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HIVCore

HIVCore HIGHLIGHTS

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WIDENING THE LENS: LOOKING AT DISABILITIES AND MENTAL HEALTH

As we work toward an AIDS-free generation, there are still various barriers to achieving this goal. It is important for example to recognize that there are other marginalized—and very vulnerable—populations that are not traditionally recognized as "key populations." In this newsletter, we share results from ongoing studies that focus on two, often overlooked populations—people living with disabilities and those with mental health issues. We highlight the importance of understanding their distinctive needs given that many programs and services do not reach—or know how to reach—these groups.

Although evidence shows that persons with disabilities may be at greater risk for HIV compared to non-disabled people, in many countries HIV programs and services are not tailored to meet the unique needs of this population. As part of the HIVCore portfolio, researchers sought to better understand the HIV-related needs and challenges of those with sensory, physical, and intellectual disabilities, and to determine ways to provide effective HIV programming for this population in a diversity of contexts and settings—Uganda, Zambia, and Ghana (page 3).

Another population with unique HIV prevention needs is people with mental health issues, such as anxiety, and

HIV-related programs and services need to be tailored to meet the needs of those with disabilities, such as the AIDS awareness activity for the deaf pictured above.

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Adolescent boys who live on the street in Addis Ababa and are part of the Retrak program, a local partner on the mental health study in Ethiopia.

Until the most marginalized—and often most vulnerable—populations can access lifesaving, HIV-related information and services, we will not have an AIDS-free generation.

depression. Evidence suggests that these factors often contribute to engaging in HIV risk behaviors. Adolescent migrants, for example, often experience situations—child domestic work, social exclusion, and/or living on the street—that increase their psychological stress and lower their self-esteem, putting them at risk of mental health problems and HIV. HIVCore researchers are developing and evaluating approaches to identify and address key mental health and psychological problems among marginalized youth in Ethiopia to reduce their vulnerability to HIV (page 7).

To ensure universal access to effective HIV prevention, treatment, and care and support programs and achieve an AIDS-free generation, evidence-based approaches that address the needs of marginalized populations should be identified. This newsletter shares just two examples of how HIVCore is providing evidence to improve the efficiency, effectiveness, scale, and quality of HIV and AIDS programs and services for the most vulnerable. We hope you enjoy it.

Sincerely,

Samuel Kalibala, HIVCore Project Director

UNDERSTANDING HIV PROGRAMMING FOR PERSONS WITH DISABILITIES

An estimated 16 percent of the world's adult population is affected by some form of disability[1], 80 percent of whom live in the developing world[2]. Yet in many respects, persons with disabilities are a hidden population. The Demographic and Health Survey, the most widely conducted, nationally representative health survey, does not routinely collect information on even the most easily observable forms of physical disability such as blindness, deafness, or paralysis. Moreover, when national disability surveys are conducted, they seldom, if ever, include questions on HIV, sexual behavior, or other risk factors for HIV. Consequently, there are few epidemiological or socio-behavioral data on the prevalence, correlates, or consequences of disability.

It is generally agreed that those with disabilities have lower levels of education, and disabilities can exacerbate the effects of poverty and gender-based discrimination and violence[3], factors that increase vulnerability to HIV. Nevertheless, in many developing countries, persons with disabilities are absent from national HIV strategic plans (NSPs), HIV-related services, and outreach efforts because of common misperceptions that persons with disabilities are not sexually active, or engage in other risk behaviors, such as drug abuse.[2, 4, 5]

A recent three-country situation analysis in Ghana, Uganda, and Zambia by HIVCore researchers revealed that persons with disabilities have specific vulnerabilities that they felt put them at increased risk for HIV infection. These risks go beyond simply not practicing prevention measures to also not being able to access HIV-related information and services. The responsiveness to the unique needs of those with disabilities in these three countries has varied, but all three have a great deal more to do to meet the minimum level of services for persons with disabilities.

Persons with disabilities face multiple challenges accessing HIV services within health facilities.

