Developing the draft framework to integrate Positive Health Dignity and Prevention (PHDP) in the National Response – A Review of PHDP initiatives

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ACRONYMS

EEHR	Enabling Environment and Human Rights
GIPA	Greater Involvement of People Living with HIV
GCBP	GIPA Capacity Building Programme
GNP+	Global Network of Seropositives
HIV	Human Immunodeficiency Virus
HPP	Health Policy Project
JABCHA	Jamaica Business Council of HIV/AIDS
JN+	Jamaica Network of Seropositives
MOU	Memorandum of Understanding
MOH	Ministry of Health
NERHA	North East Regional Health Authority
NFPB	Natonal Family Planning Board
NHDRRS	National HIV-Related Discrimination Report and Redress System
NHP	National HIV/STI Programme
PEPFAR	President's Emergency Plan for AIDS Relief
PHDP	Positive Health, Dignity and Prevention
PLHIV	Persons Living with HIV
RHA	Regional Health Authority
SERHA	South East Regional Health Authority
SRHA	Southern Regional Health Authority
UNAIDS	Joint United Nations Program on HIV/AIDS
UNGASS	United Nations General Assembly Special Session
USAID	United States Agency for International Development
WRHA	Western Regional Health Authority

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Introduction

The process of developing the draft framework to mainstream Positive Health Dignity and Prevention (PHDP) into the National HIV Policy Response involved two- steps. The first step in the process was to conduct a review of the PHDP initiatives and programmes. This included a desk review and consultations through In-Depth Interviews (IDIs) and Focus Group Discussions with implementers, key partners in the response and beneficiaries of the programme. The second step was to develop the framework as guided by the findings of the review and partner consultations.

Two documents have been produced. One document outlines the findings of the desk review and the interviews and the focus group discussions. For the first step the documents reviewed included, annual reports, project reports, Manuals, GARPR/UNAIDS Report, Technical Consultation Report, International reports.

The second document is the draft framework informed by the findings of the review.

Desk Review

Background and structure of PHDP initiatives

The Greater Involvement of People Living with HIV (GIPA) Unit, situated in the Enabling Environment and Human Rights (EEHR) Unit at the National Family Planning Board has coordinated and implemented the Positive Health, Dignity and Prevention capacity building initiatives in the Jamaica National HIV Response. Greater Involvement of People Living with HIV (GIPA) is a principle that aims to realise the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making process that affect their lives (UNAIDS 2007). The 2006 Political Declaration on HIV/AIDS

unanimously adopted by 192 member states representative of all continents advocated for the greater involvement of people living with HIV.

The benefits of GIPA are wide ranging, at the individual level; involvement can improve self-esteem and boost morale, decrease isolation and depression, and improve health through access to better information about care and prevention. Within organisations, the participation of people living with HIV can change perceptions, as well as provide valuable experience and knowledge. At the community and social levels, public involvement of people living with HIV can break down fear and prejudice by showing the faces of people living with HIV and demonstrating that they are productive members of, and contributors to, society (UNAIDS, 2007).

The National HIV/STI Programme established a desk in 2008 to support the Greater Involvement of People Living with HIV and AIDS (GIPA) and their integration into the national HIV/AIDS response (UNGASS, 2010). A person living with HIV was hired as the GIPA Coordinator to manage the process under the Enabling Environment and Human Rights (EEHR) Component.

The core functions of the GIPA office include; administration, implementation and coordination of the GIPA Capacity Building Programme. The sub-project operates on four main levels:

1. To expand the participation of PLHIV in existing interventions e.g. involvement in the workplace programme by delivering sessions on Basic HIV/AIDS Facts, GIPA and the National HIV Related Discrimination Report and Redress System (NHDRRS
2. To participate on special committees and panels representing the people living with HIV/AIDS (PLHIV) community
3. To coordinate the selection, sensitization and training of 20 PLHIV per year for their greater involvement in risk reduction and HIV-related discrimination reduction interventions (Capacity Building Programme)
4. To assist the Jamaican Network of Sero-positives (JN+) and the National HIV Related Discrimination Reporting and Redress System (NHDRRS) through active participation in selected interventions.

