Developing an Effective Referral System: Key Elements for Successful Health Systems Integration
2013
ACKNOWLEDGEMENTS

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TABLE OF CONTENTS

I. Overview .............................................................................................................................................................................. 1
II. Bantwana’s Referrals & Networking Strategy for STAR-EC ................................................................................................. 2
III. Developing a Functional Referrals & Networking System .................................................................................................. 3
IV. Integrating Linkage Facilitators: A Pivotal Element in the Referral System ........................................................................ 4
V. Improving Communication and Relationships: The ‘Missing’ Element .................................................................................. 9
VI. Conclusion: Lessons Learned and Way Forward .................................................................................................................. 10
GLOSSARY OF TERMS

**Community-Facility Referrals:** Establishing a two-way facility-community referral system ensures that clients have access to and receive needed clinical health services as well as follow-up support for health and other urgent wrap-around care and support. Bantwana-trained community-and facility-based *linkage facilitators* address both the supply and demand side of an integrated referral system.

**Linkage Facilitators:** *Linkage facilitators* act as a ‘referring agent’ (at community level) and ‘receiving agent’ (at facility level) to ensure that clients have access to health services, are guided through the process to ensure that services are received, facilitate inter- and intra-facility referrals and make referrals to non-clinical but urgent wrap-around services (e.g. food security and nutrition, economic strengthening support, child protection, psychosocial support (PSS) and legal support). Community-based and facility-based *linkage facilitators* are drawn from PLHIV groups, Village Health Teams (VHTs), expert clients and mentor mothers and are trained and supported by Bantwana under STAR-EC.

**Village Health Teams (VHTs):** VHTs are mostly comprised of PLHIV network and support group volunteers that are selected and are trained by government (when resources permit) to mobilize communities to seek health services. In very low HIV-prevalent districts, members may or may not be PLHIV.

**Expert Clients:** *Expert clients* are HIV positive clients who, in their role as VHT members, members of PLHIV network and support groups, or paid community-level agents, are recruited and trained by district (government) and local CSOs/NGOs (community) to support PLHIV clients in a range of ways. Under STAR-EC, Bantwana has drawn from, trained and provides ongoing support to a cadre of *expert clients* in their role as *linkage facilitators*.

**Mother Mentors:** *Mentor mothers* are PLHIV who have been trained by mothers2mothers (m2m) - another sub-partner on the STAR-EC program - to provide health education and psychosocial support to their peers in order to ensure success of prevention of mother-to-child transmission of HIV. *Mentor mothers* are stationed at high antenatal care output health facilities and play a vital role in task sharing and task shifting at this level.

**Referral Focal Person (RFPs):** Instituted by Bantwana, RFPs are designated full-time, trained health staff (e.g. In-charge, Senior Nursing Officer, etc.) that help safeguard the link between *linkage facilitators* and other health staff members at health facilities. RFPs ensure referrals become part of the service delivery system by creating regular opportunities for *linkage facilitators* and other health facility staff to understand each other’s roles and identify and address gaps to improve the overall referral system.

**Inter-facility Referrals:** Clients transferring from one facility to another for urgent care are easily overwhelmed and commonly unable to effectively navigate the transfer process. Bantwana-trained *linkage facilitators* help to ensure that the transfer process is successful sometimes by physically transporting or accompanying clients to the new referral facility.

**Intra-facility Referrals:** Particularly in larger facilities (e.g. district and regional hospitals), clients have difficulty navigating the transfer process between departments in the same facility. Bantwana-trained *linkage facilitators* help clients successfully navigate this process to ensure necessary services are received.
I. OVERVIEW

“Working with health workers was complicated at first. They looked at us as laypeople who knew nothing in the area of health. STAR-EC (Bantwana) brought us together in training meetings and workshops and this helped to concretize our relationship. We are now one people and we respect each other. They [health providers] now listen and pay attention to what we say.”

People Living with HIV (PLHIV) Coordinator, linkage facilitator

This rich testimony, by a linkage facilitator\(^1\) who has participated in the Strengthening TB and HIV/AIDS Responses in East Central Uganda (STAR-EC) project during the past four years, was echoed by many respondents during a research exercise carried out by STAR-EC partner the Bantwana Initiative of World Education\(^2\) to identify key factors that have contributed to the development and maintenance of an effective referral and networking system.

