GHAIN SUPPORT TO HIV CARE & SUPPORT IN NIGERIA

END OF PROJECT MONOGRAPH

GHAIN
Global HIV/AIDS Initiative Nigeria

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FOREWORD

Dr. Otto Chabikuli
Chief of Party, GHAIN

The Global HIV/AIDS Initiative Nigeria (GHAIN) comes to an end, it is an opportune time to reflect on its achievements and draw lessons from challenges encountered in order to inform future HIV programming in Nigeria and similar context. The GHAIN program was designed to support the Government of Nigeria's response to HIV/AIDS, particularly in scaling up proven HIV prevention, treatment and care and related interventions. The comprehensive nature of GHAIN's scope and ability to leverage different sources of funding for greater impact made it a very complex program. However, a genuine partnership made GHAIN implementation successful.

Working in close collaboration with stakeholders at the federal, state, local government and community level, GHAIN managed in a relatively short period of time to contribute to increased access to ART and related services in Nigeria. The project's support was channeled mainly through public health facilities and communities in a manner that empowered staff in these facilities and communities to deliver HIV and related services by themselves. The purpose of this monograph is to share the experience of GHAIN implementation with policy makers, program managers, public health practitioners and health care workers.

The achievements and lessons described stand in testimony of the invaluable work of staff in government ministries, GHAIN-supported public health facilities, communities and support groups of people living with HIV (PLHIV) who worked tirelessly to overcome numerous challenges to make HIV services more accessible. None of these achievements would be possible without the United States's PEPFAR funding of the project through the United States Agency for International Development (USAID).

The manuscript benefited tremendously from reviews by experts from the WHO Nigeria office, for which we are grateful.

It is hoped that GHAIN has contributed to lay a solid foundation for a future evidence-based, efficient, sustainable and government owned HIV response in Nigeria.

Otto Nzapfurundi Chabikuli
Chief of Party, GHAIN

LIST OF ACRONYMS

AIDS	Acquired immune deficiency syndrome
ANC	Antenatal care
ART	Antiretroviral therapy
ARV	Antiretroviral
ATM	AIDS, tuberculosis and malaria
BMI	Body Mass Index
CBO	Community-based organization
CD4	Clusters of differentiation 4
CEDPA	Centre for Development and Population Activities
CHBC	Community home-based care
COP	Country Operating Plan
CoP	Chief of Party
CTX	Cotrimoxazole prophylaxis
CV	Community volunteer
DBS	Dried blood spots
DCT	Data collection tools
DHIS	District Health Information System
DOTS	Direct Observed Treatment Short Course
FBO	Faith-based organization
FCT	Federal Capital Territory
FHI	Family Health International (now FHI 360)
FMOH	Federal Ministry of Health
FP	Family planning
GHAIN	Global HIV/AIDS Initiative Nigeria
GIS	Geographic Information System
GLRA	German Leprosy and Tuberculosis Relief Association
GON	Government of Nigeria
H2H	Heart-to-Heart
HAD-FMOH	HIV/AIDS Division of the Federal Ministry of Health
HAST	HIV/AIDS, sexual and reproductive health, and tuberculosis; the LGA HAST model of service delivery
HBC	Home based care
HCW	Health care worker
HEAP	HIV/AIDS Emergency Action Plan
HIV	Human immunodeficiency virus
HMIS	Health Management Information System
HSS	Health systems strengthening
HTC	HIV testing and counseling
IA	Implementing agency

