Introduction

The early 1980s saw the beginning of the HIV epidemic in Jamaica, when an index case of uncertain origin came to the island. The first diagnosed case of HIV in Jamaica was registered shortly afterwards in 1982. It was also the first reported case of AIDS in the Caribbean. Over the next few decades, that single case grew to an epidemic affecting the general population as well as key and vulnerable groups. Its concentration within key and vulnerable high-risk groups included men who have sex with men (MSM), female sex workers (FSW) and their clients, and more recently, women of trans experience.

At the beginning of 2017, the Jamaica Ministry of Health (MOH) and Jamaica AIDS Support for Life (JASL) began implementing the World Health Organization (WHO)'s “Treat All” approach, which recommends initiation of antiretroviral therapy (ART) for all clients who test positive for HIV. The Treat All approach contributes to the UNAIDS 90-90-90 goals of 90% of all people diagnosed with HIV infection on sustained antiretroviral therapy (ART) by 2020 and, ultimately, 90% of all people receiving ART reaching viral suppression. In 2017, about 81% of the estimated 29,000 people living with HIV (PLHIV) in Jamaica knew their status, 35% were on treatment, and 21% had achieved viral suppression.

The 90-90-90 goals are based on the HIV care continuum—sometimes also referred to as the HIV treatment cascade—that outlines the basic steps or stages of HIV medical care that PLHIV move through, beginning with testing and counselling and continuing through achieved and continuous viral suppression.

Jamaica AIDS Support for Life

JASL’s beginnings are arguably similar to those of other HIV civil society organizations (CSOs). A group of friends organised to assist a peer who had acquired the highly stigmatized HIV and was facing discrimination in the healthcare system.

In 1991, the organisation was officially established as Jamaica AIDS Support (JAS) and was the first non-governmental organisation (NGO) specifically responding to HIV. In 1995, the agency opened Life, an AIDS hospice that provided treatment and care for PLHIV who were unable to source acceptable treatment at clinics and hospitals island-wide. As the government’s health response at the time was focused on broader prevention of sexually transmitted diseases (STDs) and did not target the most vulnerable groups, JAS would eventually be encouraged by the Ministry of Health to continue their work among PLHIV, MSM, and SW as JAS was recognized as providing a stigma-free zone in which people could access HIV-related services irrespective of sexual orientation, gender, race, occupation, colour, class, economic status, or religion.

Twenty-five years after its inception, the organisation, now Jamaica AIDS Support for Life (JASL), has developed into Jamaica’s largest HIV/AIDS-focused, human rights NGO, fighting against the spread of HIV and ensuring the preservation of the rights and dignity of those most vulnerable to the disease. As a key implementing partner of the Ministry of Health, JASL has consistently supported the development of its national HIV/AIDS strategic plans and shares its reports with the national HIV programme. With a goal of being the lead civil society partner to the government in the national response to HIV/AIDS through rights-based programme implementation, JASL’s work has expanded to include services focused on HIV education, prevention, and linkage to care; treatment, care, and support; and advocacy for an enabling environment and the preservation of human rights. Services are offered to MSM, SW, people who are hearing impaired (HI)/deaf, women of trans experience, orphans and vulnerable children (OVC) including adolescents living with HIV (ALHIV), women affected by violence in the context of HIV, and the general population.
JASL’s Treatment Model

Treatment, care, and support are JASL’s core functions. It is currently the only CSO providing antiretroviral therapy (ART) service delivery in the English-speaking Caribbean. JASL provides a suite of treatment, care, and support services through its three treatment sites located at its chapters in Kingston, St. Ann, and Montego Bay. The treatment sites are an avenue for increasing access to healthcare services, especially for key populations, offering a user-friendly, stigma-free zone. JASL’s three treatment sites are among the country’s 36 HIV treatment sites and offer multidisciplinary services to provide antiretroviral treatment, while supporting client adherence to ARVs and retention in care.

