Review of the Literature: AIDS Exceptionalism and the Integration of AIDS Service Delivery

Rethinking ASOs? Deliberative Dialogue Process

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Literature review

- **Research Question**: *How have the mandates of AIDS service organizations changed over the last 30 years and what are the changes seen with regards to professionalization, the relationship with advocacy, and service provision shifts away from exceptionalism to integrated service delivery?*

- **Databases**: *Academic Search Complete, Medline, Canadian Public Policy Collection, PubMed, Web of Science, Worldwide Polisci Abstracts*

- Suggestions from experts were gathered and reviewed

- Reference lists of relevant sources were reviewed for additional sources

- **Exclusion criteria**: not relevant to Canadian context, focus not directly on HIV public health (i.e. immigration, justice, or drug policy)

Search strategy

- **Search terms**: *AIDS, HIV, community, service(s), organization(s), government(al), agency(ies), group(s), policy(ies), mandate(s), guide(s), strategy(ies), ASO, CBO, exceptionalism, integrat(e)(ion)(ed), advocacy, professionalization*

- **Sample search**: *"(HIV OR AIDS) AND (exceptionalism OR integration OR advocacy OR professionalization) AND (service OR organization OR community OR government OR agency OR group) AND (policy OR mandate OR guide OR strategy) AND (community OR ASO)"*

- Over 2000 results were found and narrowed down by title

- More than 500 abstracts were reviewed

- A total of 78 sources were included (52 sources from the literature searches in addition to 25 expert suggested sources, and 1 personal communication)

Exceptionalism: What we found in the literature

- 15 sources in total were found (8 expert suggested, 6 through searches, and 1 personal communication)

- Most of the sources had a global focus or were written within an American context. One source was from Europe

- This presentation will review 4 themes drawn out of the literature: how exceptionalism is defined, the history of exceptionalism, and presentations of arguments on both sides of the debate on the future of exceptionalism

What is AIDS exceptionalism?

- Treating HIV as different from other diseases in law and policy[1,2]

- Emphasizing the rights of people living with HIV especially, with regards to privacy, confidentiality, and autonomy[1,2]

- Counselling and informed consent with testing[1,2]

- Guaranteed anonymity in public health reporting[1]

- Exceptionalism in resource allocation, i.e. HIV/AIDS funding is separate from that of other illnesses or health issues reference[3]

- AIDS being prioritized over other health issues and drawing what some say is a "exaggerated" amount of global resources[2,4]

1. PositiveLite.com. (2014). Is This the End of AIDS Exceptionalism. http://www.positivelite.com/component/zoo/item/is-this-the-end-of-hiv-exceptionalism
2. Whiteside, A. & Smith, J. (2009). Exceptional epidemics: AIDS still deserves a global response. *Globalization and Health, 5*(15).
3. Casarett, D.J. and Lantos, J.D. (1998). Have we treated AIDS too well? Rationing and the future of AIDS exceptionalism. *Annals of Internal Medicine, 128*(9), 756-759.
4. Forman, L. (2011). Global AIDS funding and the re-emergence of AIDS 'exceptionalism'. *Social Medicine, 6*(1), 45-51.

Why and how did AIDS exceptionalism develop?

- AIDS was unique and there were concerns that standard public health measures (testing, contact tracing, quarantine, isolation) would force the epidemic underground[1]

- An exceptional alliance formed by the gay community, injection drug users, and other groups considered "affected" as well as liberal and left-wing parties, and sections of healthcare and psychosocial professions advocated for a human rights approach to HIV prevention and treatment, including the importance of informed consent[1,2,3]

- Fear was intensified by the fact that people had started to rely on antibiotics for infectious diseases – but modern medicine appeared powerless in the face of AIDS[4]

- Routes of transmission, infectiousness during latency and archaic fears around "social modernization" practices of the 70s (sexual permissiveness, differentiation and liberalization of narcotics) led to people seeing this disease as unique[3]

1. Whiteside, A. (2009). *Is AIDS Exceptional?* Working Paper 25 Commissioned by the aids2031 Programmatic Response Working Group.
2. Bayer, R. (1991). Sounding board: Public health policy and the AIDS epidemic: An end to HIV exceptionalism? *New England Journal of medicine, 324*(21), 1500-1505.
3. Rosenbrock, R., Schaeffer, D., Dubois-Arber, F., Moers, M., Pinell, P., and Setbon, M. (1999). *The AIDS Policy in Western Europe: From Exceptionalism to Normalization.* Publications series of the research unit Public Health Policy
4. Burris, S. (1994). Public health "AIDS exceptionalism" and the law. *The John Marshall Law Review, 27*, 251-272.