THE RESPONSE

Recent years have seen a growing recognition that persons with disabilities are at risk of HIV yet less likely to access HIV services[6]. The United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted in 2006, advocates equal access to health care including sexual and reproductive health[7]. More than 30 countries in sub-Saharan Africa have signed and/or ratified the CRPD. However, while some African countries recognize the needs of persons with disabilities in their NSPs, only a few have made concerted efforts to make services and materials accessible to those with disabilities.

To better understand the HIV-related needs and challenges of persons with disabilities and improve HIV and sexual and reproductive health programming for them, HIVCore and partners conducted a three-country situation analysis in late 2012. The study explored

existing HIV services for persons with disabilities, determined the factors affecting access to and use of HIV services, and identified opportunities and gaps for addressing HIV service needs among persons with disabilities. The findings are intended to guide the implementation of disability-inclusive programming.

The study took place in Uganda, Zambia, and Ghana—which span the continent and represent different degrees of responsiveness to persons with disabilities. Uganda is considered a "high recognition" country: its NSP identifies disability as an issue for HIV programming, requires inclusion of persons with disabilities in sexual and reproductive health services, and recognizes the need for specific impact mitigation and support services for persons with disabilities.[5] Uganda was also the first of the three countries to sign (2007) and ratify (2008) the CRPD. Zambia is a "moderate recognition" country: its NSP does not specifically identify disability as an issue but does reference disability in its response.[5] Zambia signed the CRPD in 2008 and ratified it in 2010. Ghana is considered a "low recognition country": its NSP does not recognize disability in any manner. When this study started, Ghana had signed (2007) but not ratified the CRPD; ratification took place in July 2012.

In order to make HIV programming truly inclusive for persons with disabilities, it is crucial to understand disabilities and HIV programming from the perspectives of all those involved.

The study seeks to understand disabilities and HIV programming from the perspective of a variety of stakeholders. Thus, fieldwork included the following activities, which took place in both the capital city and one rural site in each country:

1. Forty-eight focus group discussions with persons with disabilities (blind, deaf, and physically disabled) and caregivers of persons with intellectual disabilities. Participants were grouped according to their disability and sex. Separate focus group discussions were conducted with those who self-identified as living with HIV. The focus groups sought to understand participants' needs and challenges with regard to access to HIV-related information and services, their experiences with HIV-related services, and their views on making these services more accessible and responsive to their needs.
2. Twenty-five structured interviews with HIV service program managers to gather information about available HIV and sexual health services, including those that are disability-inclusive or disability-targeted.
3. Twenty-one key informant interviews with government officials and local program managers of HIV services and targeted programs for persons with disabilities. The interviews examined challenges respondents face in tailoring existing programs to persons with disabilities and explored their views on making HIV services more accessible and responsive to persons with disabilities.

Creating accessible HIV-related materials, such as pamphlets in Braille for the blind, is an important step to respond to the needs of those with disabilities.

The study protocol was reviewed and approved by the Institutional Review Board of the Population Council, The AIDS Support Organization (TASO) of Uganda, the Uganda National Council for Science and Technology, the Ethical Research Committee of the Ghana Health Services, and the Research Ethics Committee of the University of Zambia. In addition to a trained research team, each country formed an advisory board to provide guidance on study design, study instruments,

results interpretation, and dissemination. Board members (see Box 1) included representatives from local nongovernmental organizations (NGOs) representing the various disability communities (i.e., blind, deaf, physically disabled, and developmentally/intellectually disabled).

PRELIMINARY FINDINGS

Despite their geographic diversity and varied policy environments regarding persons with disabilities, study findings were quite similar across the three countries.

Persons with disabilities felt they were at high risk for HIV. Participants indicated that limited access to HIV prevention information, services, and commodities made them less able to protect themselves against HIV.

> *…[I] am blind, I will not go to the health center, people will laugh at me.... Supposing I went and told this health worker now I have come for HIV services, the health worker will ask herself how I contracted HIV yet am blind. Therefore we still have very low esteem; we are not very confident. We stay back because we fear going out there….*
>
> —Female, 30, blind and physically disabled, Kampala, Uganda

They also cited a number of vulnerabilities that may increase their HIV risk, including high levels of sexual abuse, being less discriminating about their sex partners, and community perceptions that having sex with persons with disabilities can cure HIV.