JASL’s overall treatment objectives align with the 90-90-90 goals by linking people who test positive to care through peer navigation and CSO testing partners, retaining them in care and treatment through case management, and achieving and maintaining viral suppression through clinical and support services. In 2016, JASL identified 161 newly diagnosed clients (55 of whom were MSM) and linked 121 to care, 43 of whom were linked by CSOs. In the Kingston clinic, retention in treatment moved from 18% in 2014 to 98% in 2016. Across all three clinics, client viral suppression increased from 2% in 2014 to 40% in 2016.

To do this, JASL developed a multidisciplinary holistic treatment model that responds to the medical, social, mental, economic, and nutritional needs of each client, taking into consideration all the factors that might influence a client’s ability to adhere to or be retained in care and treatment.

JASL’s treatment, care, and support model employs the use of case management to help realise the organisation’s strategic objectives of increasing retention in care and improving the overall health outcomes of PLHIV. In 2015, an HIV/AIDS Case Management protocol was drafted to provide standardised guidelines for case management services for persons living with HIV (PLHIV) in Jamaica. The guidelines assist providers of case management services in public health facilities and non-governmental organisations to better understand their roles and responsibilities and to identify opportunities for improved coordination and integration of services provided to clients living with HIV.

Linking into care

Since JASL began providing clinic-based ART, the gap between clients receiving testing and starting treatment and care has shrunk considerably. Through the networks JASL’s peer navigators have developed and the relationships the organisation has developed with CSOs providing HIV testing and counselling services, linking those who have tested positive to treatment has become simpler and faster.

One of the challenges to linking key and vulnerable populations to care is that the MSM, transgender, and sex worker populations in Jamaica are small and overlap. For this reason, some clients fear that their status will be disclosed without their consent. Peer navigators work with clients to build trust within these communities and guide those who test positive to develop good relationships with JASL staff—including their case manager, psychologist, nutritionist, and adherence counsellor—to make sure all clients get the clinical and support services they need. Through peer navigation and case management, clients can be linked to and retained in care, stay treatment adherent, and achieve and maintain viral suppression.

Intake and assessment

JASL recognizes that clients’ social needs, such as employment status and education, can act as barriers to their health outcomes. Therefore, supportive or non-medical case management, where social services are provided alongside medical ones, strengthens the continuum of care to help lead clients to viral suppression. JASL case managers ask themselves, “What can we do for this client other than tell them, ‘Take your medication’?” They also ask their clients, “What do you need?” and “How can we help you meet those needs?”

To identify client needs, the JASL case manager leads an assessment of each client. Based on the particular needs of the client, a service plan is then developed that indicates economic, social, and psychological needs. The client is then referred to a social worker, adherence counsellor, psychologist, and nutritionist to determine what is needed for their full and holistic care.
Once a client is diagnosed and linked to JASL's care, the client is seen by a doctor and nurse for ART services and syndromic management (which refers to the diagnosis of STIs and other opportunistic infections).

Case managers do an initial assessment of each client, then develop a service plan.

Based on their needs, the client is then referred to:

- Social worker who identifies educational, housing needs, and other support needs
- Adherence counsellor
- Psychologist
- Nutritionist for nutritional assessment and meal plan
- Clinical services (Based on medical needs identified throughout the client's treatment and care, they may be referred to private facilities for specialized care and diagnostic services)
- Other internal resources
  - Skills building training
  - Treatment literacy

Ongoing assessments are very important; therefore, team members conduct case conferencing to review difficult cases and discuss solutions to improve respective clients' health outcomes. In order to best help a client, case managers underscore that clinic staff has to meet a client “where they are at” and provide them with the resources to grow and become independent and empowered.

**Clinical, ART, and support services**

JASL’s team builds and maintains partnerships with many other health and non-health organisations and businesses in order to deliver the types of clinical, social, and economic support that meet the needs of their clients. Their clinical services include safer sex commodities promotion, sexually transmitted infection (STI) testing and treatment services, additional diagnostic and laboratory support, ART, opportunistic infection and other health condition management, and gender-based violence (GBV) screening.

For each client, as required, an assessment details the types of clinical, social, and economic support they need. JASL’s team endeavours to meet their needs as best as possible. One of JASL’s strengths is the depth and breadth of services available to test, treat, and support their clients. This “one-stop shop” approach has made it easier for JASL’s clients to get their medications, laboratory testing, follow-up monitoring, and support from a single place, thus helping them stay in the system, in care and treatment, and achieve good health outcomes.