By the end of 2009, the PLHIV community was represented on interview panels for the selection of consultants and officers; and on special committees such as

the Interim Investigation Team for the National HIV-Related Discrimination Reporting and Redress System (UNGASS, 2010).

The PHDP global policy framework initiated in 2011 by Global Network of People Living with HIV(GNP+) and UNAIDS provides a holistic framework for people living with HIV(PLHIV) to manage their health, advocate for high quality HIV services, and prevent onward HIV transmission. The PHDP policy framework was an evolution from a mere focus on positive prevention. Positive prevention strategy was embraced by the National response in 2008.

Positive Health, Dignity and Prevention (PHDP) highlight the importance of placing people living with HIV at the centre of managing their health and well-being (GAA, 2012). It is a model which links HIV treatment, prevention, and support and care issues within a human rights framework. Positive Health, Dignity and Prevention emphasises the importance of addressing prevention, and treatment simultaneously and holistically. Instead of a singular focus of preventing HIV transmission from people who test HIV positive, the Positive Health, Dignity and Prevention model promotes holistic health and wellness, including human rights, legal protection and a policy environment free of stigma and discrimination.

Concept to action: GIPA/PHDP Capacity Building Programme

The main strategy undertaken by the GIPA unit in operationalizing the PHDP principles has been building the capacity of PLHIV. This approach seeks to raise the level of awareness and improve the skills for effective and meaningful involvement and community leadership in the response. This approach has been utilised for the past nine (9) years informed by the GIPA conceptual framework.