> *The female persons with disability are more vulnerable and the culprits are able bodied men because they think female persons with disability are not promiscuous...and are not infected with HIV.*
>
> —Male, 37, physically disabled, HIV positive, Lusaka, Zambia

Persons with disabilities face particular challenges accessing HIV services. Facilities delivering services for the broader population do not meet the needs of persons with disabilities. Transportation challenges and escort requirements often render facilities physically inaccessible. Even upon reaching the health facilities, participants cited long queues and poor infrastructure, lack of confidentiality, stigma toward persons with disabilities, inaccessible HIV informational materials, and lack of skills and sensitivity of providers in working with persons with disabilities.

> *Some of the nurses don't have patience for us, they can pull you here and there and inject you anyhow, sometimes shout on you, "So if you are blind, are you also deaf, can't you hear what I am saying?"*
>
> —Male, 39, visually impaired, Amasaman, Ghana

BOX 1 COMMUNITY ADVISORY BOARDS

Ghana	Uganda	Zambia
Ms. Rita Kyeremaa (Co-Investigator) *Ghana Federation of the Disabled*	Mr. Edson Ngirabakunz (Co-Investigator) *National Union of Disabled Persons of Uganda*	Mr. Felix Mutale (Co-Investigator) *Formerly with Zambia Agency for Persons with Disabilities*
Mr. Yaw Ofori-Debrah *Ghana Association of the Blind*	Mrs. Rose Acayo *National Union of Disabled Persons of Uganda*	Mr. Sylvester Katontoka *Mental Health Users Network of Zambia*
Mrs. Bruce Lyle *Ghana Society of the Physically Disabled*	Mrs. Robinah Alamboi *Mental Health Uganda*	Ms. Merreny Kalomba *Zambia Federation of Disability Organisation*
Mr. Kofie Humphre *Mental Health Society of Ghana*		

Many stakeholders lacked knowledge and skills to provide services to persons with disabilities. Stakeholders expressed frustration that they do not have the skills to provide services for this population. While they acknowledged that they needed training, they also cited limited funding for the tailored, resource-intensive services needed for persons with disabilities.

Nonetheless, some respondents did cite progress. In Uganda and Zambia, some organizations and providers use outreach and home-based care to deliver medications and health services to persons with disabilities. TASO in Uganda uses sign interpreters in some facilities to offer HIV testing and counseling. Zambia National Federation of the Blind provides information about HIV and then refers persons with disabilities to a clinic for the actual testing.

THE IMPACT

The findings from this assessment will inform country stakeholders as well as donors on existing HIV and disability programming, highlight gaps in programs and policies, document best practices, and make recommendations for ensuring the persons with disabilities have access to appropriate HIV and sexual and reproductive health services.

ENDNOTES

[1]Frontera, W.R. 2012. "The world report on disability," *American Journal of Physical Medicine and Rehabilitation* 91(7): 549.

[2]Groce, N. E. et al. 2004. *Global Survey on HIV/AIDS and Disability*. Washington, DC: World Bank.

[3]Groce, N.E. 2003. "HIV/AIDS and people with disability," *The Lancet* 361(9367): 1401–1402.

[4]Hanass-Hancock, J., A. Strode, and C. Grant. 2011. "Inclusion of disability within national strategic responses to HIV and AIDS in Eastern and Southern Africa," *Disability and Rehabilitation* 33(23–24): 2389–2396.

[5]Hanass-Hancock, J. 2009. "Disability and HIV/AIDS—a systematic review of literature on Africa," *BioMed Central* 12: 34.

[6]CRPD, Article 25.

For more information about this study, contact Waimar Tun (wtun@popcouncil.org).