STAR-EC is a six-year, district-based initiative funded by USAID and implemented by a consortium of five partners led by JSI Research & Training Institute, Inc. (JSI) to increase access, coverage and utilization of quality and comprehensive HIV/AIDS and TB prevention, as well as comprehensive care and treatment services within district health facilities and their respective communities. The project serves a population of approximately 3.1 million (9% of the country’s total population) in nine districts in the East Central region of Uganda. In March 2013, researchers interviewed more than 80 stakeholders and made observations at hospitals and health centers in three, STAR-EC supported districts in East Central Uganda.

Under STAR-EC, the Bantwana Initiative has led the team in one of the project’s major objectives: development of a referrals and networking strategy to improve accessibility to comprehensive HIV/AIDS, TB and wrap-around services. Bantwana’s referrals and networking approach is aligned with national policy while focusing on strengthening inter-facility, intra-facility, and community-facility referrals, and improving key coordination and networking mechanisms at community and district levels.

The most significant finding was the positive impact and far-reaching contribution that strengthening institutional and community level linkages had on the referral process when linkage facilitators were fully integrated into the health system. Improving communication and

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1. Linkage facilitators is a term used to describe different categories of people who assist in referring and linking clients to HIV related services. They include community volunteers, peers educators, and PLHIV groups.

2. Launched in 2006 by JSI and WEI, the Bantwana Initiative builds the skills, networks and capacity of individuals, organizations and local governments to expand access for children and caregivers made vulnerable by HIV and poverty to a full range of comprehensive care. www.bantwana.org
relationships between health providers and linkage facilitators, and ensuring scheduled opportunities for them to meet together to understand the value that each contributes and to problem solve together, were viewed as the most important influences in ensuring a smooth journey for clients being referred, accessing initial services and receiving follow-up care and support.

“Working together with our volunteers [linkage facilitators] has made the work of our health workers easier and better. The referral process has also motivated us as health workers to work hard, and has made the community aware of the services we offer. Before, people would fear to come for treatment but with the involvement of these volunteers in the referral process, stigma among the people has reduced.”

Psychiatric Nurse, Health Provider

This document provides a brief overview of Bantwana’s referrals and networking strategies for the STAR-EC program, reviews key steps taken to develop a functional referral system, and uncovers how concerted efforts to integrate linkage facilitators into the health system have significantly contributed to more than 100,000 individuals and their families residing in East Central Uganda receiving much needed HIV-and TB-related services.
Bantwana’s referral strategies and activities were designed to address a number of systemic gaps identified at the outset of the project. The overall goal of the strategy is to strengthen networks and referrals by:

- Strengthening and expanding partnerships to improve accessibility to comprehensive HIV and TB services;
- Engaging individuals openly living with HIV and AIDS (PLHIV) as services providers, advocates (linkage facilitators) for improving HIV and TB services rather than just passive recipients;
- Strengthening the capacity of CSO partners to deliver quality health and comprehensive wrap-around services: Food security and nutrition, economic strengthening, support child protection, psychosocial support, and legal support;
- Strengthening the capacity of decentralized, community-level HIV coordination structures for more effective coordination.

Bantwana’s efforts to foster effective linkages and strengthen community structures has led to a nearly ten-fold increase in the number of persons who accessed HIV-related services through referrals in East Central Uganda in the four year period from 2009 (the start of the project) to 2012.

In addition, nearly 20,000 PLHIV and their household members have been reached with much needed wrap-around services that go beyond the core health needs of these individuals yet are an integral part of assisting a PLHIV client holistically.

**II. BANTWANA’S REFERRALS & NETWORKING STRATEGY FOR STAR-EC**

REFERRALS MADE & SERVICES RECEIVED IN STAR-EC SUPPORTED FACILITIES 2009-2012

<table>
<thead>
<tr>
<th>Years</th>
<th>2009/10</th>
<th>2010/11</th>
<th>2011/12</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referrals Made</td>
<td>10,826</td>
<td>91,275</td>
<td>103,890</td>
</tr>
<tr>
<td>Services Received</td>
<td>6,604</td>
<td>83,973</td>
<td>89,999</td>
</tr>
</tbody>
</table>

*Services received:*
- 2009/10 - 61%
- 2010/11 - 92%
- 2011/12 - 86.6%
III. DEVELOPING A FUNCTIONAL REFERRALS & NETWORKING SYSTEM

“STAR-EC [Bantwana] has made sure we meet together regularly with the district and other key stakeholders, that we plan together, share our experiences, challenges and that we forge a way forward on how to overcome some of the bottlenecks—not only in referrals but also in the operation of other activities. They [the meetings] allow us all to make sure we are all working together for the same goal.”

CSO, Team Leader

Due to the diverse needs of the communities in which STAR-EC works and the clients the project serves, Bantwana recognized that it is not possible for one single organization to provide a comprehensive package that caters for the needs of people accessing HIV/AIDS and TB services. Hence, the development of an effective referrals and networking system is crucial to ensure access to multiple needed services and continuity of care for clients.

