Impact of community-led and community-based HIV service delivery beyond HIV:

case studies from eastern and southern Africa

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TABLE OF CONTENTS

ABBREVIATIONS

AIDS	acquired immunodeficiency syndrome
ASWA	African Sex Workers Alliance
BONELA	Botswana Network on Ethics, Law and HIV/AIDS
COVID-19	coronavirus disease 2019
GDX	Gender DynamiX
GIPA	Greater Involvement of People Living with HIV/AIDS
Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
HIV	human immunodeficiency virus
KELIN	Kenya Legal and Ethical Issues Network on HIV and AIDS
LGBTQI	lesbian, gay, bisexual, transgender, queer, intersex
RMU	Rainbow Mirrors Uganda
SDGs	Sustainable Development Goals
SWEAT	Sex Workers Education and Advocacy Taskforce
TASO	The AIDS Support Organization
TB	tuberculosis
TNU	Tranz Network Uganda
UYP	Uganda Young Positives
WHO	World Health Organization
WOFAK	Women Fighting AIDS in Kenya

Introduction

The United Nations Member States' commitments of 2016 and 2021 to end AIDS by 2030 recognize the importance of community leadership in the HIV response. Through the Greater Involvement of People Living with HIV/AIDS (GIPA) principles, the meaningful inclusion of networks of people living with HIV and affected communities in the HIV response is necessary in decision-making, planning, implementation and monitoring *(1)*.

Communities of people living with or affected by HIV have been at the forefront of delivering HIV-related health services and critical social inclusion responses since the start of the HIV pandemic. They deliver health services (e.g. health promotion, retention, screening and testing, antiretroviral therapy), encourage community mobilization, create demand for services, and increase legal literacy. At the same time, they facilitate social inclusion, social justice and social protection, and promote the rights of people from marginalized populations by addressing health determinants and enhancing opportunities and access to resources and services *(2)*.

In the context of universal health coverage, all people should have access to the full range of good-quality health services they need, when and where they need them, without financial hardship. This covers the full continuum of essential health services, from health promotion to prevention, treatment, rehabilitation and palliative care across the life course *(3)*.

Not every country in eastern and southern Africa has achieved universal health coverage, but 75% have integrated universal health coverage as a goal in their national health strategies *(4)*. Translating resources for health and development assistance into equity, good-quality health services and financial protection has been slow *(5)*. Universal health coverage cannot be reached by delivering health services in clinics without considering political, social and economic factors. Community-led organizations have challenged pervasive social and economic inequalities to protect the right of communities to health.

Community responses to HIV can contribute significantly to achieving universal health coverage. With more than two decades of experience in HIV service delivery, community-led organizations hold duty-bearers accountable and shape the ecological systems of health delivery processes. When health systems are people-centred, communities make the most of the critical decisions in the system by accessing services as clients; setting rules and allocating resources as policy-makers; or dealing with those rules as implementers, managers, providers and service users *(2)*.

Community-led services have several benefits, including demand creation, rapid scale-up of interventions, and improved health outcomes *(3)*. Community-led services are critical to achieving universal health coverage and beyond. Achieving universal health coverage means that "all people have access to the full range of quality health services they need, when and where they need them, without financial hardship" *(5)*.

> "all people have access to the full range of quality health services they need, when and where they need them, without financial hardship"

Many people in developing countries have substandard access to health services. The World Health Organization (WHO) and the World Bank estimate that at least half of the world's population is underserved *(5)*. Health is not the only concern for these people—for example, socioeconomic conditions may push people into poverty, and they may have to pay for health-care services out of pocket.

The eastern and southern African region struggles with huge health inequalities along sociocultural, economic and political fault lines *(6)*. The region needs to reach people from marginalized communities with health services. About 20.8 million people in the region were living with HIV in 2023 and 450,000 people newly acquired HIV. About 83% of these 20.8 million people were receiving antiretroviral therapy. Treatment coverage in the region ranges from 22% in Madagascar to 96% in Rwanda *(7)*.

Punitive laws that criminalize people from key populations marginalize many communities *(8)*. This reality and the high disparities in treatment coverage between countries reflect the disparities across countries and among the diverse populations of people living with HIV in each country.

The increasing burden of chronic lifestyle-related conditions is alarming. The advent of health emergencies such as COVID-19, Ebola and yellow fever underscores the vulnerability and fragility of public health systems.

The role of non-state actors and civil society in expanding access to HIV services remains central to achieving health outcomes. The success of universal health coverage depends on delivering services closer to where people are, and for services to meet people's needs without them having to pay. It is critical to learn lessons from HIV communities in delivering community-led and people-centred health services.

