ecologies of care

Queer

Addressing a deep seam of prejudice, the provision of social infrastructures in the HIV/AIDS epidemic applies ethics of care to architecture, writes *Torsten Lange*

TONY BOCK / TORONTO STAR / GETTY

Those who died at the hospice Casey House are remembered in an annual memorial quilt (opposite above). Gay Pride Day in Yonge Street, Toronto, 1989, called for action on AIDS (opposite below). The first issue of *The Body Politic*, the largest Canadian gay and lesbian newspaper 1971-87, came out in Nov/Dec 1971 (right), and from 1973 publicised gay hotspots (below)

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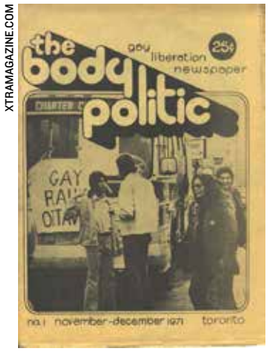

The early years of the HIV/AIDS epidemic, between the first 'rare cancer' reports in 1981 and the approval of AZT in 1987, were characterised by a paradoxical mix of inertia and blind actionism with equally destructive consequences. At one end of the spectrum was widespread lack of government action coupled with the ostracisation, public demonisation and stigmatisation of risk groups, especially after in 1983 the Centers for Disease Control and Prevention had identified key risk groups, colloquially referred to as the 4-Hs: homosexuals, haemophiliacs, heroin addicts and Haitians. At the other end was the increasingly heavy-handed policing, surveillance and clampdown of queer spaces. Under siege, in particular, were spaces that catered for anonymous casual sex such as gay bathhouses that were labelled a threat to public health, disregarding their communal value.

In addition to these aspects, the disastrous level of care of the increasing number of people with HIV/AIDS in the medical system had grown into an endemic problem. In his 2017 book *After Silence: A History of AIDS through its Images,* the artist, activist and writer Avram Finkelstein recounts the traumatising experience of his partner Don being admitted to hospital after he first began showing signs of immunosuppression in 1981: 'Days went by before the orderlies would even enter the room, and it was only after I threatened them. They left his food in the hall, wearing masks and gloves while they did, and never returned for the trays. There was blood under the bed from the previous patient. We brought in supplies and cleaned the room ourselves'.

Even though specialist outpatient and inpatient wards were set up throughout the mid-1980s, the level of medical and psychosocial care remained extremely poor in most places. This meant that people with AIDS were frequently subjected to appalling treatment in an environment dominated by fear and paranoia, isolation, and without hope for effective management of their symptoms.

Against this backdrop, the hospice Casey House in Toronto opened its doors to its first resident on 9 March 1988. He was greeted with a hug after having been transferred from hospital by fully masked, gowned and gloved ambulance attendants. The building, a semi-detached Victorian mansion on the corner of Huntley and Isabella Street constructed in 1900, provided a home for up to 13 people with AIDS, usually in the final stages of the illness. Its location near the Church Wellesley area, Toronto's 'gay village', was determined above all by the need for closeness to the community the hospice served; HIV/AIDS was especially prevalent in major metropolitan centres, with 96 per cent of infections among men, 83 per cent of whom were either gay or bisexual.

The idea of a free-standing AIDS hospice in Toronto – the first in North America – dated back to 1985, when public awareness and debate grew as the syndrome had

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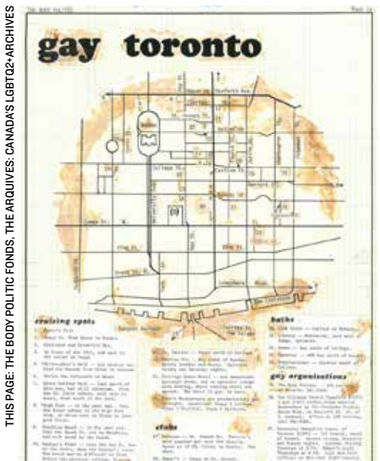