Moreover, certain essential elements need to be in place to optimize the referral system’s operational effectiveness and outcomes for PLHIV, their caregivers and their family members. These include:

- A group of organizations that, in the aggregate, provide comprehensive services to meet the needs of PLHIV, their caregivers and their families within a defined geographic area;
- A unit or organization that coordinates the whole referral network;
- A directory of services and organizations within a defined catchment area;
- Designated Referral Focal Person(s) at each organization and at community level;
- Documentation of the referral; and
- A feedback loop to track referrals (i.e. to determine if a client is satisfied with the service received and whether her/his needs were met).

To establish these essential elements for the referral system in East Central Uganda, Bantwana, in its coordinating role, has been working through partnerships with local government structures and staff (e.g. district level HIV focal persons, PLHIV networks) and civil society organizations (CSOs) by providing grants to CSOs and offering direct financial and technical support activities carried out through public health facilities. At the start of the project, CSOs and PLHIV network leaders were invited to participate in a Referrals & Networking Workshop delivered by Bantwana. The workshop laid the foundation for these community agents to engage effectively in conducting referrals and establishing and promoting networks in their catchment areas.

Bantwana has continued to support local government, CSOs and PLHIV groups in activities geared towards strengthening their relationships and linkages. Early on in the project, Bantwana recognized that a key obstacle preventing stakeholders from further expanding their partnerships and integrating services for clients was the lack of consistent opportunities for collaboration and the designing of unified strategies to improve referrals in their communities. Hence, through STAR-EC, Bantwana has provided technical and financial support to these groups to institute a number of joint planning, management and evaluative meetings.

Evidence from this study reveals that these deliberate Bantwana-initiated activities, have improved networking and resulted in a more harmonized working relationship between the CSOs and districts by helping to bring key stakeholders together regularly. As one CSO Team leader stated:

“What I like seeing is that the relationship between us [CSO] and the district has become a healthy one. Now there is a level of maturity in the implementation of projects, the districts see us as coming in to help with services, and they see that this will help [the government] to reach their targets and serve our communities better.”

CSO, Team Leader
Bantwana has also worked directly with the Ministry of Health (MOH) to develop standardized, easy to use referral tools as another essential element to facilitate the referral process for the client, and to offer data to help providers as well as program planners and districts to effectively assess whether community members are receiving comprehensive services. Bantwana continues to engage directly with health facilities to assist them in understanding the importance of these tools and to help key stakeholders use the data generated by these tools to monitor progress, improve referrals and client follow-up, and ultimately enhance service provision.

Visits to various health facilities during this study confirmed that the main tool being used most consistently in the referral system is the standardized MOH Referral Form, which is viewed as the most vital tool in the referral process. Most importantly, the form benefits the client by making it easy to access a needed service: the referral form helps us access services easily and quickly because once we show it [the form], the health worker doesn’t ask a lot of questions—with the form it is clear what we want (Client information), and referrals forms smooth the process of seeking services and clients feel honored to be given referral form with a feedback section (Health Provider). In addition, providers and program planners acknowledged the benefits of capturing relevant data through the Referral Forms.

Both health workers and linkage facilitators claimed that without this tool the referral process could be crippled. Since the Referral Form has been standardized and endorsed by the MOH, users remain hopeful that the MOH will continue to supply this referral tool to them in the future.

**IV. INTEGRATING LINKAGE FACILITATORS: A PIVOTAL ELEMENT IN THE REFERRAL SYSTEM**

“Right from the inception of this project we knew there was a disconnect between community-based services and health facility-based services. As much as we worked to improve service delivery, we knew we could not provide a continuum of care unless we worked with the community.”

**STAR-EC, Deputy Chief of Party**

Bantwana’s efforts to strengthen coordination within districts and develop standardized referral tools are recognized as necessary elements and actions needed to develop a functioning referral system. However, evidence from this study suggests that Bantwana’s focused and intense effort to develop stronger institutional and community-level linkages has been the most critical element in developing and maintaining an effective referral system.