Whether formally or informally organized, UNAIDS describes community-led organizations, groups and networks as "entities for which the majority of governance, leadership, staff, spokespeople, membership and volunteers reflect and represent the experiences, perspectives and voices of their constituencies and who have transparent mechanisms of accountability to their constituencies. Community-led organizations, groups, and networks are self-determining and autonomous, and not influenced by government, commercial, or donor agendas. Not all organizations that are based in community settings are community-led" *(9)*.

Community-led responses are "actions and strategies that seek to improve the health and human rights of their constituencies, that are specifically informed and implemented by and for communities themselves and the organizations, groups and networks that represent them" *(9)*.

Through community-led and people-centred approaches, services relevant to the needs of affected populations can be delivered to where people are—thus challenging the notion of "difficult-to-reach" populations.

Case studies
of HIV community-based and community-led service delivery

The objectives of the research presented in this report were to:

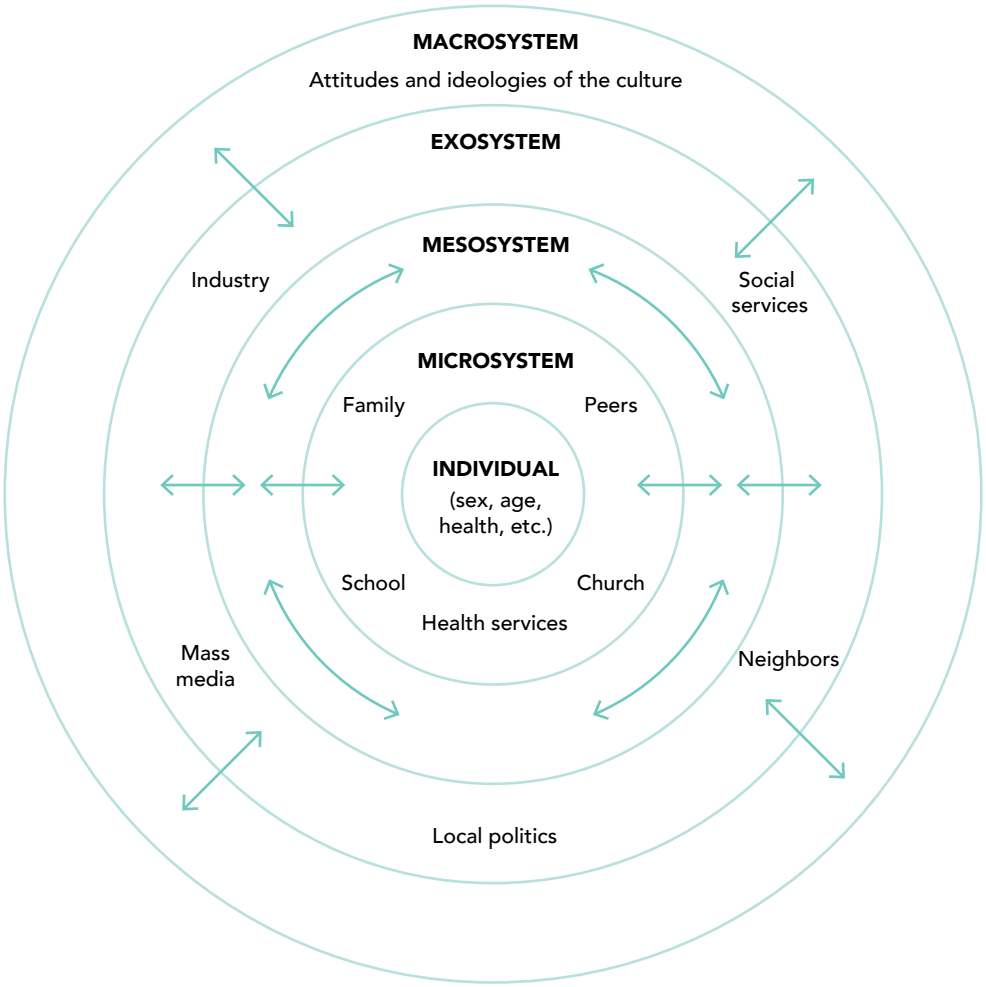
- Identify case studies of community-led HIV-related health and social inclusion service delivery organizations in eastern and southern Africa.
- Describe the typologies of the services provided.
- Identify evidence of their service delivery and contribution beyond HIV, including advancing universal health coverage.

The study reviewed 22 organizations across nine countries in eastern and southern Africa and Burundi in central Africa. Of these, 17 were included as case studies (16 in eastern and southern Africa, one in Burundi). The report presents carefully selected case studies from community-led organizations in the region whose HIV service delivery demonstrates potential impact beyond HIV.