NEW PUBLICATIONS FROM HIVCORE

Available at www.hivcore.org

HIVCore Operations Research Workshop Summary Report, Washington, DC, 21 July 2012
In order to obtain input from program managers as well as share its research agenda, HIVCore convened an operations research (OR) workshop for selected national-level HIV program managers and researchers attending the International AIDS Society conference in July 2012 in Washington, DC. This report summarizes the proceedings of the workshop. These discussions are an important contribution to the refinement of HIVCore's OR framework and agenda. It is also hoped that, as a result of this workshop, participants will be better able to apply OR principles in their respective settings as a simple, problem-solving approach to program improvement.

From Problem-solving to Research Utilization: How Operations Research and Program Evaluation Can Make Programs Better
Operations research (OR) and program evaluation can help managers be more systematic in examining existing program information, collecting new data if needed, and looking for alternative solutions. This brief discusses the challenges program managers, researchers, and evaluators face to produce data that are good enough to answer the question at hand in a cost-effective manner that respects the privacy and confidentiality of program beneficiaries as well as HIVCore's mandate in relation to OR and program evaluation.

IMPROVING MENTAL HEALTH AND REDUCING HIV VULNERABILITY

Mental health difficulties in childhood and adolescence are associated with various negative social and health outcomes, including addiction to harmful substances and increased risk taking behavior, which can predispose young people to HIV infection. Evidence indicates that difficult situations, such as when children move from rural to urban areas for educational or work opportunities or to escape hardships in their homes, are risk factors for mental health problems.

In response to the growing number of migrant adolescents in Ethiopia and their attendant mental health needs, HIVCore and local partners are developing and evaluating approaches to identify and address key mental health and psychological problems among marginalized adolescents and reduce their vulnerability to HIV.

HIVCore and local partners are developing and evaluating approaches to identify and address key mental health issues among marginalized adolescents to reduce their vulnerability to HIV.

CHILD MIGRATION IN ETHIOPIA

As more Ethiopians seek new opportunities in urban areas, there is increasing concern with the rural-urban migration of children who are seeking better job or educational opportunities.[1] Many migrant children have little or no education and end up living on the street or as a domestic worker.[2] Migrant girls are at risk of coerced, transactional sex, and exploitive labor, including child domestic work with extremely long hours and low pay. These girls also experience significant forms of psychological stress due to social exclusion, including lack of friends, community support networks, and group membership. In addition, these girls have also been found to have lower self-esteem and levels of HIV knowledge.[2, 3]

Young migrant boys in Ethiopia are in similarly precarious situations. Many live on the street with no guardian or place of residence, and are at high risk of sexual abuse and exploitation. A 2009 study found that 29 percent of male street children in the Merkato area of Addis Ababa had been sexually abused—likely an underestimate since the majority of abuse cases go unreported.[4] This type of abuse affects children's physical, social, and psychological well-being, especially those without traditional social protections.[4]

ADDRESSING THE PROBLEM

In response to these challenges, the HIVCore research team is working with two service delivery programs

Adolescent boys from the Retrak program participate in a community awareness raising activity, one component of the study intervention.

in Addis Ababa to incorporate mental health programming into their ongoing activities. *Biruh Tesfa* (Amharic for 'Bright Future'), a joint program of Population Council Ethiopia and Regional Bureaus of Women, Children and Youth Affairs, provides migrant girls with referrals to counselors, psychologists, and medical staff for routine check-ups and sexually transmitted infection testing as well as basic education, life skills training, and mentoring. Retrak works with boys living on the street, offering them food, shelter, education catch-up classes, medicine, and voluntary HIV testing and counseling services, with the ultimate aim of enabling them to return to their families.

Mental health difficulties in childhood and adolescence are associated with negative social and health outcomes...which can predispose children and adolescents to HIV infection....

This two-year study from February 2012 to March 2014 consists of three phases: formative assessment (completed), adaptation and validation of a psychometric screening tool and development of intervention content (completed), and implementation and evaluation of the intervention (ongoing). Each phase has been approved by the Population Council and the Addis Ababa Health Bureau Institutional Review Boards.

FORMATIVE PHASE

Working with Biruh Tesfa and Retrak, researchers conducted in-depth interviews with 30 service recipients aged 15–24 and 11 service providers, including social workers, counselors, mentors, and nurses.