**WHAT ARE LINKAGE FACILITATORS?**

For an effective referral system to take shape, the ‘referring agent’ at community level and the ‘receiving agent’ at service provider level are paramount. Consequently, Bantwana placed great emphasis on tapping into existing ‘referring agents’ from the community, to strengthen their capacity and motivate them to act as linkage facilitators responsible for, as their title suggests, linking clients from the community to institutions and services. These linkage facilitators are volunteers, peers, and PLHIV individuals and groups, most of whom are part of existing community structures. They include Village Health Teams (VHTs), who comprise a wide network of volunteers selected and trained by the government and are meant to be a key structure for mobilizing communities to seek health services; expert patients/clients, who are HIV positive clients that assist the health system; and other PLHIV networks and support groups who work as volunteers or paid community-level agents, and are recruited and trained by districts, as well as local CSOs and NGOs to support PLHIV clients in various ways.
WHY INVOLVE LINKAGE FACILITATORS IN THE REFERRAL SYSTEM?

The project identified at the beginning of its implementation that these various potential linkage facilitators were being under valued or under utilized in the districts STAR-EC was to support. The project uncovered that most lacked the skills and the motivation to actively engage in referral practices and activities to improve access to services among their own community members, yet in most cases they were community members who had been selected to be agents of change in their communities. To avoid developing parallel structures, Bantwana revitalized these existing structures and groups by building their capacity and motivating them with modest financial incentives.

Bantwana, in its effort to eliminate the apparent disconnection between the health facilities and community-based services, offered technical and financial support to ensure that linkage facilitators were trained and gained skills and knowledge on health service delivery and operations, as well as information and resources on how to link clients to more services, advocate for more services, and utilize and leverage other available government resources. The rationale was that enhancing these various linkage facilitators’ skills, motivating them to take part in the referral process, and strategically placing or connecting them to the health system, would result in a desired increase in community-facility, inter-facility and intra-facility referrals.

HOW DID BANTWANA INVOLVE LINKAGE FACILITATORS IN THE REFERRAL SYSTEM?

Community-based linkage facilitators
As part of the government structure, VHTs are meant to serve as the primary, village-level health contact for all villages in Uganda. They are volunteers who are selected by their communities, and in theory they are supposed to receive training (from the government) to provide correct health information, mobilize communities and provide linkages to health services. However, given Uganda’s nascent efforts to decentralize its health care system whereby districts are responsible for the delivery of health services, VHTs, like many other local health structures, have not been able to operate effectively. Districts lack the funds or capacity to train these VHTs and many districts have relied on outside donors and projects to train and motivate VHTs.

With support from STAR-EC, several districts in the East Central region trained and oriented VHTs in health service delivery and operations, including information on how to link community members to health services. In addition, Bantwana integrated these VHTs to work with specific health facilities as linkage facilitators. In other words, VHTs were linked to specific health facilities to refer their clients, which also allowed them to develop relationships with particular health facilities and health providers.

The training and integration of VHTs has significantly enhanced community-facility referrals in STAR-EC supported districts, and has created synergy and strengthened community mobilization to create demand for services.

“With involvement from these volunteers [linkage facilitators], the demand for services has increased. Misconception about health facilities has also reduced. There is a reduction in time wasted by clients and they are now able to access health services quickly. Maternal deaths appear to have reduced and mothers turning up for immunization has increased. We attribute these improvements mainly to the new mobilization skills and effort by VHTs and other community volunteers.”

Senior Medical Officer

Health facility-based linkage facilitators
Through continuous interactions with health providers, volunteers and clients, Bantwana recognized that soliciting and training volunteers or peers who work in the communities to send or refer patients to the facilities were not enough to ensure a ‘complete’ referral (i.e. ensure that clients receive all the necessary services). Data revealed that new referral patients were often ‘getting lost’ upon arrival at a health facility, and that several patients, despite being referred from the community, were still not receiving all the services they needed. Clients needed a specific person at the health facility to help them navigate the system. However, it was evident that the already overstretched health workers could not take on this additional task.

4 An assessment of HIV coordination structures conducted early in the program by STAR-EC with technical support from the Uganda AIDS Commission (UAC) indicated that many district and lower level coordination structures, including PLHIV networks and VHTs, had not been functional due to lack of funds and/or capacity to facilitate their operations. This lack of local level implementation had hindered smooth referrals and coordination as well as awareness of services available.
In Uganda, health staff shortages have been acknowledged and several health facilities have already begun to shift some health workers’ tasks to expert clients. Expert clients are HIV positive individuals who assist the health system to provide services to others. This ‘task-shifting’ approach at health facilities has proven successful in improving service delivery in different locations in Uganda. As one recent study reports: expert clients are highly engaged regardless of the level of financial support they receive, however financial incentives were important to the expert clients because they enable them to spend more time on the work. The study also noted that systematic support for expert clients has not been standardized or guided by national policy. Hence, as with VHTs, who are expected to do a great deal of work for their communities with no compensation from the government, the long-term sustainability of this approach is still in question.