ECOLOGICAL SYSTEMS APPROACH

The study used ecological systems theory to analyse people-centred and community-led service delivery approaches used by the 17 organizations. This approach recognizes that complex multiple factors affect people's health and well-being (Figure 1).

FIGURE 1. BRONFENBRENNER'S ECOLOGICAL SYSTEMS APPROACH



The ecological systems approach highlights the five environmental systems with which people interact. A systems framework helps to understand inherent socioeconomic and health inequalities and their negative effects on well-being. This approach also accepts that people are not passive in their environment and can influence and shape health services over time *(10)*.

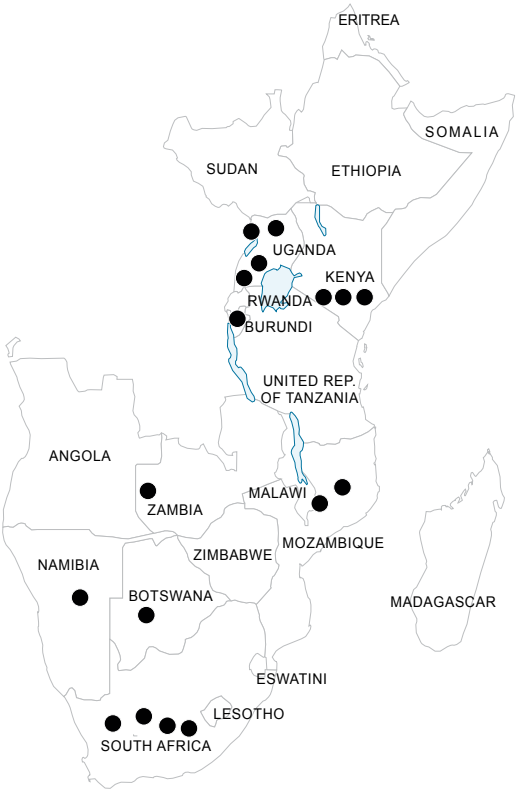
An holistic multisystem approach to health and development is critical for people living with HIV and their communities as active participants in shaping systems. This captures complex connections between individual, community, sociocultural, economic and political factors. Various intersecting factors shape community health systems and service delivery, such as socioeconomic factors (e.g. poverty), lack of access to basic health-care services, poor uptake of services, and social structures *(11, 12)*.

This model supports the belief that if health is viewed through a lens of medical, individual and physical conditions, the burden of care is placed on the person to prevent illness, change their behaviour and manage their conditions. In so doing, the context within which a person is vulnerable to ill health is overlooked. Socioeconomic factors are also critical enablers and structural barriers that must be considered.

METHODOLOGY

The study reviewed 22 organizations across nine countries in eastern and southern Africa and Burundi in central Africa (Figure 2). Of these, 17 organizations from eight countries were included as case studies on community-led and people-centred organizations delivering HIV-related health and social inclusion services.

FIGURE 2. SEARCH FOR AND SELECTION OF CASE STUDIES



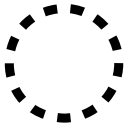
22 CIVIL SOCIETY ORGANIZATIONS REVIEWED

17 selected

- 4 UGANDA
- 3 KENYA
- 2 MOZAMBIQUE
- 4 SOUTH AFRICA
- 1 BOTSWANA
- 1 NAMIBIA
- 1 BURUNDI
- 1 ZAMBIA

Inclusion criteria were:

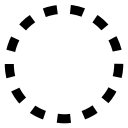
- Organizational self-identity.
- HIV, human rights and social inclusion services delivered.
- Provincial or national reach.
- Evidence of population or beneficiary involvement in leadership and service delivery.
- Track record of service delivery with partners and collaborators.
- Literature or reports available for 2015–2022.



Most of the data collated from the case studies are empirical and not available in published journal articles, but they do exist in grey literature. The case studies present a wealth of data and new insights. The data include organizations' annual updates and monitoring and evaluation reports. The personal experiences of activists as affected people often present nuanced data through direct engagement and shared spaces with fellow activists. Direct contact with practitioners or activists across community-led organizations likely to collect relevant data may offer researchers more dynamic data than extensive online searches.

There is an ongoing challenge to recognize the need to support large-scale research about the impact and contribution of community-led organizations in achieving health outcomes *(13)*. This is particularly important because the knowledge and science of community-led responses and people-centredness are produced within socioeconomic and political realities and actions. Community-led studies are often discredited as less rigorous or characterized as biased compared with large-scale, costly, randomized controlled studies *(14)*. There is often little recognition that all studies struggle to accurately define concepts and capture meaningful information, and that different methodologies serve different purposes. Community-led research, when done well, can investigate more deeply than large-scale quantitative studies into causes, effects, meanings and actionable outcomes.