**Clinical, ART, and support services**

As part of the intake process, a clinician evaluates each client. In addition to evaluating clients to establish disease stage, screening, diagnosis, management of opportunistic infections, and so on, the clinician discusses initiating ART. This discussion builds on the adherence and support services counselling already provided by a social worker/adherence counsellor with the aim of establishing ART readiness.

Clinicians providing ART services are hired by JASL on a part-time basis and serve as part of JASL’s clinical team. The clinicians are expert HIV practitioners who also manage HIV clients within the public health system.

Management of clinical services is by MOH standards and guidelines, as documented in the Clinical Management of HIV, which establishes standards of care. The National Public Health Laboratory (NPHL) and Ministry of Health are engaged for routine and specialized testing, such as viral load and liver function, that cannot be processed in-house. Once results have been received from the NPHL and MoH, the results are given to clients at their next visit.

JASL has also developed a number of tools to standardise and effectively monitor treatment and support services, such as a Gender-Based Violence (GBV) Screening tool, Pill Count monitoring tool, and an Adherence Management tool. These tools are designed to help clients and the organisation work together toward the common goals of adherence, retention, and viral suppression. Additionally, the clinic teams provide robust outreach, including follow-up phone calls and home and hospital visits for clients who miss their medications.

Due to fear of disclosure, amongst other issues, many clients do not access pharmaceutical services on their own. In order to provide clients with their ARVs, JASL’s pick-up system is linked to several private pharmacies across the island. JASL also works with clients to accommodate any special needs or requests, such as home delivery of medication for those who cannot come to the clinic or prescriptions filled for longer periods to help clients who travel.
Support Services

JASL’s support services include support groups tailored to different populations and their varying needs, nutritional support, transportation stipends, income-generating grants, life skills development, educational support, treatment literacy, home/hospital visits, and individual, couple, and group counselling.

Support Services: A Focus on Treatment Literacy

Sensitisation on “Treat All” is the first step in the process for JASL’s staff, while treatment readiness is the organisation’s policy for all PLHIV clients not yet on ART.

JASL developed a treatment literacy curriculum, delivered through a series of workshops aimed at providing clients with the knowledge they need to understand issues related to HIV and treatment. The workshop series includes sessions on understanding HIV/AIDS and all aspects of ART; antiretroviral drugs (ARVs), how they work, and their side effects; the value of nutrition; the importance of treatment adherence; and HIV drug resistance and other issues. The sessions are supported through treatment literacy videos and simple-language treatment posters to reinforce messages and address people with low literacy. Using this curriculum, JASL delivers a six-week training programme to each client and one supporter, who can be a family member, friend, or even another person living with the virus. This curriculum is unique to JASL and helps clients not only understand why adherence to ARVs and retention in care is crucial for their health and the health of their partners and/or families, but also empowers them to serve as peer ART educators and trainers.

JASL also uses a Treatment Readiness Assessment Tool (TRAT), developed by the Ministry of Health, to aid with the treatment readiness process and complement treatment literacy.

In conjunction with the “Treat All” thrust, the push to get more clients virally suppressed has become a priority. This meant improving different aspects of the HIV treatment cascade and intensifying interventions to move people along the continuum of care towards viral suppression.

JASL’s treatment cascade is closely monitored by the treatment team to ensure that programmes are responsive to clients’ emerging needs and challenges all the way through to viral suppression. As of September 2017, 612 clients were in care, with 94% receiving ART and 57% of those achieving viral suppression.

Monitoring and Evaluation

JASL has a dedicated monitoring and evaluation (M&E) team that measures the effectiveness of its services and the program as a whole. Through a series of forms, the M&E team is able to capture each client’s clinical and psychosocial status, needs, and service usage across the care and treatment continuum.

JASL’s key forms include Voluntary Counselling and Testing (VCT) intake forms, peer outreach reports, service plans, and other monitoring tools that document clients through the continuum and the various services accessed. Client-specific assessment documents are placed at the front of each client’s file to track what
services they used and to help prompt the case worker to follow up or schedule services. Aggregate data from the three sites is used for programmatic decision-making.