Voice of Mandida, an appreciative community-facility referral beneficiary:

“I used to get malaria so often. I would go to the drug shop, buy malaria medicine, take it and become okay. Then I would get the same disease again after a few days. Over time, I became so weak I could not walk on my own. I tried different treatment options but none worked. Finally everyone lost hope for me. It was not until Stephen, my neighbor who is a VHT, came and visited me that things got better. He asked me if I could go to the hospital for a blood check-up. Since I was tired of falling sick and was in bad shape, I agreed and he wrote for me a paper [referral note] that I carried along with me to the hospital. When they checked me, I was found HIV positive. Because I was very weak, the hospital gave me food supplements to help me regain energy and started me on ARVs immediately.

Stephen later came back to my home to see if I was taking my drugs correctly. He also counseled my family members, and they now remind me when to take my drugs. I am grateful to Stephen because he saved my life. I have been on ARVs for the last three years and I feel very fine. I can go to the garden, cook and do all my household chores well. I love the treatment as I love my life.

Stephen has done a perfect job. There are a number of other people he has referred, and they too have received ARVs and are back to normal life. I did not know that I would ever put my foot on this soil again! I am so happy for the support I received through Stephen and the health workers in my district.”

Ms. Rose Mandida, Client

Once again, Bantwana tapped into this existing system of ‘task shifting’ and using expert clients. The project also recruited, compensated and trained additional expert clients, including mentor mothers, to serve as health facility-based linkage facilitators. STAR-EC’s PMTCT Specialist explains how these mentor mothers and other expert clients (supported by STAR-EC) are strategically placed within health facilities and how this has positively benefitted clients in the referral process:

“Voice of Ivan, an active linkage facilitator:

“I come here [Kamuli Hospital] every day and I help in the morning with gathering patients’ record files. I also conduct health talks about available services. I link people to the next level or department based on their different needs. At times I escort the patient after giving him or her a referral, talk to the clinician about the client I have brought, hand over the referral to the health workers, and go back to see other clients. Later, I come to cross-check whether the client got to the service or not. Some clients get back to me to give feedback while others do not. I also do rapid tests, engage in counseling for HCT and give results to clients.

“I can now do testing, I know how to organize client forms, and I have done a great job in mobilizing and counseling men to accompany their wives for ANC. I am also happy that we work as one team with health workers. By the way, here we are also called Basswoo (health workers).”

Ivan, linkage facilitator

Researchers’ visits to hospitals and conversations with expert clients working at various health facilities substantiated that the ‘physical escort’ of clients to different services was viewed as a highly effective means to ensure that clients do not get lost or intimidated in the process and reach more services within a facility.

**PLHIV support system linkage facilitators**

A recent survey revealed that up to one-third of PLHIVs in Uganda are volunteers or members of PLHIV groups or associations that make efforts to provide a range of support for other PLHIV. The study found that while being a volunteer improves their knowledge and enhances self-esteem through helping others, most experience limited capacity building opportunities and ‘receive no remuneration,’ and this lack of support is viewed as a considerable constraint to the effectiveness of the volunteers.7

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Bantwana recognized the vital role that PLHIVs can play in the response to TB and HIV/AIDS services: they provide much needed peer support and link PLHIV to much crucial services that go beyond clients’ clinical health needs. Bantwana provided PLHIV networks and groups with management and leadership support, vital materials such as cell phones, and continued assistance in identifying partners and linkages to become better sources of information and support for their communities. The project continues to provide ongoing support to these networks to help them establish and support additional local PLHIV groups, conduct support supervision and stakeholder review meetings, provide psychosocial support to fellow PLHIV and conduct referrals for health and wrap-around services.

“Star-EC [through Bantwana activities] has built the capacity of PLHIV to handle cases of different categories of people, like young positives, adults and discordant couples. We have learned how to counsel young positives against being stigmatized by friends, facilitate supported disclosure and link positives to various organizations for comprehensive services in psychosocial support, education, economic strengthening among others. Network members also participate in referring people to health centers for HIV counseling and testing services. Those found positive are linked to care and support while those negative are sensitized on positive living.”

PLHIV Coordinator

In communities, linkage facilitators make decisions on who should be referred. They encourage clients to seek services and they act as a key entry point for clients to access services. They are linked to specific health facilities so they are able to stay connected and follow up with clients back in their communities. At health facilities, linkage facilitators’ involvement and support has allowed for a reduction in the client-health worker ratio, and ‘created order’ as these volunteers are involved in a number of organizing tasks including pill counting, PLHIV records’ updating and filing, as well as counseling, educating and escorting patients. They save clients time and help ease the flow for clients through the system.