CASE STUDY SELECTION, KEY INFORMANT INTERVIEWS AND DATA ANALYSIS



A total of 178 organizations whose website profiles matched the selection criteria were engaged to confirm the data found on their websites for interviews. Of these, 22 organizations agreed to be interviewed or to complete a questionnaire.

Open-ended semistructured interviewing is widely recognized as a valuable research method. In this study, it allowed respondents to talk about their experiences and communicate their attitudes and beliefs in their own words. It also enabled the investigators to explore specific issues in depth and to obtain information from the respondents and their circumstances.

The interviews were conducted online or by telephone. The questionnaire was self-administered and shared via email. All engagements were carried out in English.

The key informant interview contacts were distributed as follows: Botswana *(1)*, Burundi *(1)*, Eswatini *(1)*, Kenya *(4)*, Lesotho *(1)*, Mozambique *(4)*, Namibia *(1)*, South Africa *(12)*, Uganda *(6)*, United Republic of Tanzania *(2)* and Zambia *(2)*. The data from the interviews and documents reviews were coded for themes and analysis through NVivo 12.

The case studies were surveyed using Google Scholar, Google and websites. Codes were assigned to organize the data anonymously according to regional location, country name and interview number for NVivo 12 analysis. Before coding, an annotation scheme was defined. For example, a case study coded ESAUG06 was from Uganda (UG) in eastern Africa (ESA) and allocated interview number 06 during the survey process. The codes were added manually. The coding scheme ensured the codes were added consistently across the data set and allowed for verification of previously coded data.

Key informants gave consent to take part in the study. It was agreed that key informants would remain anonymous and their details kept confidential. To acknowledge their efforts in the study, it was agreed that the names of organizations would be included in the final report and presentation of evidence.

NVivo 12 as a qualitative data management software is useful for large data management and coding to allow ideas and issues from different sources to unify to build themes. NVivo 12 eased the process of interrogating and probing the data. The software accommodates various types of data, including interview transcripts, documents, pictures, videos and audio records, all of which were coded. The codes were organized into categories until the categories developed into broader themes. Creation of categories and allocation of data into classifications enabled a conceptual plan to emerge *(15)*. Themes were identified to describe commonalities and divergences in service delivery modes and broader social inclusion and engagements. This offered opportunities to understand underlying issues beyond descriptions and explanations. It also allowed for connections between micro-, meso- and macro-level factors to understand the socioeconomic and political influences in the work of communities.

The researchers developed a codebook from analysis of the transcripts and questionnaires that included seven parent codes, 29 child codes, and over 50 child subcodes in NVivo 12. The theme "direct service delivery" was the most common parent code. This theme included types of service delivery, collaborations and partnerships, links to other social protection services, organization highlights and challenges, and research and advocacy.

The second most common theme was "types and characteristics of organizations". This encompassed the organization age, formal/informal registration, primary focus, internal structures and evolution. The third most common theme was "contextual factors", which encompassed political, cultural, social and economic factors affecting the organization's functionality.

Informed consent was obtained for the key informant interviews. The definition of community-led organizations places an emphasis on the meaningful inclusion and involvement of people living with HIV, gay men and other men who have sex with men, people who use drugs, sex workers and transgender people in designing, implementing, managing and evaluating programmes *(14)*. UNAIDS defines community-led organizations, groups and networks, whether formally or informally organized, as entities for which most of the governance, leadership, staff, spokespeople, membership and volunteers reflect and represent the experiences, perspectives and voices of their constituencies and who have transparent mechanisms of accountability to their constituencies *(16)*.

Of the 17 case studies selected, nine are community-led organizations and eight are community-based organizations (Table 1). Community-led organizations are led by and for people living with HIV, women and people from key populations. The executive director and

the management and governance bodies are led by people living with HIV, women or people from key populations that the organization serves.

Community-based organizations provide services or support locally or nationally, in close proximity to the communities they serve. People living with HIV and people from key populations are on the board of directors, form part of management and deliver services. The majority of the governance, management and leadership bodies may not be people living with HIV or members of the key populations that the organization serves.