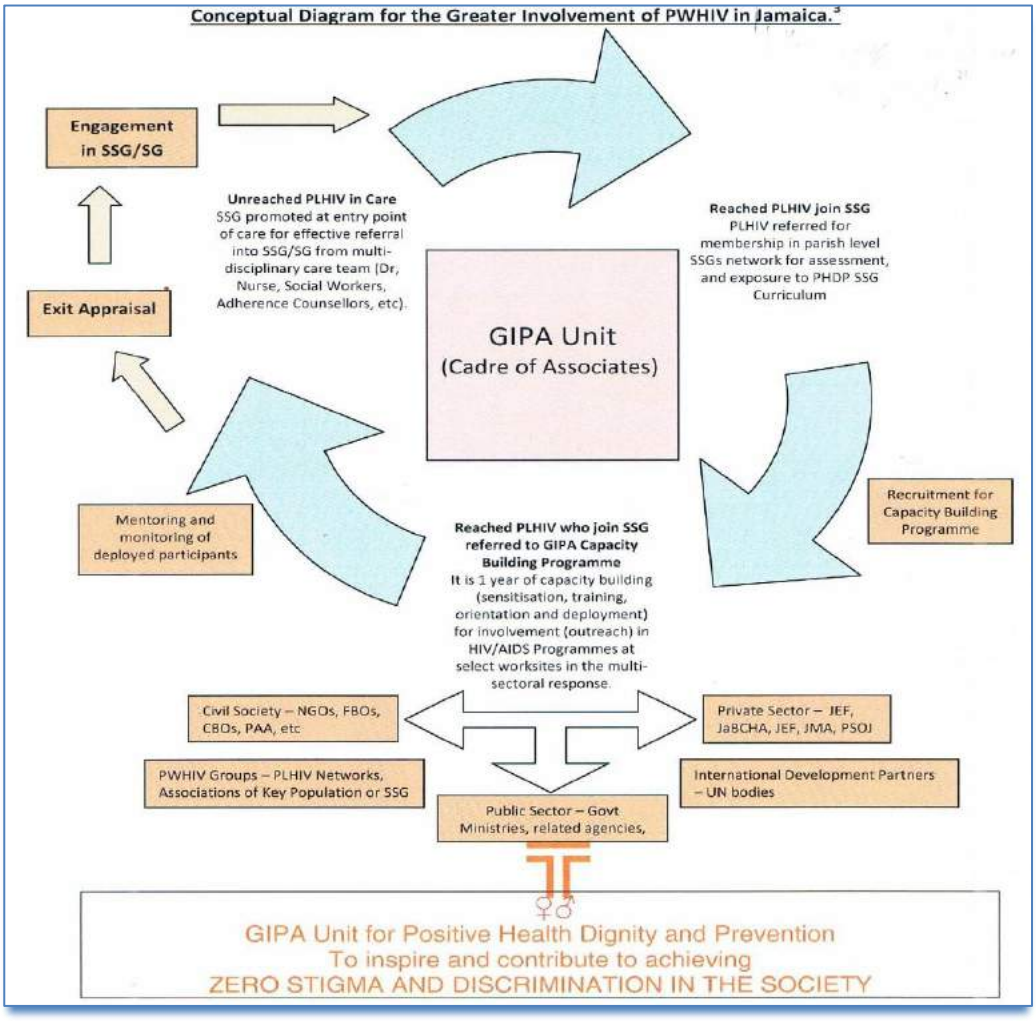

Figure 1: Conceptual framework for GIPA in Jamaica (*Source: Annual Report, GIPA Unit, 2014).*

The priorities of the GIPA Capacity Building Programme include;

- Capacity Building Programme
- Development of the Positive Health, Dignity and Prevention (PHDP) Curriculum
- PHDP with Key Population (MSM) Initiative and
- Representation of PLHIV Community on decision making bodies (GIPA Annual Report, 2014)

The Positive Health, Dignity and Prevention Curriculum

The Jamaican Ministry of Health's National HIV/STI Program (NHP-GIPA Unit), the Jamaica Network of Seropositives (JN+) with support from and the USAID; and the President's Emergency Plan for AIDS Relief (PEPFAR) funded Health Policy Project now Health Policy Plus, Plus created a capacity-building curriculum led by people living with HIV (UNGASS, 2010). The curriculum is based on the Positive Health, Dignity and Prevention (PHDP) strategy's operational guidelines as developed by the Global Network of PLWHA (2013).

The curriculum aims to implement and advocate for Positive Health, Dignity, and Prevention and promote community leadership at the level, by training leaders to advocate and educate communities to reduce HIV-related stigma and discrimination, including Gender-based violence. The curriculum is intended to enhance the understanding, and skills of communities living with HIV in PHDP in Jamaica.. The original curriculum consisted of fourteen (14) modules, and topics include; HIV basics, framework for PHDP, stigma and discrimination, sexual and reproductive rights, gender, sexuality, sexual diversity, disclosure issues, positive health and health promotion, loss and grief, continuum of care, advocacy, combination prevention, and self -care. This curriculum was revised in 2015 under the aegis of the above listed partners with additional module, Module 15: Treatment Literacy.

The manual was updated in 2017 is now comprised of 17 modules based on new evidence and to align with the Ministry of Health's recent adaptation of Test and Start and better addresses the needs of the key populations. The manual covers a range of participatory learning modules including the three new modules: HIV and Human Rights, Sexual Health and Resilient Leadership.

A companion manual was developed focusing on HIV Basics, Treatment Literacy, Stigma and Discrimination and Disclosure to assist in the transfer of skills to community facilitators (PLHIV participants) and other suitable health care providers who will actively use the PHDP curriculum.

The PHDP curriculum was conceptualized to be implemented through five phases, they are as follows:

Phase1: Recruitment and Orientation: June - December 2010

The first Cohort of People Living with HIV (PLHIVs) were recruited and participated in the development of the curriculum with other key stakeholders in 2010. The criteria for selection were as follows:

- Adults living with HIV from Treatment sites across Jamaica referred by Contact Investigator, Medical Officers, Social Workers, Nurses, and Adherence Counsellors
- Possess a minimum of One (1) subject at the Secondary Education Level

The GIPA Unit was tasked with screening the potential candidates through an interview process. The first cohort comprised of twenty (20) persons.

Phase 2: PHDP Curriculum Development: July – December 2013

In 2011, a second cohort of people living with HIV was engaged and the curriculum was tested for efficacy and ease of use with a view to improve group literacy and participation in the rollout of each module. Both cohorts combined consisted of fifty-four (54) persons being engaged in the GIPA Capacity Building Programme.