Debate:

AIDS still warrants an exceptional response

- Changes to AIDS exceptionalism have the potential to undo gains and momentum achieved by prior advocacy efforts[1]

- The populations affected and the stigma attached still warrants exceptional response[2]

- Criminalization alone makes AIDS exceptional[3]

- "Criminalization must come off the table before an exceptional response can move towards an equitable blood borne pathogen model of service and care delivery"[3]

- Exceptionalism remains necessary in certain conditions and should be determined by a) prevalence (high prevalence deserves exceptional response); b) demographic dynamics of the country; and c) availability and affordability of treatments[4]

- Exceptional for whom? Some argue that for indigenous people and other groups experience extreme marginalization, HIV/AIDS remains a significant challenge that warrants an exceptional response[5]

1. Alcorn, K. (2009). AIDS exceptionalism a defensible concept, says Stephen Lewis. http://www.aidsmap.com/AIDS-exceptionalism-a-defensible-concept-says-Stephen-Lewis/page/1435162/
2. Piot, P. (2008, May). *AIDS Exceptionalism Revisited*. Speech presented at the London School of Economics and Political Science, London, ENG
3. PositiveLite.com. (2014). Is This the End of AIDS Exceptionalism. http://www.Positivelite.Com/component/zoo/item/is-this-the-end-of-hiv-exceptionalism
4. Whiteside, A. (2009). *Is AIDS Exceptional?* Working Paper 25 Commissioned by the aids2031 Programmatic Response Working Group.
5. Wilson, C.L., personal communication, August 22, 2014

Debate:

AIDS should no longer be treated as exceptional

- Exceptionalism undermines other health systems by drawing away resources[1]

- AIDS has become less threatening with advances in therapeutic prospects[1,2]

- Exceptionalism threatens the efficacy of public health strategies for prevention and care[3]

- The argument that HIV has been historically different with regards to stigma and politicization is only true in relation to other present health threats. Syphilis, tuberculosis and cholera were all badges of vice and dissipation in their prime[4]

- HIV exceptionalism has fulfilled its purpose[5]

- Treating HIV as exceptional creates barriers and perpetuates stigma through separation and difference[5]

1. Whiteside, A. (2009). *Is AIDS Exceptional?* Working Paper 25 Commissioned by the aids2031 Programmatic Response Working Group.
2. Bayer, R. (1991). Sounding board: Public health policy and the AIDS epidemic: An end to HIV exceptionalism? *New England Journal of medicine, 324*(21), 1500-1505.
3. Forman, L. (2011). Global AIDS funding and the re-emergence of AIDS 'exceptionalism'. *Social Medicine, 6*(1), 45-51.
4. Burris, S. (1994). Public health "AIDS exceptionalism" and the law. *The John Marshall Law Review, 27*, 251-272.
5. PositiveLite.com. (2014). Is This the End of AIDS Exceptionalism. http://www.positivelite.com/component/zoo/item/is-this-the-end-of-hiv-exceptionalism

Integration: What we found in the literature

- 40 sources were included in total (11 expert suggestions, 29 through searches)

- Specific models (22), technical guides (10), discussion pieces (8)

- Most of the sources came from the United States (14), Canada (9), and International (7) but it is notable that unlike in the other 2 sections of this review there were a number or sources from African countries (6). There are also a few articles from Europe, and one from Australia

- This section will provide an overview of how integration is defined in the literature, specific types of integration, and cited benefits and concerns with integrating services

What is integration?

- "The management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system."[1]

- Integration may refer to the combination of funding or services for the prevention, testing and/or treatment of any or all of the following: HIV/AIDS, tuberculosis, viral hepatitis, other sexually transmitted infections, cancer screening, mental health, substance use, housing, food security, integrating health an social services

- Service integration is a continuum that may include aspects of coordinated referral, streamlined access points, record sharing, co-location, and multiple services provided by one practitioner[2,3,4]

1. World Health Organization. (2008). Integrated Health Services – What and Why?
2.. Richardson, D., & Patana, P. (2012). Integrated service delivery: why, for who, and how? Organization for Economic Co-operation and Development.
3. Legido-Quigley, H., Montgomery, C. M., Khan, P., Atun, R., Fakoya, A., Getahun, H., & Grant, A. D. (2013). Integrating tuberculosis and HIV services in low- and middle-income countries: a systematic review. *Tropical Medicine & International Health, 18*(2), 199-211.
4. Aral, S.O., Fenton, K.A., & Lipshutz, J.A. (2013). *The New Public Health and STD/HIV Prevention.* Springer, NY

Types of integration

- **User integration:** access to multiple services appears seamless with minimal visits required[1]

- **Provider integration:** separate services are provided, managed, financed, and evaluated together, or in a closely coordinated way[1]

- **Macro level integration:** managerial, policy, organizational, and professional coordination across service areas[1]

- **Co-location**: infectious disease specialist or other health care providers may come to a drop-in ASOs or remote areas on a regular basis to treat people in the community – minimizes barriers like transportation, stigma from hospital staff etc.[2]

- **Coordination**: close collaborative relationships to ensure strong referrals, accompaniment to appointments, and reduced stigma (by stronger relationships and understanding among service providers)[2]

1. World Health Organization. (2008). Integrated Health Services – What and Why?
2. Sutton, P. (2014). No More Silos. Canadian Treatment Action Council.