IMNCH	Integrated maternal, neonatal, and child health
IP	Implementing partner
IPAC	Infection prevention and control
LAMIS	Lafiya Health Management Information System
LGA	Local Government Area
LTFU	Lost to follow up
LMIS	Logistics management information system
M&E	Monitoring and evaluation
MARPs	Most at-risk populations
MCH	Maternal and child health
MIP	Malaria in pregnancy
MIPA	Meaningful involvement of people with HIV/AIDS
NACA	National Agency for the Control of AIDS
NASCP	National AIDS and STDs Control Program (now HIV/AIDS Division of the FMOH)
NEPWHAN	Network of People Living with HIV/AIDS in Nigeria
NGO	Non-governmental organization
NHMIS	National Health Management Information System
NPC	National Population Commission
OI	Opportunistic infection
OVC	Orphans and vulnerable children
PABA	People affected by AIDS
PEPFAR	President's Emergency Plan for AIDS Relief
PHC	Primary health care
PLHIV	People living with HIV
PMTCT	Prevention of Mother-to-Child Transmission
PwP	Prevention with Positives
RH	Reproductive health
RUTF	Ready-to-use therapeutic food
SACA	State Agency for the Control of AIDS; State Action Committee for the Control of AIDS
SDP	Service delivery point
SMOH	State Ministry of Health
SOPs	Standard operating procedures
SRH	Sexual and reproductive health
STI	Sexually transmissible infection
TA	Technical assistance
TB	Tuberculosis
TWG	Technical working group
UNAIDS	Joint United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	United States Agency for International Development
USG	United States Government
VCT	Voluntary counseling and testing

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INTRODUCTION

Thirty years into one of the worst pandemics in recorded history, HIV continues to rank high on the list of the most important challenges facing the world today (Sten Hermund et al, 2009). Global mobilization to stem the tide of HIV has also been phenomenal in the last few decades. As a result, access to antiretroviral treatment (ART) has substantially increased the chances of survival for patients. An increasing number of people living with HIV/AIDS (PLHIV) now have the possibility of a near normal life expectancy if they adhere to treatment regimens. Although the number of people accessing ART has increased significantly in recent years, only a third of the 15 million people in need of HIV treatment are accessing it. Worse still, for every two people accessing treatment, there are five new infections (UNAIDS, 2010).

The high burden of morbidity and mortality due to HIV/AIDS, particularly in poor nations, underscores the need for adequate care and support programs to improve the quality of PLHIV lives. It is critical to ensure programs have a comprehensive integrated approach within a well-managed care continuum to mitigate the effects of the HIV/AIDS epidemic.

In response to this huge challenge, the Federal Government of Nigeria (GoN) through the HIV/AIDS Emergency Action Plan (HEAP-2001-2004) provided the first guide to multi-sectoral response to HIV/AIDS in Nigeria. In addition, the 2005 declaration of commitment by all HIV/AIDS stakeholders in Nigeria and the National Strategic Framework (NACA, 2005) paved the way for increased funding and technical support to the national response.

The Global HIV/AIDS Initiative Nigeria (GHAIN) Project was awarded by USAID in December 2004 under the Presidential Emergency Plan for AIDS Relief (PEPFAR). It is one of the largest comprehensive HIV/AIDS project ever implemented in a single country through USAID to contribute to achieving USAID's intermediate results (increased demand, increased access and strengthened enabling environment).

At the beginning of the project, Home Based Care (HBC) programs existed, building on a fairly strong community structure. However, there was limited geographic distribution and integration of HIVAIDS clinical or psychological care, with no common definition of palliative care and a lack of national guidelines/strategic plan or standard training of volunteers and professionals

Providing HIV/AIDS care to people living with HIV/AIDS and their families require a broad range of services that include not only clinical care (diagnosis and treatment) but also supportive services that address nutritional, psychosocial and income generating needs and strengthening prevention among HIV positive individuals whenever opportunities arise. Most PLHIV do not necessarily require hospital care and may just benefit from services within their homes and community.

This monograph aims to describe how the GHAIN project supported care and support activities in Nigeria, major achievements and lessons learnt from a 7 year experience (2004 to 2011)

GHAIN'S CARE AND SUPPORT STRATEGY

Although Palliative care was traditionally associated with terminal or end-of-life care(FMOH, 2006), the PEPFAR guidelines took a broader view that encompasses care provided from the time that HIV infection is diagnosed and throughout the continuum of HIV infection. It focused on the patient and family, promoting prevention, treatment of pain and infections, symptoms and suffering from the onset of HIV diagnosis through death and bereavement.