Voice of Samuel, a motivated PLHIV linkage facilitator:

“In 1994, I fell sick for some time but could not establish what the problem was, despite having taken some medication. Later I decided to come to Bugiri Hospital for an HIV test and I was found HIV positive. Local organizations took good care of me and gave me all the medicine and the necessary psychosocial support I needed. When I became strong, I became interested in serving my community.”

“We [PLHIV] are a living referral because we share our personal experiences on how we were and where we got the services that changed our lives. People believe in us. Sharing my personal experience has motivated a number of my community members to take HIV tests, and those who turn out to be positive I work closely with to ensure that even their family members get tested. Sometimes I do supported disclosure for some of my friends/clients who find it difficult to disclose to their family members.”

“We [linkage facilitators] escort clients to the health facilities and we help them to access other needed services. I have some PLHIVs in my community that I referred, and they have benefited from the NAADS program, and nutrition services from hospitals. STAR-EC [Bantwana] has been motivating me to do more community work. I have been facilitated with referral materials (forms and registers), data reporting tools and have also been trained in various fields including TB screening, psychosocial support, positive prevention, minor health management, testing and counseling.”

Samuel, linkage facilitator
Empowered and equipped PLHIV volunteers and groups who serve as *linkage facilitators* have been influential in linking positive clients to care and support services that extend well beyond the clinical needs of clients. This peer-to-peer influence has led to increased uptake of HIV/AIDS services.

**V. IMPROVING COMMUNICATION & RELATIONSHIPS: THE ‘MISSING’ ELEMENT**

*“Our improved relationship with the formal health system has benefitted PLHIV clients a lot. Regular communication has improved the number of people accessing treatment and care services.”*  
**PLHIV, linkage facilitator**

Despite building capacity, providing incentives, and strategically placing *linkage facilitators* to integrate them into the health system, there was still one identified ‘missing element’ that had the potential to undermine the entire effectiveness of the referral system: poor relationships and communication among health providers and *linkage facilitators*, mainly due to the lack of trust by health providers about the value and relevance of *linkage facilitators* in helping clients access services they need and deserve.

During field visits, both health staff and *linkage facilitators* readily admitted that at first health providers were often rejecting referrals from *linkage facilitators* for various reasons including mistrust of the intentions of the *linkage facilitators*, lack of understanding of their role in strengthening the health system, and in some cases simply because the flood of new patients being referred from the community or from a different department within a facility overwhelmed health staff.

Bantwana created opportunities for health staff and *linkage facilitators* to come together to participate in joint networking and planning meetings initiated by Bantwana at both district and sub-district level. Bantwana also strongly encouraged and supported health facilities to institute monthly meetings between health staff and *linkage facilitators* at health facilities. During these meetings the roles and responsibilities of each stakeholder are made clear, and challenges, successes and “ways forward” are discussed as a team.

Finally, to help solidify the relationship between the health staff and *linkage facilitators*, and to help coordinate the referral system at facility level, Bantwana instituted designated Referral Focal Persons (RFP) at each health facility. An RFP is a full-time, trained health staff member (e.g. In-charge, Senior Nursing Officer, etc.) and s/he is meant to help safeguard the link between the *linkage facilitators* and other health staff members at his/her health facility. These designated RFPs have also helped other health staff within their facility to accept and appreciate the role of *linkage facilitators*. They are responsible for ensuring that regular meetings and exchanges between the health staff and *linkage facilitators* are held, including continuing medical and health education exercises that bring both groups together, and ensuring that referrals are not ignored but actually become part of the service delivery system.

Evidence from the field reveals that recruiting a health staff person to facilitate the referral process at health facilities, as well as supporting facilities to engage in various gatherings that bring health staff and *linkage facilitators* together (e.g. monthly meetings, health education sessions, etc.) have proven, over time, to be very useful in enhancing the relationship between health staff and *linkage facilitators*.

*The substantial, positive impact on the referral system that improved communication and understanding and acceptance of roles between health staff and the various linkage facilitators was one of the strongest findings from this case study.* In nearly all field discussions, both health staff members and *linkage facilitators* emphasized the efforts made by STAR-EC staff to improve the relationships between them. Scheduling meetings for both groups to discuss and learn more about the value and limitations that each contributes, were viewed as the most pervasive influences in ensuring a smoother journey for a client being referred and followed up on. In most cases where the referral process was deemed as ‘going smoothly’, it was due in large part, according to health providers and district level staff, to the dedication and significant contributions made by the *linkage facilitators* with whom they work.
Continuous support for community-facility linkage integration is key:
As this case study asserts, Bantwana’s approach to integrate linkage facilitators into the health system to improve referrals has been effective. Deliberate efforts to improve communication and relationships has resulted in health providers and linkage facilitators working well together (in some places), enabling more clients to be successfully referred and followed-up. In reality, these linkage facilitators have become both front-line service providers and strong advocates who often work full-time in either their community or local health facility. They help relieve the burden on particular points within the health care system, and enable more clients to access and receive much needed HIV related services. Continuous skill and relationship building, as well as the integration into the health system of various linkage facilitators, who serve to strengthen community links and service providers, is indeed fundamental for the success and sustainability of the referral system.