Two other cohorts of people living with HIV were trained with the then completed curriculum. Cohort 3 was trained between **June – August 2015** and Cohort 4 between **March- August 2016**

Phase 3: Skills Transfer

On completion of the training in the PHDP curriculum participants were then trained in communication skills to improve their ability to share PHDP related insights, knowledge, information and experiences among select audiences. The audiences included: Peer/PLHIV, HIV service providers such as, Case Managers, Social Workers, Adherence Counsellors, and Pharmacists. The training was conducted as stated: Cohort 1, October 4—6, 2012, Cohort 2, November 14-16, 2013, Cohort 3, April 30 – May 1, 2015 & May 4- 5, 2015 and Cohort 4, July 22-24, 2016.

Phase 4: Interim Assessment

The objective of the interim assessment is to determine how the participants benefitted from the knowledge exchange and skills transfer aspect of the project. There was significant delay in conducting this phase owing to limited funds. The delayed assessment was conducted in March 2015 after all four (4) cohorts were trained and did not precede the deployment process as conceptualized.

Phase 5: Deployment

This phase commenced in 2014. Selected graduates from cohorts 2-4 were deployed in various worksites including private sector and health facilities prior to the assessment and included the orientation and deployment of Community Facilitators to worksite as well as the mentoring and tracking of their progress.

Implementing the PHDP curriculum

The PHDP curriculum is ideally delivered through six (6) months to one (1) year of sensitisation and training. Each cohort in this programme participate as a leadership group to build in-depth knowledge about HIV; distil root causes of stigma, discrimination and gender-based violence; and develop skills and confidence to be able to strengthen their leadership in the space were they are active (UNGASS, 2010). The modules are facilitated during a series of workshops at varying locations throughout the island. Methods of facilitation include presentations, interactive exercises and group discussions.

After the completion of workshops facilitating the introduction of all modules in the PHDP curriculum, participants attend a four (4) day Skills Transfer Workshop. Participants are required to give a presentation on a risk behaviour of their choice, with the aim of applying the trans-theoretical model (TTM) or the Stages of Change Model to describe the potential for change process. This will enable them to be better able to assist their peer as they work through behaviours to be changed. Each participant is assessed and assigned a score at the end of the skills transfer capacity building activity.

According to the GIPA Unit over the period 2011 - 2016, one hundred and five (105) PLHIV have benefitted from active involvement in the GIPA/PHDP Capacity Building Project (GCP). Of the one hundred and five (105), only seventy-five (75) have successfully completed the programme that includes participation in all didactic workshops focusing on all modules of the PHDP curriculum and the assessment component of the programme.

# Participant who completed GCP by region			
Region	**Male**	**Female**	**Total**
South-Eastern (SE)	19	14	33
Southern (S)	5	4	9
North-Eastern (NE)	1	16	17
Western (W)	5	11	16
Total	**30**	**45**	**75**

Table I: Number of participants in GIPA capacity Building by regions

Deployment of graduates/community facilitators

Participants in all four (4) cohorts who receive high scores based on their presentation and overall performance in both PHDP workshop and Skills Transfer Training are offered deployment opportunities in one of the following sectors: Civil Society Organisation, Private Sector and Government Agencies. Individual may also be deployed to work within the PLHIV community, such as Support Groups. These opportunities are usually short term and the individual is sometimes provided with a stipend. They are now designated Community Facilitators and mentorship and support continues to be provided by the GIPA Coordinator. They are assigned to health facilities within the Regional Health Authorities as Community Facilitator, for a period of six to nine months. The Community Facilitator works alongside healthcare providers such as a psychologist to reach PLHIVs experiencing trauma, a Social worker to develop Support Groups for PLHIV to help with adherence, and with a BCC interventionist

to reach key affected populations. This initiative was supported by Health Policy Plus, (the predecessor to HP+) Jamaica.