TABLE 1. ORGANIZATIONS INCLUDED IN THE CASE STUDIES

COMMUNITY-LED	COMMUNITY-BASED
Ahitipaluxene	Dlalanathi
Gender DynamiX (GDX)	Botswana Network on Ethics, Law and HIV/AIDS (BONELA)
Ishtar MSM	Kenya Legal and Ethical Issues Network on HIV and AIDS (KELIN)
Kwasha Mokwena	Kulima
Rainbow Mirrors Uganda (RMU)	MenEngage
The AIDS Support Organization (TASO)	Philani
Tranz Network Uganda (TNU)	Sex Workers Education and Advocacy Taskforce (SWEAT)
Uganda Young Positives (UYP)	TOV HIV/AIDS Orphans and Vulnerable Children Organization
Women Fighting AIDS in Kenya (WOFAK)	

AIM OF THIS REPORT

This report synthesizes findings from the 17 community-led and community-based case studies whose approaches to HIV-related health and social inclusion service delivery demonstrate impact beyond HIV. The report describes and analyses their service delivery and draws out evidence on how their approaches contribute to universal health coverage.

LIMITATIONS OF THIS REPORT

This report is not intended to include all the impactful work of the many community-led and community-based organizations that exist. Instead, it uses selected examples of community-led and people-centred HIV-related health and social inclusion services to demonstrate evidence of their work and impact.

The lack of face-to-face engagement and use of English as the only language of communicating with representatives from the organizations were limitations. Most community-led organizations are poorly resourced and have low capacity to transition swiftly towards regular use of digital tools and virtual engagement. The sole use of virtual means of engagement with participants may have limited the level and extent of responsiveness of the identified organizations.

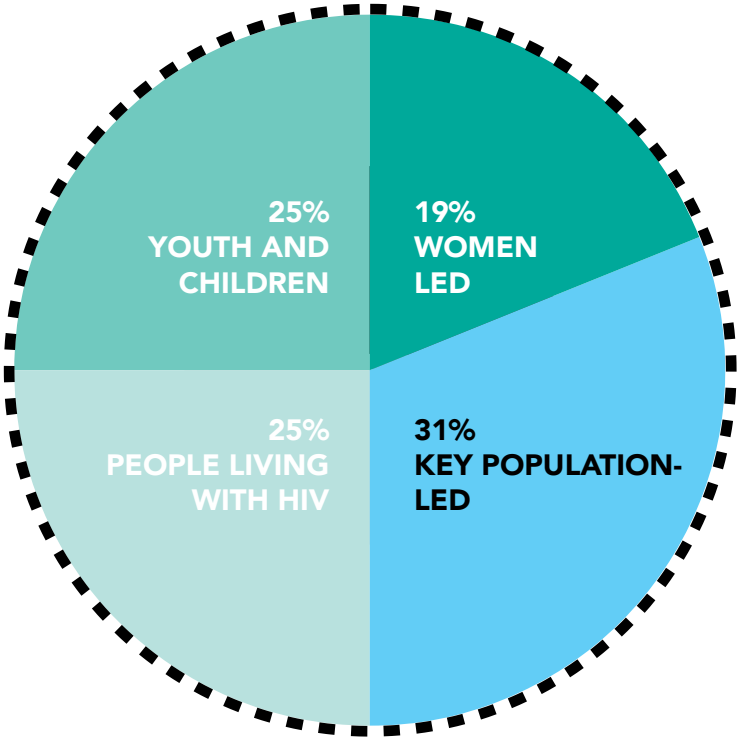
In addition, although English is one of the main official languages spoken in eastern and southern Africa, communities across the region are diverse and engagements at the community level are often carried out in local languages rather than English. Drawing reflections from representatives only in English limits the nuances and depth of narratives from their experiences, which are often linked to language familiarity.

All the organizations in the case studies offer HIV-related services, but their mandates and core constituencies characterize their unique contributions to the study (Figure 3). Key populations referenced in the category of "key population-led" include sex workers, gay men and other men who have sex with other men, and transgender people.[1]

One of the 17 case studies is not included in this categorization. The unique focus of Gender DynamiX (GDX) is on gender-based violence and engaging men and young boys. It is included in this study because of its added focus on an HIV gender lens.

1 The key populations referenced are based on the constituencies represented and served by the organizations included in the study. None of the organizations included in the study reported services specific for people who use drugs.

FIGURE 3. ORGANIZATIONAL MANDATE AND CONSTITUENCY OF CASE STUDIES



In this report, groups of people with shared interests delivering services to their peers and sharing a common geographical place form part of community-led organizations *(16)*.

Not all nongovernmental organizations included in this report are community-led. A few organizations rooted in local and national communities and their needs that bring together a broader group of allies, such as human rights lawyers and defenders working with affected community members, were also included.

Community-led organizations are community-centred groups of people and networks with shared interests, with affected people in the leadership, that deliver services to their peers, and that share a common geographical place. Community-led organizations are diverse in nature, as demonstrated by the case studies in this report. Community-led organizations, groups and networks are self-determining and autonomous, and are not influenced by government, commercial or donor agendas *(16)*.