VI. CONCLUSION: LESSONS LEARNED AND WAY FORWARD

Strengthening referrals and networks is a critical component in increasing demand and utilization of HIV/AIDS and TB services. Uganda, like many countries suffering from the HIV epidemic, is interested in integrating various HIV services into a seamless continuum of services within and outside the health system. The referral strategies and activities initiated by Bantwana through STAR-EC, and implemented by districts and communities in East Central Uganda, have made more comprehensive services accessible to vulnerable people, and improved the lives of many individuals and families residing in that area. Bantwana has initiated, jointly implemented, and documented key referral strategies used to significantly improve collaboration and communication among key stakeholders involved in a referral system by:

• Strengthening local coordination structures and expanded partnerships;

• Equipping PLHIV individuals and networks with skills and data to advocate for more services and utilize and leverage other government resources; and,

• Improving institutional and community linkages by integrating linkage facilitators into the health and referral system to mobilize communities and create more demand for services.

“Our VHTs and expert clients do so much to help here. They do health education, assist in recording patients, retrieving files and ensuring that patients who have delayed at the health facility are helped. They also follow up specialized cases of very sick patients or patients who have taken long without coming for treatment and those missing appointments. We have learned to really appreciate these helpers and we now work together as one unit or family, for the benefit of our clients.”

In-Charge, Health Centre III
focus on assisting districts to recognize the resources, and political and organizational commitment required to continue implementation of the referral system.

**Strengthen facility-community linkages to improve access to critical non-clinical comprehensive services:** Bantwana has also established that PLHIV play a vital role in response to improving access to TB and HIV/AIDS services. The project aimed to engage individuals openly living with HIV and AIDS as services providers and advocates (linkage facilitators) rather than passive recipients. Bantwana worked directly with PLHIV networks to help them gain skills and knowledge on how to advocate for more services, and to utilize and leverage other available government resources. However, the reality is that there are serious constraints to access quality and comprehensive HIV services in Uganda, especially with regard to accessing non-clinical, HIV-related services.

Bantwana identified that limited referral points for wrap-around services have hampered the efforts of linkage facilitators referring clients, including OVC, for non-clinical services. Bantwana also learned that even when wrap around services are available, there is often a lack of any standardized referral system or agreements between those who provide wrap around services and those providing health services. The two groups of providers often have different mandates, different funding streams, and they do not necessarily communicate or understand one another. Hence, Bantwana will use the same successful approach it used to integrate linkage facilitators into the health system, to try and eliminate the disconnect between health and wrap-around service providers, and aim to continue to expand institutional and community-level linkages.

**Continue to test and support effective remuneration strategies for community volunteers:** The referrals and networking model developed by Bantwana under STAR-EC is heavily reliant on a robust volunteer cadre. While volunteers have responded very positively to the sense of satisfaction they experience from working as part of the clinic and community service teams, the increased skill set from effective training and follow-up support, and the elevated status they enjoy in their communities, issues of adequate support and remuneration remain ongoing challenges to sustainability. Bantwana will continue to work with volunteers, CSO partners, participating clinics and the MOH to develop creative, sustainable approaches to retaining volunteers during the next year.
**APPENDIX I**

**REFERRALS CASE STUDY METHODOLOGY**

**Data Collection: Methods, Team and Tools**

The key data collection methods used to develop this case study were:

1. A review of relevant project documents,
2. Interviews with STAR-EC technical staff, and
3. Field visits to three STAR-EC supported districts to make observations at health facilities and engage in discussions with several stakeholders and beneficiaries involved in the referral system.

The table below shows the category, district, title and number of respondents included in this study.