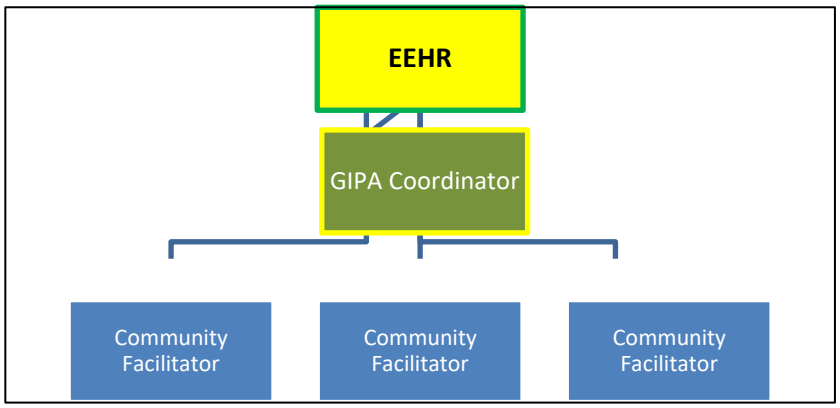

Figure 2: The community facilitator in the EEHR/ GIPA Unit Administrative Hierarchy

The Community Facilitators are required to conduct at least two sessions per week, consisting of a minimum of five (5) participants. Reports related to their activities must be submitted fortnightly.

Partners in the response such as, Ministry of Health, SERHA, JASL and JN+ have used specific modules from the curriculum to train members of the HIV service provider teams based on the needs of the organization. The most commonly used modules include; Disclosure, Treatment Literacy, HIV Basic Facts, and Stigma and Discrimination.

The GIPA End of Project Report for USAID, October 2015-2016 indicated the following as overall achievement of the capacity building programme:

- Positioning of Community Facilitators to improve visibility of Community Representation – Nationally at service delivery levels, Regionally through Caribbean Regional Network of Seropositives (CRN+), and Internationally through UNAIDS
- Community mobilisation and awareness building on PHDP.
- Work of CFs are best practices – Patient Satisfaction Survey (PSS), Training of Community Leaders in Self Support Group Model,

Offering of coordinated Peer Support (facility-based, community-based, and home-based) to PLHIV and Key Populations, etc

- Finalisation and publishing of the PHDP Curriculum through HP+ support
- Development of an Instructional Guide, developing three additional modules, namely Sexual Health, Human Rights, Resilient Leadership, and customising the curriculum for future cohorts.
- 16 participants graduated from Cohort 4 with certificates of completion
- 46 participants from Cohort 1 – 3 also received their Certificates of Completion.
- 15 community leaders who assisted in the development of the PHDP Curriculum were also given Certificates of Appreciation
- Sixty two (62) graduates of the GCBP – PHDP Course were inducted into JN+'s membership. This was being done for the first time and was a request of the GIPA Core Group.
- A PHDP Newsletter called Jamaica Lifeline was developed and also launched at the graduation ceremony.

Partner consultations: Interviews & Focus Group Discussions Findings

Partner consultation involved engaging the coordinators from GIPA-EEHR, the implementing partners, trainers and beneficiaries in key informant interviews and focus group discussions. Interviews were conducted with stakeholders from the Ministry of Health, GIPA/EEHR unit, National Family Planning Board, Civil Society Organizations and the Jamaican Network of sero-positives and the Regional Health Authorities (RHAs). Focus group discussions were conducted with trainers and beneficiaries.

Achievements

- The stakeholders recognized that the PHDP capacity building programme has value especially for the PLHIV community. The 2015 version of the

PHDP curriculum in particular was commended as an excellent tool suitable for addressing the critical issues relating to the population at the individual and health service delivery levels.

- Focus group participants who were, trainers, graduates and community facilitators identified specific modules which were especially beneficial to them. These included the models on: disclosure, advocacy, self- care, treatment literacy, stigma and discrimination, grief and loss, and human rights.
- All of the participants reported that they had derived benefits from the training which included: a reduction or lack of fear surrounding disclosure, increase appreciation of how to effect change in the minds of people as well as personal growth and development.
- Some community facilitators reported that they have become more self-aware, and confident and also more sociable with peers and family members. They have also developed group facilitation and other communication skills. The contribution of the community facilitator towards other PLHIV reaching viral suppression was also acknowledged.
- Some of the graduates of cohort 1 and cohort 2 are now trainers and facilitators in the delivery of the curriculum to cohorts 3 & 4 as well as other persons within and outside the health sector.
- Although the PHDP curriculum was designed for and by community leaders living with HIV, partners in the response reported that selected modules of the curriculum were being used in the training of members of the health service delivery team as well as persons in other sectors.
- Partners conducting training using select modules from PHDP curriculum
    - The Ministry of Health has trained 166 members of the health team in treatment literacy this include BCC teams and Community interventionist in all four regional authorities.
    - South East Regional Health Authority also trained the entire cadre of community interventionist in treatment Literacy.

