health when we were fighting for the drug plan. She was actually the person—I remember yelling at her in City Hall or something. I said, I don't know if you remember me, but I remember you." [*laughter*] And she also said that the Trillium Drug Plan was one of the things that she was most proud of, of anything that she had done in her life. So, okay.
> AS: Nice to facilitate.
> GB: Yeah, you're welcome! [*laughter*] (Brown 2014, 25)

This mix, this sometimes painful muddle, produced the conditions for increased (though contingent) possibility for living. I am interested in holding the complexity of how these things were produced in view as we try to tell complex histories about

the vital and vibrant work that movements of the past did to shape the lives we can have now.

Conclusion

Fighting for the Emergency Drug Release Program to allow drug access, or for the Trillium drug funding program to make that access available to people regardless of how much money they had, came out of following the lead of people with HIV and AIDS, who were articulating what they needed to live and flourish. Practicing epistemic responsibility for better practices of knowing and being will, then, involve also practicing an in-process attention to collective epistemic responsibility and what Code productively theorizes as ecological thinking. Sometimes this might be accidental; the people we've talked to about their attempts to multiply who was "at the table" and making decisions in AAN! often seemed to feel that they had failed their comrades, or that they had been kicked out for their views; conversations about these things were painful for them. And yet, reflecting on these complexities has convinced me that it was partially through their work that a practical effect—of a policy that was more capacious and friendly to people in poverty, racialized people, unhoused people, imprisoned people—was won. Staying with the trouble that inevitably comes out of such an approach might, as in the case of the Trillium win, produce liberatory effects, vectors of freedom, for people experiencing multiple co-shaping vectors of oppression and vulnerability. This kind of approach might help us practice politics of responsibility from however and wherever we are situated toward worlds that don't yet exist but that we can draw into being through our collective yearning and struggle.

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