Cited reasons for integrating services

- Quicker response times[1]

- Improved strategic planning and system integrity[1]

- Reduced demand for crisis services – swifter and more coordinated assistance can help stabilize peoples' conditions and as a result limit the need for high-cost crisis intervention[1]

- Increased capacity and value for money – reduced administration costs[1,2,3,4]

- Eases data and record sharing[2,3]

- Simplified access – one-stop-shop for clients, no wrong door[1,2,3,4,5]

- Holistic and customized support – as duplicated services are phased out and case managers have access to client information via shared databases[1,4]

- Improved outcomes and user experiences[1,2,4,5]

1. KPMG. (2013). The Integration Imperative: reshaping the delivery of human and social services.
2. Richardson, D., & Patana, P. (2012). Integrated service delivery: why, for who, and how? Organization for Economic Co-operation and Development.
3. Aral, S.O., Fenton, K.A., & Lipshutz, J.A. (2013). *The New Public Health and STD/HIV Prevention.* Springer, NY.
4. Gold, J. with J. Hjartarson. (2012). *Integrating Human Services in an Age of Fiscal Restraint.* Toronto: Mowat and KPMG.
5. Witicar, P. and Liberti, T. (2007). Advancing integration of HIV, STD, and viral hepatitis services: state perspectives. *Public Health Reports, 122*(2), 91-95).

Concerns with service integration

- Integration of services contrast with ideas of HIV/AIDS exceptionalism (i.e.one approach does not necessarily work for all blood borne pathogens)[1]

- Responding to integration pressures may lead to institutional directions that are not true to an organization's mandate[1,2]

- Many worry that integration really means doing more with less – without moves to increase core or project funding or increase number of staff this could lead to service providers experiencing burnout from trying to do more without additional resources[1,2,3]

- Data sharing concerns, especially with regards to protecting confidentiality[4]

- Stigma: qualitative data from an African study suggests that many clients felt more confidentiality when services were stand-alone- when they knew those around them were also positive[5]

1. Exploring the impacts of the shifting of HIV/AIDS policy landscape around the integration of services. Summary report from the Vancouver Policy Symposium Satellite Session August 26, 2013
2. Warren, C. E., Mayhew, S. H., Vassall, A., Kelly Kimani, J., Church, K., Dayo Obure, C., . . . Watts, C. (2012b). Study protocol for the Integra Initiative to assess the benefits and costs of integrating sexual and reproductive health and HIV services in Kenya and Swaziland. *BMC Public Health, 12*(1), 973-988.
3. Sutton, P. (2014). No More Silos. Canadian Treatment Action Council
4. KPMG. (2013). The Integration Imperative: reshaping the delivery of human and social services
5. Church, K., Wringe, A., Fakudze, P., Kikuvi, J., Simelane, D., & Mayhew, S. (2013). Are integrated HIV services less stigmatizing than stand-alone models of care? A comparative case study from Swaziland. *Journal of the International AIDS Society*, **16**, 1-9.

Concerns with service integration (con't)

- Increased exposure to tuberculosis with integrated HIV and TB services[1]

- Although complicated systems may create difficulty accessing services, redundancy sometimes provides the diversity needed for individuals to access services that work for them[2]

- A cost analysis of integrated sexual health and HIV services in Kenya and Swaziland showed mixed results but there was no clear evidence to support conventional assumption that more integrated health facilities operate more efficiently[3]

- Integration is complex when attempted in practice, co-locating services doesn't mean that they will work together[4]

1. Legido-Quigley, H., Montgomery, C. M., Khan, P., Atun, R., Fakoya, A., Getahun, H., & Grant, A. D. (2013). Integrating tuberculosis and HIV services in low- and middle-income countries: a systematic review. *Tropical Medicine & International Health, 18*(2), 199-211.
2. Chambre, S.M. (1999). Redundancy, third-party government, and consumer choice: HIV/AIDS nonprofit organizations in New York City. *Policy Studies Journal, 27*(4), 840-854.
3. Vassal, A. (presenting work by Obure, Sweeny, Terris-Prestholt, etc). Cost analysis of integrated HIV and Sexual Reproductive Health Services in Kenya and Swaziland.
4. Lawn, S., Lloyd, A., King, A., Sweet, L., & Lyn, G. (2014). Integration of Primary Health Services: being put together does not mean they will work together. *BMC Research Notes, 7*(1), 1-17.