DICK LOEK / TORONTO STAR / GETTY

In 1986, June Callwood transformed a Victorian house in Toronto into Casey House (left), the first specialised facility for AIDS patients in Canada. Margaret McBurney, who oversaw the refurbishment work, and June Callwood (both pictured below) had lost sons to impaired drivers and were intent on giving comfort to vulnerable young people

become the leading cause of death for men between 35 and 44. The project was initiated by the AIDS Committee of Toronto, established in 1983; their goal was to address the lack of information in the face of the unfolding epidemic by providing community education around AIDS with the help of government grants. Following a series of unsuccessful attempts to raise funds, a steering committee led by the journalist and social activist June Callwood was set up, and eventually, in October 1986, Casey House was registered as a charity and granted a large chunk of the funds by the Ministry of Health. Yet, this fundraising success was also viewed critically by some – for instance, by AIDS activist Michael Lynch, founding member of AIDS Action Now!, a group demanding decisive action on treatment options, who remarked that Toronto's philanthropic community seemed more willing to fund the death of people with AIDS than their living.

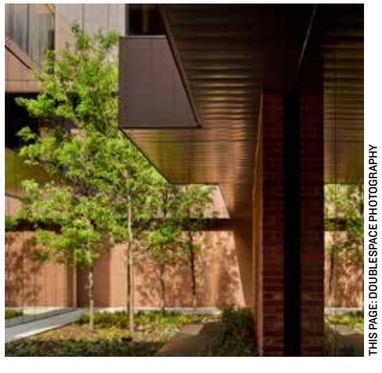
Refurbishment work began in spring 1987 and was overseen by designer, historian and writer Margaret McBurney. Despite 'flying blind', as she later noted, since guidelines for such a facility didn't exist, the hospice's mission to 'provide a specialist care option in a home-like environment' guided the project. Doors were widened for stretcher and wheelchair access; rooms were fitted with electrically adjustable beds with a matching adjustable chair and an individual television; ceiling lights were dimmable to adjust to residents' photosensitive eyes. The accomplished Canadian interior designer Eleanor Brydone waived much of her design fee, alongside other consultants, contractors and suppliers who donated labour and materials (according to internal reporting, pro bono work and donations were in excess of 2 million Canadian dollars).

Casey House's limited capacity meant, however, that its model of support, specialist treatment and palliative care was not generally available. To expand its services, a home hospice programme was rolled out in 1993. Only two in 10 residents were discharged before effective treatment became available in the second half of the 1990s. Since 1988, those who died at Casey House are remembered with an annual quilt – an homage to The Names Project AIDS Memorial Quilt, conceived by Cleve Jones and other activists in 1985 as both a form of social art and collective mourning.

In addition to adequate medical support and care, access to safe housing also led to the creation of community organisations such as Housing Works in New York in the late 1980s. Housing Works is minority-controlled, community-based and not-for-profit, which sets it apart from other contemporaneous efforts. This matters, not only because the experiences of marginalised groups have often been left out of the historic accounts of HIV/AIDS, written from the perspective of white cisgender gay men, but also because racialised people (BIPOC), along with those struggling with poverty, mental health, addiction or other social issues, have historically encountered barriers to

'The first resident was greeted with a hug after having been transferred from hospital by fully masked, gowned and gloved ambulance attendants'

JOHN MCNEILL / THE GLOBE AND MAIL



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Casey House was renovated and extended in 2017 by Hariri Pontarini Architects (this page). The regeneration of the hospice used the quilt as a source of inspiration

In 1991 Housing Works' first Gay Pride float was a home on wheels (right). Their Bookstore Café in Crosby Street, New York (below left), opened in 1996, and became a significant cultural institution. The charity's T-shirt (below right) was designed for the VI International AIDS Conference held in San Francisco in 1990

COURTESY OF HOUSING WORKS HISTORY / GAVIN BROWNING

'Inequitable access persisted due to residents' effective exclusion from and lack of control over social infrastructures'

accessing medical support and housing.

Founded in 1990 by four members of the ACT UP (AIDS Coalition to Unleash Power) Housing Committee – Keith D Cylar, Charles King, Eric Sawyer and Virginia Shubert – Housing Works sought to address the overlapping public health and homelessness crises that surged in the United States during the 1980s, resulting from benefit cuts, the deinstitutionalisation of mental health patients and the closure of (short-term) affordable housing. In contrast to traditional shelters which often turned away substance users in urgent need of housing, Housing Works prioritised shelter as a crucial first step before accessing other support services, while offering needle exchanges to reduce health risks.