The following were strategic areas of focus:

1. To expand access to comprehensive clinical, psychological, spiritual, and social service delivery in home, community and facility based care
2. To increase demand for services through community mobilization and involvement of HIV infected persons within programs to reduce stigma and discrimination at the individual and community level
3. To support adequate coordination and program referral/linkages between community and facility based services in order to provide clients and families with an accessible continuum of comprehensive prevention, treatment, care and support services
4. Collaborate with GoN/Ministry of Health (MOH) officials to develop national policy (strategic framework) for palliative care under the auspices of the national palliative care technical working group. The framework should include: the basic set of palliative care services, training standards, and formulary

USAID allocated care and support responsibility in GHAIN to two consortium partners. FHI was responsible for care and support services within health facilities while Centre for Development and Population Activities (CEDPA) provided complimentary services in the community and wrap around services. It was envisaged that facility based and community based services will be linked through referrals. Services provided in the facilities included: treatment and prevention of opportunistic infections (OIs), pain and other symptom management, basic nursing care, psychosocial support, adherence counselling and support including defaulter tracking, clinical nutritional assessment/counselling, food demonstrations and support, clinic based end of life care and referral linkage to wrap around services.

Care and support services in GHAIN were implemented in collaboration with GoN at all levels. At federal level, GHAIN participated in all Technical Working Group (TWG) meetings and guidelines development and reviews.

At State and Local Government Area (LGA) level, GHAIN conducted advocacy and mobilisation of relevant stakeholders, initiated partnership with Community Based Organizations (CBOs)/Faith Based Organizations (FBOs). At facility and SDP level, GHAIN supported limited infrastructure upgrade and built capacity of health care workers & care givers, as well as provision of basic care kits and other supplies, and established/ strengthened support groups.

FHI expanded its palliative care services for PLHIV and Persons Affected by HIV/AIDS (PABAs) to some selected communities in 2009.

GHAIN provided care and support services to PLHIV and PABA in line with the Nigerian National Guidelines aimed at:

1. Early identification of HIV- infected persons, linkage, and retention in care
2. Reduction in HIV-related morbidity and mortality
3. Improved quality of life
4. Reduction in transmission of HIV infection from HIV-infected to uninfected persons

Building on the success of the HIV/AIDS, SRH and Tuberculosis (HAST) mode of integrated services piloted in two LGAs, community care and support for PLHIV was implemented in 14 LGAs covering eight states along with the OVC program.

The key components of the HAST model include a strong involvement and participation of stakeholders at state, LGA and community levels to ensure ownership and continuity; partnerships and linkages across board to provide access to comprehensive care and support services within a continuum; strengthening the local governance and coordinating systems; strengthening of data recording and reporting; building capacity of service providers/care givers, PLHIV and PABA for meaningful involvement and participation.

GHAIN focused on ensuring good physical, social and mental wellbeing of PLHIV and PABA through the provision of basic essential services such as health care, prevention with positives (PwP), psychosocial support, food & nutrition and access to wrap around services through referral linkages.

GHAIN in partnership with Network of People Living with HIV/AIDS (NEPWHAN) supported the formation and strengthening of existing support groups in both the facilities and the communities to assist clients overcome social problems such as stigma and discrimination,

loss of income and rights abuse. The health facilities had functional support groups of PLHIV who participate actively in service provision and tracking of defaulters.

The continuum of care from facility to community and vice versa was being made possible through a strengthened referral system. The system ensures that clients have access to a full complement of services both at health facilities and within the communities. Specific activities carried out in each state included stakeholders' workshops, participatory mapping exercises, and support to the referral networks. These include provision of tools to facilitate the referral process, monitoring and evaluation and community mobilization to use and support the referral network. A referral unit coordinated tracking of patients who were enrolled into care and treatment and patient transfers. Standard Operating Procedure (SOP) for tracking of ART patients and retention guided the work of tracking teams in each facility, made up of a referral focal person, adherence counselor, site pharmacist, M&E staff, support group members and the facility finance clerk. A defaulters list is generated using the pharmacy appointment diary 1-day after a missed drug refill or clinic/laboratory appointment. Record of patient tracking effort made through phone calls and home visits are kept in the tracking register. Clients who fail to report back after 3 months (90 days) or are not found after 1st, 2nd, 3rd and fourth attempt are recorded in the ART register and Lafiya Management Information System (LAMIS), an electronic medical record, as lost to follow up (LTFU). These referral/patient tracking activities were coordinated by the Referral Officer in the country office, 11 referral coordinators in the zonal offices and trained referral focal persons at facility and organizations.