Shifting ASO mandates: What we found in the literature

- 22 sources included in total (6 expert suggestion and 16 through searches)

- The majority of sources were from a Canadian context (11), 7 came from the United States, 2 were from South Africa, 1 from a global perspective, and 2 spanned multiple jurisdictions

- This section will share what was found in the literature with regards to shifts in the political climate in Canada in the 1980s and 1990s, and how these shifts are documented to have affected AIDS service organizations' composition and mandates

Shifts in ASO mandates (a brief overview)

- In the early 1980s most of the response to AIDS came from community groups primarily run by gay men and people living with HIV[1,2]

- Early government engagement was mostly in the form of collecting epidemiological data[3]

- In the mid/late 1980s advocacy from community groups demanded state action, development of strategies, and increases in funding[1,2,3]

- With government funding came the following shifts in the organization, composition and mandates of AIDS service organizations[2,4,5]:
  - Shifts towards professionalization of AIDS service organizations
  - Shifts away from core funding to project-based funding
  - Mission drift
  - Advocacy chill

1. Maguire, H., Hardy, C. & Lawrence, T.B. (2004). Institutional entrepreneurship in emerging fields: HIV/AIDS treatment advocacy in Canada. *Academy of Management Journal, 47*(5), 657-679.
2. Poindexter, C. C. (2007). Management successes and struggles for AIDS service Organizations. *Administration in Social Work, 31*(3), 5-28. doi: 10.1300/J147v31n0302
3. Rayside, D.M, & Lindquist, E.A. (1992). AIDS activism and the state in Canada. *Studies in Political Economy, 39,* 37-76.
4. Scott, K. (2003). *Funding matters: The impact of Canada's new funding regime on nonprofit and voluntary organizations.* Canadian Council on Social Development.
5. Cain, R. & Todd, S. (2008). Managing funding constraints in frontline HIV/AIDS social services in Canada. *Journal of HIV/AIDS & Social Services, 7*(3), 265-287.

Professionalization of ASOs

- Competition for governmental funding meant hiring staff who were comfortable with government and medical circles and administrative and bureaucratic practices[1]

- Organizations that may have started as grassroots and PHAs-led may now be primarily run by professionals who are not PHAs[2] and that are increasingly bureaucratic and hierarchical

- "While reliance on paid staff indicates professional legitimacy, losing volunteer involvement may also [mean] losing valuable connections with the community at large, as well as communities at risk. ASOs without thriving volunteer programs may struggle to achieve access to or obtain representation from affected communities"[3]

- **Benefits**: clearer confidentiality, accountability, training, expertise[4]

- **Concerns**: changing philosophical basis, bureaucratization, shifting power out of the hands of services users[4]

1. Rayside, D.M, & Lindquist, E.A. (1992). AIDS activism and the state in Canada. *Studies in Political Economy, 39,* 37-76.

2. Maguire, H., Hardy, C. & Lawrence, T.B. (2004). Institutional entrepreneurship in emerging fields: HIV/AIDS treatment advocacy in Canada. *Academy of Management Journal, 47*(5), 657-679.

3. Poindexter, C. C. (2007). Management successes and struggles for AIDS service Organizations. *Administration in Social Work, 31*(3), 5-28. doi: 10.1300/J147v31n0302

4. Cain, R. (1997). Environmental change and organizational evolution: reconsidering the niche of community-based AIDS organizations. *AIDS Care, 9*(3), 331-344. doi: 10.1080/713613158

Funding

- Shifts away from core funding has heightened competition and non-profit organizations must devote more time to securing short term funding, often at the expense of organization' missions and core activities[1,2]

- Project-based funding means funding agencies have more control over what an organization does[1]

- Mission drift: organizations may be pulled away from their primary mission in order to secure funding[1]

- Advocacy chill – fears of "biting the hand that feeds," and increasing government talk of "partnership" lead to concerns around mounting activist campaigns or making critiques of government policy[1,3]

1. Scott, K. (2003). *Funding matters: The impact of Canada's new funding regime on nonprofit and voluntary organizations.* Canadian Council on Social Development
2. Cain, R. & Todd, S. (2008). Managing funding constraints in frontline HIV/AIDS social services in Canada. *Journal of HIV/AIDS & Social Services, 7*(3), 265-287.
3. Rayside, D.M. & Lindquist, E.A. (1992). AIDS activism and the state in Canada. *Studies in Political Economy, 39*, 37-76.

Questions to consider…

- What key elements of current AIDS service models need to be preserved moving forward? What could be released or let go of?

- Do you think service integration and AIDS exceptionalism are mutually exclusive?

- What concerns arise for you when picturing a more integrated system across systems, provider and user levels?

- How can HIV-related stigma continue to be addressed within developing community-based service models?

- Do you think the concerns discussed from the literature around professionalization, mission drift, and advocacy chill are warranted? How have you seen these play out in your experience?

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