Between 1995 and 1997, Housing Works' first permanent project was realised with the East 9th Street Facility (now Keith D Cylar House Health Center), designed by Alan Wanzenberg, which combined individual housing units with various social and medical care infrastructures and business enterprises. It was followed a year later by the opening of the East New York Community Health Center in Brooklyn, designed by the Pratt Planning & Architectural Collaborative. These housing and community health infrastructures were embedded in a wider local ecology comprising training programmes, links to private businesses, and medical institutions such as St Vincent's; still, many of these projects faced community opposition due to widespread fear and stigma of people with HIV/AIDS. Housing Works now operates 12 residences and supportive housing projects, three healthcare centres and 10 social enterprises across New York.

Housing Works' ecology of care from the outset was more expansive than that of Casey House, whose reach has steadily expanded since the late 1990s, to run an innovative day health programme for about 200 registered clients. While we lack detailed data concerning Casey House's early residents' income status, class, race or ethnicity, the largest proportion were presumably white middle-class gay men. Queer social geographers such as Gordon Brent Brochu-Ingram have critically noted that inequitable access, particularly for people of colour, persisted into the health crisis of the 1980s and 1990s due to their effective exclusion from and lack of control over social infrastructures. As a minority-run organisation, Housing Works stands out in this regard.

What about alternative forms of caretaking that move beyond traditional, gendered concepts of care? Figures from the Casey House report of 1991 show that between 70 and 90 per cent of its professional care staff were female (depending on whether full- or part-time staff are counted), and we can only speculate whether the reason for this enduring feminisation of care work lay in the hospice's association with St Michael's Hospital (founded by the Catholic Sisters of St Joseph in 1892), which may have led to a more traditional outlook on nursing. At the same time, nurse uniforms were abandoned in favour of casual sweaters, jeans and trainers, suggesting that conventional roles and hierarchies between caregivers and care receivers were questioned. We have no information about the gender of the 126 volunteers who worked at Casey House that year; nor can we make definitive statements as to the gendering of Housing Works' community-based care model.

Looking back to the ways queer communities have collectively responded to the trauma of illness and death during the height of the HIV/AIDS epidemic in the 1980s and 1990s (an epidemic that, of course, is far from over) offers ways to rethink the 'reigning carelessness' and endemic global crisis of care of the present. In the recently published *Care Manifesto* by the UK-based Care Collective, they argue that an 'ethics of promiscuous care' grounded in 1980s and 1990s AIDS activist theory – and indeed practice – holds the potential to reorient our 'contemporary hierarchies of care in the direction of radical egalitarianism', redefining 'caring relations from the most intimate to the most distant', while 'caring more and in ways that remain experimental and extensive'.

Both Casey House and Housing Works can be understood as what we might call queer ecologies of care, with reference not only to recent interdisciplinary engagements between, among others, queer theory, ecofeminism, feminist materialism and posthumanism, but also the work of scholars such as Shannon Mattern, who urges us to think physical infrastructures and social ecologies in relation to one another, reframing care in terms of a complex ecology of human and non-human actors. Applying care theory to architecture involves a shift in perspective, as the feminist care theorist Joan Tronto notes, which considers not the completed 'thing', but 'all who are engaged through this thing' – meaning that we need to think of buildings and spaces 'in relationships that exist through time as well as in space'. In this case, these relationships were formed by a deadly virus, and by the creative and life-affirming (rather than resigning to death) responses to this health crisis, by the forms of solidarity, alliance and care developed among queer people. Yet we must be careful not to romanticise these responses in retrospect, as Douglas Crimp has already warned in relation to efforts like 'Art against AIDS' in 1987, and instead recognise that they were rooted in the colossal failure of governments and the medical profession to respond adequately – and above all quickly – to the epidemic. LGBTQI+ infrastructures can be apprehended as the totality of social spaces, organisations and services to fight trans- and homophobia as they intersect with misogyny, racism and xenophobia – the social and material ecologies as well as collective forms of labour that sustain these infrastructures and their specific community of users.

JULIE TURKEWITZ / HOUSING WORKS

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THIS PAGE: BRIAN ROSE

The mission of the East New York Community Health Center (this page) in Brooklyn – again an initiative by Housing Works – by Pratt Planning & Architectural Collaborative, is to combat HIV and homelessness. It further expanded in 2012 to reach 2,600 new users