PROGRAM ACHIEVEMENTS

3.1 Delivering a successful HIV counseling and testing program

The GHAIN project has contributed immensely to early identification of PLHIV through its successful HTC program introduced in a variety of settings including facility, stand-alone, mobile and community-based services. An increased number of infected individuals are identified through HIV integration with TB, RH and MNCH. 2,339,506 (M=1,124,640; F=1,214,866) individuals were tested, counselled and received their results in GHAIN supported sites over the course of the project (see GHAIN HTC monograph for more details).

Out of the total number of clients tested for HIV within the project, 420,956 (9.4%) were HIV infected, of this number 295,404 (70%) were enrolled into care and treatment.

3.2 Referrals, Linkages and Retention in Care

Meeting the needs of the growing numbers of PLHIV, their care-givers and family members requires the collective effort of many facilities and organizations. GHAIN provided care and support for PLHIV and PABAs in 125 comprehensive ART sites and 267 HTC sites across the 36 states of Nigeria and Federal Capital Territory (FCT). GHAIN adopted the GoN cluster model, a situation where services are provided around the hub (ART centre), to ensure continuum of care in each state. The GHAIN supported community component of the program (WHO, 2009) which started in two LGAs in Yakurr, Cross River State and Nassarawa in Kano State. This was eventually extended to 12 more LGAs across eight states; Bauchi and Shira in Bauchi state, Wudil in Kano, Wamakko in Sokoto, Abuja Metropolitan Area Council (AMAC) in FCT, Katsina-Ala and Oju in Benue, Udi and Nkanu-West in Enugu, Calabar Municipal in Cross River, Ajeromi in Lagos and Orhionmwon in Edo.

GHAIN in collaboration with State Agency for the Control of HIV/AIDS (SACA) and other stakeholders supported formation of 37 functional referral networks (one in each state and the FCT). These networks meet quarterly to review data, discuss challenges, quality assurance and quality improvements of the referral system. A total of 995 facility staff and community volunteers (referral focal persons and the tracking team from comprehensive sites, feeder sites, support group members and CBOs) were trained on a three day course on referral and tracking of clients. Referral directories and a data base were produced for each state and the FCT. Discussions on getting the directories, tools and data base adopted for national use are underway.

3.3 Improved access and uptake of care and support services

GHAIN has made significant contributions to improved access to services through collaboration with Global Fund and the adoption of the GoN cluster model which promotes universal access to comprehensive services across the country. GHAIN thus has the widest network and the largest pool of beneficiaries in the country. By June 2011, 511,487 people were provided with at least one care service and 108, 438 (including 49,780 pregnant women) with support services (food and/ other nutritional services) through health facilities and organizations supported by GHAIN. The following are achievements recorded in specific service areas.

3.3.1 Health Care

In the area of health, GHAIN supported the distribution of preventive care kits (basic care kits) to PLHIV and OVC as follows: 43,960 Insecticide Treated Nets, 32,832 Buckets, 535,544 Water guards/Purifiers and 7,000 lubricants. Other services include laboratory investigations (baseline, monitoring and OI diagnosis where over 4 million tests have been conducted), health education, management of opportunistic infections, referrals and linkages to other services. Based on literature and program experience, GHAIN has developed a standard formulary of 20 essential OI drugs and palliatives to ensure availability at facilities at all times.

3.3.2 Home based care

Community home-based care and support provides compassionate care and support to PLHIV and their family members. GHAIN supported CBOs and community volunteers (CVs) to make regular home visits to PLHIV. The support given to CBOs/CVs to make effective home visits included what to do before, during and after home visits. In addition, the program procured and distributed 1,200 community home based kits. About 3,026 PLHIV benefited from health services in the community from July 2009 to June 2011. These services include health education, distribution of basic care kits, replenishment of water guard, treatment of minor ailment and referrals to health facilities.

3.3.3 Nutrition

GHAIN supported the provision of nutritional needs of PLHIV both in the facilities and the communities. A locally produced nutrient, MIMAGROWS (produced form millet, maize, ground nut, and wheat and soya beans) was distributed to PLHIV in need. Caregivers were also trained on production of MIMAGROWS. Other nutritional services supported by GHAIN were nutritional counselling, nutritional assessment, supply of ready to use therapeutic feeds (plumpy nuts) for community treatment of acute malnutrition in children, food demonstrations and counselling on home gardening.