The interviews identified themes on what makes the organizations in this report community-led. These organizations create mutually beneficial relationships between service users and providers. The social contract is critical to ensure inclusion through agency, voice and active participation of all communities in their diversity. People are empowered to participate and lead in their own and their community's health. Community-led health services are embedded in community systems to form inclusive partnerships between communities, health-care users and health-care providers.

The organizations in this report are community-led and people-centred because they are led by and employ peers as community health workers to deliver services to their peers. Community-led and people-centred services reach people where they are through outreach services, mobile services, drop-in centres and home-based testing. They create demand for

services through increased awareness of services through peer-to-peer support, and access to legal and human rights services. They expand the reach of health services and add human resource capacity to marginalized communities.

1 BOX
APPROACHES OF COMMUNITY-LED AND COMMUNITY-BASED SERVICE DELIVERY OF ORGANIZATIONS IN THIS REPORT

88% deliver diverse and differentiated services. The other 12% deliver single-approach services. All organizations in the case studies can adapt their approaches to continue reaching their constituencies.

76% offer mobile services, drop-in centres and home-based testing.

52% offer community mobile health service delivery (flexi-clinics, drop-in centres, wellness clinics, mobile clinics).

65% offer locally trusted health services through people-centred and holistic ways.

88% lend expert knowledge combined with lived experience from people living with HIV and people from key populations to inform and improve health-care service delivery.

65% facilitate inclusion through agency, voice and active participation of all communities in their diversity.

82% expand their reach by employing people from the community as community health workers, with significant impact in increasing human resources for health and access to health-care services for people from poor communities.

88% create demand for services by using peers to increase awareness.

MUTUALLY BENEFICIAL RELATIONSHIP
BETWEEN HEALTH SERVICE USERS AND PROVIDERS

Community-led services facilitate mutually beneficial relationships between providers and users of health services. This is central to strengthening social inclusion and respect for diverse voices in an ecological system, where people live and interact with each other and services. These mutually beneficial relationships are negotiated through moral and political behaviours that ensure sustainable systems. Achieving universal health coverage needs a level of social inclusion that ensures service users lead, influence and monitor the services they receive. Users of health services have not always been seen as active agents of their own care.

Involving users in decision-making, leadership and delivery follows the principle of "nothing about us without us", a slogan often used by people living with HIV. The GIPA principle is a good example of how involving people living with HIV in rights-based, equitable and nondiscriminatory ways is a cornerstone in providing effective good-quality services for people living with HIV *(1)*. Community-led organizations facilitate conducive and equitable engagement platforms for marginalized people.

Many key informants stated that service users lead their organizations. For example, Women Fighting AIDS in Kenya (WOFAK) is led by a woman director who is openly living with HIV. There is leadership of service users at the centre, and the people receiving services take on leading roles at all levels.

The GIPA principle provides a blueprint for the meaningful relationship between users and providers of services *(1)*. For example, the work of GDX secures access to direct services by brokering partnerships with service providers; facilitates linkages with service providers; and invests in and maintains databases of service providers. GDX activists continue to push for equal rights in access to health services. A key informant said: "Even where the legal and policy system is conducive, such as in South Africa, gender-affirming health-care services are mainly found and offered in urban settings, and many health-care workers lack the knowledge to prescribe and manage hormone therapy."

The social contract humanizes and de-medicalizes health by giving people living with HIV and people from key populations expert knowledge to shape service delivery worthy of inclusion in policy engagements.

"Even where the legal and policy system is conducive, such as in South Africa, gender-affirming health-care services are mainly found and offered in urban settings, and many health-care workers lack the knowledge to prescribe and manage hormone therapy."

KEY INFORMANT

Case study profiles

AHITIPALUXENE

Ahitipaluxene[2] was formed in Mozambique in 2004 as a national association of women living with HIV. It is a community-led organization, led by women for women. It offers essential services to poor rural women, including HIV prevention and care services, food programmes, community development, home-based care, human and land rights advocacy, community financing (e.g. savings clubs), and economic skills development (e.g. making and selling clothes).

BONELA

The Botswana Network on Ethics, Law and HIV/AIDS (BONELA)[3] was established in 2002 as a national nongovernmental organization led by people living with HIV and people from key populations in Botswana. It is a community-based organization that focuses on human rights, access to and protection of services for sexual and reproductive health and rights, tuberculosis (TB), HIV and gender-based violence. It works with women, children, lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) people, migrant workers, sex workers, people with disabilities, people living with HIV, and people in prisons and other closed settings.

BONELA draws its membership from people and organizations that share its values and vision. The membership is organized into several sectors, including organizations led by and for populations most at risk, people living with HIV, the research, policy and law sector, trade unions, businesses and individual members. Members inform and help shape BONELA and ground it in a constituency that gives legitimacy to its work.