Additionally, the data is also used by the grant writing team to support funding applications and inform donor and MOH reporting.

**Facilitating Factors for JASL Implementing the Treatment Model**

**Enabling environment and human rights**

The promotion of a rights-based approach to HIV services helps to reduce stigma and discrimination in health facilities and in communities. Addressing fears and changing perceptions about HIV and AIDS has a direct impact on the uptake of HIV testing and counseling services. JASL’s model guides the organisation and their partners to build and support a human rights-based enabling environment to improve factors that affect their clients and contribute to the overall national response.

An enabling environment encompasses many things. At the clinic and local level, it means creating safe spaces for clients by reducing or eliminating factors that might create or enforce stigma and discrimination: not using signage to identify clinics, choosing discreet, well-trained staff and volunteers, providing legal support, and using the peer model to reach and build trust with key and vulnerable populations within their networks. At the national level, it means harnessing partnerships with state and non-state actors, gaining representation on national committees in order to make sure the voices of marginalised populations are heard, engaging in policy dialogue and ensuring representation in legislative discourse, and working with the MOH to make sure social and traditional media campaigns are inclusive and non-stigmatizing.

JASL’s key advocacy initiatives include developing policy papers, position papers, and parliamentary submissions regarding the repeal of punitive laws and other policies that infringe on the rights of PLHIV and key groups vulnerable to HIV. The organisation has also lobbied to reduce stigma and discrimination and lack of accountability among service providers; provide sexual and reproductive health (SRH) services to persons with disabilities and key groups of women affected by violence; hold information dissemination sessions; engage of media; and host training workshops on topics including gender equality, human rights, and violence against women within the context of HIV.

Enabling environments help reduce structural barriers to HIV prevention and treatment programmes by increasing access to testing; reporting and addressing provider mistreatment, confidentiality breaches, stigma, and discrimination; and revising laws and policies to eliminate institutionalised discrimination and protect the human rights of all citizens.

**Strategic partnerships**

Strategic partnerships are considered a key tool for the effective implementation of JASL’s treatment programme. Over the years, JASL has forged successful partnerships with the MOH, key donor and international technical agencies, other CSOs, and communities of key populations. It is through strategic partnerships that enabling environments are built and strengthened and partners are able to work together and support each other, focusing on their unique strengths but working in tandem to ensure a coordinated response. JASL has leveraged these partnerships to support their programmes and effectively deliver care, treatment, and support services to their clients.

At the clinical level, partnerships have strengthened the services and support JASL is able to provide their clients. For example, through their partnership with the MOH to provide ART services, MOH laboratories process
The Jamaica Civil Society Forum was created to give CSOs a space to talk about and analyse common concerns. The group must agree on a common issue before submitting a request to Parliament to review or consider new legislation. For example, the Sexual Offenses Act punishes sexual behaviour and acts inconsistently—it recommends strong sentences for ‘buggery,’ defines rape as a penis penetrating a vagina (a penis or non-penis penetrating any other place is not considered rape), and criminalises sex work. The specific language of the Act is important, as it guides implementation of health care. For example, forced anal penetration (buggery) is not considered rape by either the law or providers implementing the law.

After much discussion about responding to the Sexual Offenses Act, the group decided not to address sex work criminalisation, because not everyone agreed to prioritise that issue. Individual CSOs could still work together to address it; however, the forum itself focused its efforts on the agreed-upon response. The Act (or the wording of the Act) is now being reconsidered by lawmakers. The formation of this group gave CSOs a collectively stronger and more respected voice with the government.

Over the years, internal and external partnerships have grown, overcoming early challenges that included a lack of technical capacity, uneven power dynamics, mistrust from both sides, and tokenistic participation. Previously, some government and international partners had questioned the legitimacy of NGOs to provide real services.

By working together at the national level, the MOH and CSOs lend their vocal support to each other when needed. For example, the MOH is better placed to suggest most policy or process changes within the government. At the same time, CSOs are able to focus on advocacy and hold the government accountable in a way the MOH cannot, even if they wish to.