**CASE STUDY RESPONDENTS**

<table>
<thead>
<tr>
<th>Category</th>
<th>District</th>
<th>Title of Respondents</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>STAR-EC Technical Staff</td>
<td>Jinja</td>
<td>TB Specialist, PMTCT/HIV/FP Specialist, M2M Project Officer, Prevention Specialist, Strategic Information Officer, Capacity Building Specialist, Deputy COP, COP</td>
<td>8</td>
</tr>
<tr>
<td>District Level Personnel</td>
<td>Kamuli</td>
<td>CAO, Acao Health, District Planner, DHO, DHEs, STAR-EC Focal Person, HOD, VHT Coordinators, PLHIV District Coordinators, PLHIV Forum Executive Members</td>
<td>18</td>
</tr>
<tr>
<td></td>
<td>Iganga</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bugiri</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Service Providers</td>
<td>Kamuli</td>
<td>Health Facility In-Charges, Clinicians, Senior Nursing Officer, Nurse, Records Clerk, Health Assistant</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Iganga</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bugiri</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Facility &amp; Community Volunteers</td>
<td>Kamuli</td>
<td>Expert Clients, VHTs, Mentor Mothers</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Iganga</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bugiri</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clients</td>
<td>Kamuli</td>
<td>Male and Female PLHIV clients</td>
<td>19</td>
</tr>
<tr>
<td></td>
<td>Iganga</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bugiri</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSOs</td>
<td>Jinja</td>
<td>**Youth Alive: Regional Coordinator and Technical Field Officer; FLEP: Field Manager and three field staff URHB: M&amp;E Data Clerk</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Bugiri</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**TOTAL = 87**
The project documents were reviewed to gain an understanding of the project rationale and scope, and to understand Bantwana’s referral and networking strategy, as well as key activities being implemented and results achieved. The staff interviews were conducted to gain more detailed insight into the referrals and networking activities being implemented, and specifically to get their perspectives regarding accomplishments and shortcomings of the system. The field observations and discussions were to collect primary data from key stakeholders and beneficiaries and to directly observe referral activities and mechanisms. These combined methods allowed researchers to understand various perspectives, identify key factors that have contributed to the development and maintenance of an effective referral system, and acknowledge ongoing challenges to implementing and sustaining the system.

The data collection team consisted of three members: a female, expatriate lead researcher and a Ugandan male assistant researcher, both of whom are independent consultants, and a Ugandan female, who is a full-time Bantwana staff member. Based on information obtained from the document review and the interviews with STAR-EC technical staff, the lead researcher, in consultation with two Bantwana field staff directly involved in the implementation of the referral system, identified broad themes to represent key components of the referral system. The lead researcher then prepared open-ended, guiding questions for each theme. These themes and questions were reviewed and finalized with the Bantwana field staff and assistant researchers. The open-ended questions were designed to obtain narratives or accounts from stakeholders in their own words. Researchers were instructed to use this guiding tool, and encouraged to ask additional questions to gather more details and clarity based on respondents’ initial responses.

Field data was collected over a 2-week period in March 2013. Researchers were instructed to take detailed notes, and to capture as many direct quotes from respondents as possible, and to also note down, separate from the raw data, their own interpretation and summary statements. In most cases, two researchers engaged in an interview or group discussion together. Both researchers would take notes, however one researcher would act as the lead interviewer and engage in direct questioning with the interviewee, while the second interviewer was expected to capture more detailed notes. Researchers typed up their daily field notes. Researchers then organized their field notes into the seven broad data collection themes identified, including a ‘miscellaneous’ category to ensure that no collected data was overlooked at this initial stage.

**Sampling**

The methodology was exclusively qualitative and the sampling of districts, health facilities, service providers and beneficiaries was a purposeful one, looking for examples where the referral system was working well or had shown significant improvements over time, as determined by STAR-EC data and Bantwana field staff’s in-depth knowledge of the program.

Bantwana field staff recommended a few key district leaders for the researchers to interview, suggested specific health facilities to visit, and identified a key contact person at each facility. From there, the snowball effect, by which these individuals would then identify other health staff, volunteers or clients, was used. Clients who were at a facility for services at during the same time as the research team’s visit were interviewed individually or in small groups. (Note: The research team was prepared to go into the communities directly to access more clients if needed, however, there were sufficient numbers of clients at health facilities who were willing to engage in brief discussions with the researchers about their experiences with referrals.)

**Data analysis**

The analysis approach must reflect the purpose of the study. The goal of this investigation is to identify the key levers of success or most critical elements to developing and maintaining an effective referral system; hence the approach was to analyze the data so authentic evidence could emerge.

Researchers’ field notes (categorized by district and according to the seven broad themes), were compiled by the lead researcher, and further clustering or categorization was done to single out emerging categories and patterns in the data. Triangulation of the data—different sources revealing or highlighting the same key points—was used to identify both the key levers of success and the ongoing challenges to the system.