Findings from the formative study corroborated previous impressions of Biruh Tesfa and Retrak staff regarding the mental health and HIV vulnerabilities of migrant adolescents in Addis Ababa. Both girls and boys mentioned experiences with violence either prior to or after migrating.

> *I know this girl who lives around where I live…. She was raped by a drunken person when there was no one at her house late at night…. After examination at health center they told her that she has HIV. Now I feel pity for the girl.*
>
> —Biruh Tesfa service recipient

Girls and boys also described occupational hazards and situations that put them at risk for acquiring HIV, including catering for overnight customers in lodges, alcohol consumption, and forced sex by peers.

> *Data collector (DC): Was he part of your group?*
>
> *Respondent (R): No he was not. He came to us to let him sleep with us. He was big.*
>
> *DC: He came to you?*
>
> *R: Yes he was permitted to sleep. Then he sexually abused a child. The child told the group in the morning. Then they took him to police. He was put in prison.*
>
> —Retrak service recipient

In addition to physical and sexual abuse, many adolescents reported being socially isolated and sad, indicating substantial psychological stress:

> *They become sad from the pressure they face by their employers, lack of sleeping place.... There are some children who cry...and they tell us it is because of their employers who blamed them for stealing and so on...they share their problems with friends in school.*
>
> —Biruh Tesfa service provider

These situations can take a toll on the psychological well-being and mental health of young people, who are already at a vulnerable stage in their lives, resulting in further social isolation and increased risk-taking behavior.

MENTAL HEALTH SCREENING TOOL

The in-depth interviews also demonstrated that specific mental health needs varied from person to person. Thus, standardized screening procedures can identify adolescents needing mental health services and pin-point their specific issues, if any.

In partnership with an Ethiopian team of psychologists, psychiatrists, and counselors, the HIVCore study team adapted an international psychometric screening tool—the Achenbach Youth Self Report (YSR) for young people aged 11–18 years—for the Ethiopian context, including translation into Amharic (See box 1). To test the validity of the adapted tool, trained nurses and counselors administered it to consenting young people, aged 15–18, receiving services at Biruh Tesfa and Retrak. While the tool was originally designed to be self-administered, due to the low literacy levels in the study population the project team decided that the tool should instead be administered by a clinical nurse. A psychiatrist then carried out an independent, clinical assessment of each study partici-

In addition to physical and sexual abuse, many adolescents reported psychological and emotional abuse, including being belittled and being bullied.

BOX 1
ADAPTED MENTAL HEALTH SCREENING TOOL

Intended audience: Ages 15–18 years

Location: Ethiopia

Language: Amharic

Time: 1 hour

Method of administration: Clinical nurses

Content: There are two sections of the screening tool.

The *social competency section* includes questions on the following three areas:

- Involvement in activities
- Social interaction patterns
- Education experience and achievement

Examples of topics included in the *behavioral profile*:

- Anxiety/depression
- Withdrawal/depression
- Social problems
- Aggressive behavior

Source: Adapted from Achenbach Youth Self Report for Ages 11–18 years., www.aseba.org

pant. HIVCore researchers compared the psychiatrist's clinical diagnosis to the outcomes of the screening tool to determine if it accurately reflects mental health status.

To assess the reliability of the screening tool, each participant was re-screened one month after the initial screening; comparison of the two screenings determined whether the tool consistently yielded similar results.

HIVCore researchers made final adjustments to the instrument on the basis of both reliability and validity testing. Biruh Tesfa and Retrak service providers are administerng this tool to identify study participants with psychological/mental health problems and prioritizing them to receive appropriate psychosocial support.

INTERVENTION AND EVALUATION PHASE

The study researchers, in collaboration with program staff, developed a three-month intervention comprising one-on-one counseling, group counseling, art therapies, and community engagement activities. The intervention is currently being pilot-tested with service recipients ages 15–18 and refined accordingly. To assess the effectiveness of the intervention, researchers will administer a social-behavioral assessment tool at the beginning and end of the intervention to measure changes in HIV-related outcomes among beneficiaries (e.g., knowledge of HIV-related services). The tested mental health screening tool will also be administered at pre- and post-intervention to measure changes in mental/psychological well-being.