In addition to their partnership with the MOH, JASL also partners with other ministries and government entities, such as the Ministry of Education and the Planning Institute of Jamaica, an arm of the Ministry of Finance. JASL's international partners include the United States Agency for International Development (USAID), the United Nations, M·A·C AIDS Fund, Elton John AIDS Foundation, the Joint United Nations Programme on HIV/AIDS (UNAIDS), and the Global Fund.

JASL also maintains strong and strategic positioning with other various partners and serves on numerous local and regional advocacy committees, including the National Technical Working Group for Most-at-Risk Populations (MARPS), National HIV-related Discrimination Reporting and Redress System (NHRDRS), Caribbean Vulnerable Communities (CVC), Caribbean Sex Work Coalition, and the Jamaica Civil Society Forum (CSF). JASL is the only local NGO with a seat on the Pan-Caribbean Partnership on HIV and AIDS (PANCAP).
Internal capacity and sustainability

JASL has stressed the importance of building strong and long-lasting partnerships with the MOH and other partners, strategically investing in staff capacity building (including on proposal writing), and targeting non-traditional donors for resource mobilisation.

While JASL's base funding is from USAID and the Global Fund via the MOH, that funding has not been enough to address gaps along the entire HIV continuum, nor does it adequately finance some of the support services that are not considered part of a traditional treatment model. With the possibility that funding from the United States and the Global Fund may change in the future, JASL and other CSOs need to seek additional sources to diversify their funding streams. To do this, CSOs have to think big—beyond the usual cake sales and BBQ fundraisers that do not contribute enough money to fund larger projects much less ensure financial sustainability. With that in mind, JASL developed key strategies to build internal financial capacity and external partnerships to fill funding gaps to create longer-term sustainability for the organisation, their clients, and the national response as a whole.

To address overall financial sustainability and meet client needs not covered by base funding, JASL invested in human resources, staff training, and persistent creative fundraising.

JASL had already begun investing in human resources by hiring staff with the competencies, qualifications, experience, passion, and capacity to strengthen the organisation and training staff in skills to make them more technically competent. Yet, JASL found they began losing well-trained staff to international organisations and ministries that could provide better salaries.

In order to get the funding to hire and retain highly qualified staff, JASL hired a dedicated Grants Manager and Programme Development Manager, who proactively seek traditional and non-traditional funding and in-kind opportunities from internal organisations such as the Elton John Foundation and M·A·C AIDS Fund, as well as from local agencies. JASL recognised that a crucial component of proposal writing is the need for costed programs. This must consider attractive and competitive salaries that will result in low staff attrition and support organisational stability and maturity.

Building on strong relationships with other CSOs, the grants team also considers how to include CSO partners in larger grants in order to more efficiently and effectively deliver services without significantly increasing overhead. Smaller CSOs are often written into proposals as sub-recipients, even if they do not have the capacity to contribute to the proposal process themselves or are not registered with the government to receive funding, to ensure that resources for the national response are secured.

Through the strength of a relationship cultivated and nurtured over several decades, the MOH works with JASL to make the organisation as financially sustainable as possible. This includes the MOH (and donors) being willing to reallocate or postpone distribution of funds if JASL receives funding from a source with restricted funding or timetables overlap. A sustained grant stream is beneficial to both entities.

Lessons Learned and Recommendations

Financing

Holistic care and treatment services greatly increase client adherence to treatment and retention in care. While the true cost of a CSO’s response in delivering services is unknown or likely underestimated, it is undoubtedly high. Costing a CSO’s response can be a challenge for the government—particularly capturing the cost of HIV services as they become more integrated and community response and outreach become more expansive and institutionalised. Despite these challenges, it is important to have the best estimated cost in order to adequately budget and plan for service sustainability.
HIV Testing

Linkage into care remains a critical element in achieving the 90-90-90 goals. The peer-link concept implemented by JASL is valuable, but networks overlap, which means effort is sometimes duplicated. At the same time, people not in those networks remain hidden until they end up in hospitals with symptoms of AIDS. To successfully test the right people in order to reduce the gap on the first 90, continued collaboration and planning is important among CSOs and with other partners engaged in HIV testing and prevention services, particularly those targeting key populations through community interventions.