- JASL trained 10 care team members in both Kingston and St. James using the treatment literacy, disclosure and self-care and other relevant modules.
- JN+ has also engaged members of the PLHIV community around selected modules i.e. treatment literacy, disclosure, Stigma & Discrimination, and Basic HIV facts. 97 PLHIV were sensitized in 2015 and 72 have since been sensitized from January to September 2017.
- The GIPA unit has exposed 150 MSM in a series of nine (9) workshops conducted in the four (4) health regions to selected modules of the curriculum. The modules used are as follows: HIV basic facts, Human Rights and Dignity and Sexual Diversity.

Opportunities

- Key partners from the PLHIV community and the national programme partners have recognized the value of PHDP and its potential role in contributing to 90 – 90 -90 targets of supporting clients' retention in care and their achieving viral suppression.
- There seem to be consensus among the participants that while there have been deliberate and strategic efforts to develop and deliver programs which focus on positive health and prevention for PLHIV, there have not been similar efforts relating to promoting and supporting the dignity of the individual living with HIV.
- While acknowledging some gains, most of the participants felt that the strategies which focus on 'affirming the dignity of the individual PLHIV' are not as evident. One participant suggested that the "the value and worth of the individual seem to change once they are diagnosed as positive". Another participant highlighted the recent proposal in parliament to criminalize willful transmission as evidence that 'the dignity piece is missing'. The need for the more deliberate promotion of dignity of the individual was emphasised.

- Lack of clarity relating to the role of the community facilitator in the multidisciplinary care team in the Regional Health Authorities. There is space to remedy this shortcoming going forward with future cohorts.

Challenges in operationalizing PHDP

The following challenges relating to the PHDP capacity building program also emerged from the conversations and discussions with the stakeholders

- Insufficient collaboration among key partners in the PLHIV community and also with key partners in the national response. Consequently the programme has not been owned by the PLHIV community and the leaders in the national response are not sufficiently aware of the programme and the potential benefits. The ad hoc engagement of partners has presented several hurdles for its effective implementation.
- Absence of a framework that guide the engagement of community facilitators and other PHDP graduates, as well as other community actors in the health care delivery system and in the wider response
- Absence of a monitoring and evaluation framework for the PHDP capacity building programme to monitor the Community Facilitator and other graduates and how their activities contribute to specific national programme indicators.
- Absence of a coordinated mechanism for the recruitment of participants in the PHDP programme; recruitment and referrals of participants was done primarily by contact investigators; this should be expanded to include other members of the multidisciplinary care tea
- Cost for programme implementation: residential workshops to train participants using the entire curriculum is costly and time consuming.

There was no budgetary allocation for salary/stipend to community facilitators hence deployment of graduates was limited

- The purpose of the programme and the expectations were not clearly articulated to participants. Therefore some had the perception that employment would be provided and that all participants will be deployed.

Consulting the partners: - Recommendations for the way forward

The stakeholders provided suggestions which can be included in the framework. These were related to:

i) Structure and coordination of the PHDP programme

- Creation of a coordinating mechanism to manage and implement the PHDP programme. The establishment of structures that facilitate ownership by the community and collaboration with key partners should be integral in the mechanism.
- Mobilize and strengthen the leadership of the community networks so that they are able to provide support to technical leaders responsible for the National response and political leaders.
- Reposition PHDP within the national response in relation to the objectives of the test and start programmatic goals and its contribution to the achievement of the 90-90-90 targets, that is, increasing HIV testing uptake and yield, treatment initiation and viral load suppression.
- Develop a monitoring and evaluation framework for the PHDP programme.
- Incorporate the lessons learned from the pilot community facilitator's deployment strategy which is currently being implemented coordinated by JN+ and the steering committee. This strategy is organized around the chronic care model and is being used "to examine how multiple structural arrangements intersect to influence health care access, health status and health outcomes". The lessons learn may be applied to address some of the challenges relating to recruitment, deployment, mentoring and

monitoring the graduates of the capacity building programme, including the community facilitator.