Its mission is to promote a just and inclusive environment to prevent HIV and provide a greater quality of life for people living with or affected by HIV by scaling up coordinated community responses and promoting accountability. Community members employed as staff members are involved in planning and delivering services.

DLALANATHI

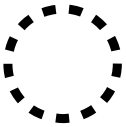
Dlalanathi[4] is a registered nongovernmental organization founded in South Africa in 2000. It is a community-based organization that delivers services to caregivers and children. It provides psychosocial support following trauma, loss and death by creating unique playful healing processes for children, youth, families and community stakeholders to restore relationships for positive action. It offers training on parental relationships, child protection and rights capacity-building for caregivers and other community-based organizations. It supports and trains children through play methodology to increase their capacity for expression of their thoughts, which is essential for resilience, mental health, development and connection with others. This affirms the value of children and relationships with their

2 https://www.facebook.com/associacaoahitipaluxene/

3 https://bonela.org/

4 https://dlalanathi.org.za/

caregivers. It offers family- and community-centred empowerment and healing to ensure independence and coping skills, and to strengthen and sustain relationships.

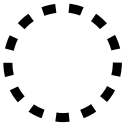


GDX

Gender DynamiX (GDX)[5] is a community-led grassroots organization. It is a transgender and broader gender-diverse movement established in 2005. It delivers services for peers though access to health services, including gender-affirming services, inclusive health care, legal reform and inclusive education.

GDX advocates for self-identification, self-determination, respect for diversity, inclusivity, meaningful participation, transparency and accountability. It seeks to position transgender and gender-diverse people through the realization of their autonomy.

GDX works with transgender people to advocate for gender-inclusive health policy and deliver services to other transgender people. It provides services for LGBTQI people, sex workers and transgender people. It incorporates health and social inclusion in its community services. It includes people from affected populations in planning, conceptualization of new projects, and delivery of services for transgender people.



ISHTAR MSM

Ishtar MSM [6]is a community-led organization established in Kenya in 1999. It is run by and for gay men and other men who have sex with men and male sex workers. It delivers peer-to-peer health and HIV services, including screening, counselling, and distribution of condoms and lubricants. It offers workshops and training on safer sex, peer education and counselling. It runs open forum discussions, post-HIV test clubs, and outreach drop-in health and HIV services.

Ishtar MSM is one of the founding members of the Gay and Lesbian Coalition of Kenya and is a lobbying and advocacy platform. In 2003, Ishtar MSM worked with the University of Nairobi and the Population Council to undertake operations research on understanding gay men and other men who have sex with men in Nairobi. It engages at the national policy level though the National AIDS Control Council to include gay men and other men who have sex with men in the Kenya National AIDS Strategic Plan.+

5 https://www.genderdynamix.org.za/

6 https://www.ishtarmsm.org/

KELIN

The Kenya Legal and Ethical Issues Network on HIV and AIDS (KELIN)[7] was formed in 1994 and registered as a nongovernmental organization in 2001. It is a community-based organization that uses a rights-based approach, prioritizing the principles of people-centeredness, accountability, equality and nondiscrimination. This approach ensures the involvement of people who are not experiencing their full rights, and duty-bearers who are obliged to protect rights.

Through a network of human lawyers, KELIN offers free legal and litigation services, with an emphasis on sexual and reproductive health and rights, HIV, TB and property rights. It facilitates access to legal services to protect and promote HIV-related rights of people from marginalized and key populations, including women and people in prisons and other closed settings.

KULIMA

Kulima[8] was established in Mozambique in 1984 and became a national nongovernmental organization in 1995. It is a community-based organization, with work embedded in community structures and with communities in leadership roles. Service delivery is led by affected communities. It offers services in rural development and social promotion programmes for women and children, including adoption, programmes for street children, and support for women.

In 2000–2003, Kulima committed to the emergency programme for major flooding in the southern part of Mozambique and encouraged other national and international nongovernmental organizations to cooperate and support affected provinces. Projects included constructing houses and social infrastructure.

KWASHA MUKWENU WOMEN'S GROUP

Kwasha Mukwenu Women's Group[9] is a community-led organization founded in Zambia in 1991. It is led by women concerned about the impact of HIV on women and children. It helps women and girls in Zambia with economic development through skills for self-reliance, establishing enterprises and gaining financial independence to prevent secondary vulnerability.