IMPACT

The HIVCore team intends to use the results and lessons learned from this study to draw attention to the often overlooked role of mental health in HIV vulnerability. This study will highlight the factors causing psychological stress among migrant adolescents, and enable policy makers and key stakeholders to design strategies for increasing psychosocial well-being and reducing vulnerability to HIV.

ENDNOTES

[1]Erulkar, A. S. et al. 2006. "Migration and vulnerability among adolescents in slum areas of Addis Ababa, Ethiopia," *Journal of Youth Studies* 9(3): 361–374.

[2]Erulkar, A. and A. Ferede. 2007. "Social exclusion and early or unwanted sexual initiation among poor urban females in Ethiopia," *International Perspectives on Sexual and Reproductive Health* 35(4): 186–193.

[3]Erulkar, A. and T. A. Mekbib. 2007. "Invisible and vulnerable: Adolescent domestic workers in Addis Ababa, Ethiopia," *Vulnerable Children and Youth Studies* 2(3): 246–256.

[4]Tadele, G. 2009. "'Unrecognized victims': Sexual abuse against male street children in Merkato area, Addis Ababa," *Ethiopian Journal of Health Development* 23(3): 174–182.

For more information about this study, please contact Sam Kalibala (skalibala@popcouncil.org).

HIVCORE STUDIES

HIVCore is initiating a range of operations research studies and program evaluations. The below studies are in various stages of development. For more information, please visit www.hivcore.org.

Country	Study Synopsis
Care and Support	
Ethiopia	Determine whether a psychosocial intervention for marginalized young people improves their responsiveness to HIV programs.
Ghana, Uganda, Zambia	Describe and identify factors affecting access to and use of HIV services for persons with disabilities as well as determine the gaps and opportunities within these services.
Global	Develop a pathway that leads to various care and support service delivery models for specific populations based on needs and vulnerabilities.
Haiti	Retrospective review with program staff and participants of a community-managed savings and internal lending community intervention for households affected by HIV.
Kenya	Evaluate a computerized alert and reminder system for medical providers to improve tuberculosis case finding and therapy for adults living with HIV.
Mozambique	Identify facilitators and barriers to linking HIV-positive patients to care, and evaluate interventions to address these barriers.
To be determined	Determine whether it is operationally feasible to implement universal tuberculosis testing in a defined group of people living with HIV who are likely to be at higher risk for active tuberculosis.
Gender	
Kenya	Evaluate the effects of addressing intimate partner violence within individual and couples HIV testing and counseling.
PMTCT/Pediatrics	
Cote d'Ivoire	Identify reasons for delays and loss to follow-up among each step of the PMTCT cascade and potential interventions to improve program effectiveness and design and implement an intervention study.
Kenya, Malawi, Rwanda, Swaziland	Assess retention across the PMTCT cascade in countries implementing WHO Options A, B, and B+.
Tanzania	Determine whether SMS reminders and notifications to mothers increase the proportion of HIV-exposed infants tested for HIV.
Zambia	Evaluate the effectiveness of the PMTCT program in reducing newborn infection rates and improving child survival.
To be determined	Test the effectiveness of community health workers in increasing follow-up of PMTCT-enrolled mothers and HIV-exposed infants in their homes and encouraging them to attend PMTCT services and bring their infants for follow up.
To be determined	Explore the operationalization of pediatric ARV resistance monitoring using early warning indicators and test approaches to address identified gaps.
Treatment	
Kenya	Determine whether a cell-phone based counseling intervention can increase early initiation of and adherence to HAART among HIV-positive pregnant women.
Kenya and Tanzania	Conduct secondary analyses of patient-level data to identify factors that contribute to the uptake of continuation on HIV treatment.
Uganda	Compare different models of task shifting for delivering ART at the community level in terms of efficiency, patient satisfaction, knowledge, retention, and cost.
Uganda	Document ART retention and adherence among adolescents living with HIV.

HIVCore HIGHLIGHTS

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