GHAIN trained CBOs/CVs carry out community sensitization/awareness on nutrition activities in the communities. They enlist the support of community stakeholders in improving the nutritional status of PLHIV/OVC through communal efforts. Monthly weighing and documentation Body Mass Index (BMI) of PLHIV/OVC during support group meetings is being carried out by the CBOs/CVs. From July 2009 to June 2011, 3,911 PLHIV were given MIMAGROWS. Agricultural counselling of households to undertake home gardens for the production of vegetables, fruits, beans and poultry was also carried out by the CBOs/CVs.

3.3.4 Prevention with Positives (PwP)

GHAIN supported site has consultations daily with PLHIV. During each encounter, healthcare workers are encouraged to provide PWP with:

- Information on transmission of HIV
- Prevention with Positive plan/follow-up on implementation
- Condom distribution (to both married and single clients) demonstration on correct and consistent use
- Encouragement on sexual abstinence
- Support to clients on HIV status disclosure to family members/couple counseling
- Screening for Sexually Transmitted Infections (STIs), pregnancy and alcohol/substance abuse and referral for PMTCT, RH and other services
- Support for adherence to anti-retroviral treatment and other medications

3.3.5 Psychosocial Support

going counselling and other services. A total of 119 facility support groups were formed with a cumulative membership of 115,990 and 33 community support groups in 14 LGAs across eight states. Support groups were supported technically and logistically to hold monthly meetings both in the facilities and communities. Support group members derived the following benefits;

- Opportunity for sharing experience among members
- Opportunity to learn more on how to live positively with HIV
- It encourages social interaction and integration
- Opportunity to know more about HIV/AIDS, opportunistic infections, and their prevention and management
- Reduction of loneliness, stigma, and discrimination
- Created avenue for support of the group by other interested individuals and bodies
- Affords members the opportunity to learn more about; nutrition, succession planning, income generating activities etc

- Affords members the opportunity for forming cooperative societies that can assist economic strengthening of group members
- It affords members opportunity to overcome challenges of living with HIV.

Other achievements recorded by the program include;

1. A total of 3,790 health care workers, CBOs and community volunteers were trained to provide quality care and support services.
2. Development of community home based care tools.

DISCUSSION

The quality of life of those who are infected with or affected by HIV/AIDS is largely determined by their access to required care; however, this is not sometimes met depending on the services available within the location the individual resides. The care and support strategy initiated by GHAIN which links care and treatment at facility with care and support at home and in the community has contributed immensely to improving their lives. Community-based approaches can also improve the ability of populations at high risk of HIV to access HIV services and to benefit from antiretroviral therapy and prevent new infections. In addition, experience from the GHAIN project has shown that support group of people living with HIV are best placed to reach populations at high risk of HIV and to provide care and support to members.

Stigma and discrimination remains the biggest obstacle to HIV testing. Globally only about 40% of people living with HIV know their HIV status. Even for those who know their status, linkage to ensure enrolment in care as well as follow up in care until client is placed on treatment is poor. The GHAIN project has demonstrated significant success in HTC, effective linkages and retention of clients in care.

GHAIN has supported interventions with proven effectiveness for reducing morbidity and mortality e.g. provision of cotrimoxazole prophylaxis (CTX) in accordance with WHO recommendations and TB identification and treatment (FHI Nigeria, 2011)
Prevention with positives (PwP) programming, integrated into HIV care services, has the potential of reducing the risk of on-going HIV transmission.

Challenges

The implementation was not without challenges. Some of these are;

- The non-availability of national guidelines and SOP for community care and support services.
- Stigma and discrimination has continued to be a major problem preventing people from accessing free HIV test and joining support groups despite repeated community dialogue sessions.
- High attrition rate of community volunteers
- The program was not able to provide enough food to PLHIV due to limited funding

CONCLUSION

Community and home based care complements the facility care given in the clinical settings and still ensures that both the PLHIV and PABA are catered for through out the continuum of care in a holistic manner. GHAIN has made immense contribution to the provision of care and support services in Nigeria. The national program needs to set clear definitions of norms and standards that address key elements of care and support especially in light of the complex interventions needed to maintain the health of PLHIV.

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