ii) Capacity building and the curriculum

- Train healthcare providers in all regions in PHDP using the approach of trained Community Facilitator alongside a clinician trainer/Facilitator. This training will include the multidisciplinary care team within treatment sites and the BCC prevention outreach teams including peer navigators. This will bolster the synergy among the adherence counsellor, the community facilitator and the peer navigator to improve client adherence

- Organization of a post PHDP training programme that seeks to address the usefulness of the manual and address gaps overtime. A refreshers course for those cohorts who were not trained in the added modules should also be organized.

- The PHDP manual should be used at the policy making level to sensitize critical stakeholders and decision makers on the issues and hence these players will be better informed during the policy development process.

- Develop educational materials, e.g. posters, videos from select modules to further sensitize PLHIV and other members of the health team on specific topics e.g., treatment literacy, self-care, grief and loss, stigma and discrimination, and human rights.

iii) Integrating PHDP outside the health sector

- Selected modules of the PHDP curriculum should be integrated into the school curriculum at Grades 7 - 9. The Health and Family Education (HFLE) curriculum provides an opportunity for the integration.
- The Ministry of Labour as the agency responsible for Occupational Safety and Health (OSH) policy and the workplaces should be trained in PHDP particularly the unit responsible for the voluntary compliance program in workplaces. The main objective is to advance the principles relating to the

dignity of the individual. The PSOJ and other Business sector organizations are also recognized as a partner in addressing the workplace

- Agencies responsible for Child Care and State care of children should also be trained in PHDP, more specifically, the following modules: HIV Basics, Stigma & Discrimination, Sexual and Reproductive Rights, and Sexuality.
- Make provision in framework for the institutionalization of training across the various agencies outside of the health sector.

The findings from the desk review and the engagement with stakeholders indicate that the PHDP principles as embedded in the PHDP curriculum and the capacity building programme are the base of a viable strategy. This strategy if effectively implemented will not only increase the skills and empower the individual participant but also has the potential for a multiplier effect within the national response. However to achieve optimal results the implementation has to be efficiently coordinated with key stakeholders and include a strong monitoring and evaluation component. There is also need for a framework which will guide the mainstreaming of this strategy into the national response.

List of documents for desk review

A Process Evaluation of the Capacity Building Programme as administered by the GIPA Unit of the National HIV/STI Programme, Nicole Simpson, March, 2015
A Compendium of New Approaches Created and Rolled-out by beneficiaries of the GIPA Capacity Building Programme, including Community Facilitators during their deployment at the Regional Health Authorities (RHA)
Annual GIPA Unit report s 2010
Annual GIPA report 2011
Annual GIPA report 2012
Annual GIPA report 2013
Community Facilitators Orientation Guide, 12/11/2015
Concept Note – Jamaica Network of Seropositives (JN+)
End of Project Initiative – PHDP with Key Populations - Targeting MSM, July – December 2014
End of Project report USAID Report 2015- 2016
Evaluation report, GIPA Capacity Building Program, Communication Skills Transfer Workshop, EEHR Component/National Family Planning Board: Dr. Sharlene Jarrett
Global AIDS Progress Report 2014 (GIPA Section)
Greater Involvement of People Living with HIV (GIPA), 2015
Positive Health, Dignity and Prevention Operational Guidelines, UNAIDS, June 2013
Positive Health, Dignity and Prevention Technical Consultation Report, Global Network of People Living with HIV (GNP) April 27 – 28, 2009
Positive Health, Dignity and Prevention, Training Modules for Promoting Leadership Among Persons Living with HIV, Developed by PLHIV in Jamaica, 2015
Update on the Positive Health, Dignity and Prevention Efforts of the GIPA Unit, EEHR, NFPB, 2017.

List for key informant interviews:

Names		Organization	Email
1	Devon Gabourel	NFPB	dabourel@jnfpb.org
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**The lists of participants in the Focus Group discussions for graduates, community facilitators and trainers have not been included owing to need to maintain confidentiality.