Treatment

Ongoing joint planning, monitoring, and follow-up with the MOH is important to ensure efficient collaboration with CSOs. This includes recognising that the MOH is the lead technical agency in defining, implementing, and monitoring standards of ART service delivery. Through this collaborative process, ART service delivery at the CSO levels will be aligned with national standards and CSOs will benefit from ongoing coaching, mentoring, and capacity building for their technical staff.

A coordinated, multidisciplinary team approach to treatment offers the best outcomes for clients. Therefore, in defining the treatment team, consideration has to be given not only to the clinical team, but also to technical staff who offer important support services: psychologists, nutritionists, social workers/counsellors, and others. Innovative strategies must be implemented to ensure the availability and competency of the team to adequately meet the needs of the client population. JASL did this by mobilising resources to offer attractive and competitive salaries that reduced staff attrition, and through close collaboration with the MOH that resulted in ongoing technical assistance and capacity building.

Providing case-by-case management of clients facilitates a better understanding of their needs and the development of a clearer management plan. Very few clients live within walking distance of the three JASL clinics: Of the 567 clients in treatment, about 30 live close enough to walk. Case-by-case management provides JASL staff with information that enhances the coordination of services in a way that accures maximum benefits for individual clients, such as improved adherence. At the same time, it allows JASL to serve their client community more efficiently, such as conducting one ARV pickup for several clients at the same time.

Care and Support

The ultimate aim of the programme is to empower clients to be independent. To do this, the multi-disciplinary approach must consider innovative support services that can assist a client in accepting their diagnosis, understanding the value of HIV treatment, and acknowledging the importance of disclosure and its impact on adherence. More importantly, there is a need to establish support systems that guard against discrimination in the workforce, training institutions, and healthcare settings. Boosting client confidence in these critical areas empowers them to be independent. This is important for their access to services, adherence, and other parameters that impact treatment outcomes. In addition, having a “one-stop shop” approach makes it easier for clients, especially key and vulnerable populations, to get the services and support they need to be healthy and feel empowered.

Monitoring and Evaluation

Monitoring and evaluation is important to understand the impact of a CSO’s response on their client population. Systems must be established to collect and analyse data that will provide insights into programme performance. Importantly, the data will provide evidence to support their work and the needs of their communities. Similarly, CSOs must take into consideration the data needs of the MOH to adequately monitor the national response. Therefore, the data collected should be robust (high-quality, accurate, and timely) and support adequate programmatic decision-making at the levels of the CSO and the MOH. Getting good data is a challenge, particularly if people in the field do not understand its importance. Ongoing capacity building of M&E staff is important, and a bottom-up approach to using data for decision-making can be a successful buy-in strategy at all levels. Close collaboration with the Ministry of Health is important to understand a CSO’s data in the context of national data, their role in the overall response, and their impact on delivering services. To this end, mechanisms at the national level, such as the Monitoring and Evaluation Reference Group (of which JASL is a member), are good examples of effective collaboration.
It is through M&E that governments are able to talk with their external partners, and it is through M&E that we are even able to talk to your governments. If we are not monitoring what we are doing, we don’t have the information or evidence to show to get things going, and it is going to be difficult.”
- Kandasi Levermore, JASL Executive Director

Sustainability

The sustainability of a response is always a challenge. In the donor funding context, it is recommended sustainability be considered during the design phase of projects. Programmes designed with the involvement and buy-in of key stakeholders, including targeted communities, have a greater potential for sustainability and continuity. Partnerships are crucial for sustainability, and successful partnerships must entail a mutual understanding of roles. In addition, all partners must feel that they have meaningful involvement in the process and response. The partnership between the MOH and a CSO strengthens everyone’s voices. It is important to find commonalities, recognise unique strengths, and leverage these for the benefit of the partnership and clients. Close collaboration will reduce duplication of efforts and accrue efficiencies that will enhance services and contribute to sustainability. Partnership also means active and transparent engagement with communities and clients. Through such a partnership, communities see the value in the CSO’s work and will advocate for and support the organisation and its mission.

For additional information, visit the PANCAP website:
www.pancap.org
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