7 https://www.kelinkenya.org/

8 http://www.kulima.org/joomla3/index.php/en/quem-somos-3/equipa-da-kulima-2

9 https://zambiasocietytrust.org.uk/blog/kwasha-mukwenu-help-your-neighbour-matero-lusaka-project-update

MENENGAGE BURUNDI

MenEngage Burundi[10] is a network of men's and boys' community-based organizations. It is a community-based organization that works in partnership with other organizations to deliver services for HIV, gender-based violence, and sexual and reproductive health and rights. It conducts community mobilization to increase awareness among men and boys on their role in ending sexual and gender-based violence and in promoting healthy reproductive practices.

PHILANI

The Philani Maternal, Child Health and Nutrition Trust[11] is a community-based organization established in South Africa in 1979. Informal settlements have a critical voice in its leadership and service delivery. Philani improves health outcomes by combining indigenous community resources, knowledge and skills to promote family health, support for pregnant women, and care for babies and children. It uses peer-to-peer mentor mothers to deliver services for prevention of child malnutrition, rehabilitation of underweight children, and support for people with chronic diseases.

RMU

Rainbow Mirrors Uganda (RMU)[12] is a community-led network led by and for transgender youth communities. It was founded in 2015 as a youth-run network and is registered as a nongovernmental organization. It supports and enables young transgender people and groups to co-create people-centred health and HIV services, and to advocate for and influence policies in the areas of gender, sexuality, health, education, creative arts and governance.

RMU organizes and coordinates activities to promote, protect and advance the human rights of young transgender women, including transgender sex workers, by building leadership and strengthening transgender-led initiatives and movements. It strives to end discrimination against transgender sex workers and realize a society that achieves fundamental fairness and equality for all people.

10 https://menengage.org/country/burundi/

11 http://www.philani.org.za/

12 https://www.facebook.com/groups/883068058446796/

SWEAT

The Sex Workers Education and Advocacy Taskforce (SWEAT) was established in South Africa in the early 2000s. It is a registered nongovernmental organization with a 20-year history of advocating for and delivering services to sex workers. It is a community-based organization with sex workers in the leadership of organizational and service delivery. Its community-based HIV and wellness services go beyond the absence of disease—they also include physical, mental and social well-being, policy participation, human rights, legal advice and an advice call centre.

SWEAT has facilitated the birth of two movements—a pan-African alliance of sex workers (African Sex Workers Alliance, ASWA) and a national movement of sex workers (Sisonke). ASWA is now an independent organization based in Kenya, and Sisonke is moving towards independence in South Africa

TASO

The AIDS Support Organization (TASO)[13] is a community-led organization founded by people living with HIV in Uganda in 1987 and registered as a nongovernmental organization in 1991. It began as a community support group and grew into a national service organization. It is led by and for people living with HIV. Its first clients were people living with HIV who had been abandoned by their families. TASO now delivers health and HIV services across Uganda for people living with HIV. It primarily serves people living with HIV, but its services have extended beyond individuals to families and communities.

TNU

Tranz Network Uganda (TNU) is a transgender and gender-diverse network of almost 20 member organizations founded in 2014. It is a community-led organization that delivers HIV and health services such as community HIV counselling and testing outreach programmes. It creates support group spaces for transgender people living with HIV in Kampala and Wakiso for networking and psychosocial support. It offers peer-to-peer antiretroviral therapy adherence and follow-up, health literacy workshops and referrals.

TNU advocates for health data on transgender and gender-diverse people to be included in HIV prevalence data. It participates in national policy spaces to include the health needs of transgender and gender-diverse people (e.g. access to gender-affirming therapy) in the national HIV response.

13 https://tasouganda.org

TOV

TOV HIV/AIDS Orphans and Vulnerable Children Organization[14] is a faith-based organization established in Namibia in 2001. It is a community-based organization based in Tsumeb that provides physical, emotional, health, shelter and educational support to children who are orphaned or otherwise vulnerable due to HIV. It provides food produced in its own gardens by community members for children who stay in its shelter. It supports more than 230 children through its innovative community self-financing through farming project.

UYP

Uganda Young Positives (UYP) is a registered nongovernmental organization established in Uganda in 2003. It is a community-led network of more than 60 000 youth living with HIV. It is led by and for young people and their peers living with HIV in Uganda. It offers services to scale up prevention, care and support services for young people by creating demand for services among youth communities. It mobilizes, coordinates and empowers young people living with HIV to participation in the national HIV policy agenda.

WOFAK

Women Fighting AIDS in Kenya (WOFAK)[15] was founded in 1994 by a group of women living with HIV to provide services for other women and children living with or affected by HIV. It is a community-led organization that believes people living with HIV deserve to live decent and dignified lives without stigma or discrimination, and that everyone has a responsibility to act against any form of injustice. For more than two decades, WOFAK has worked with partners to overcome complex challenges and improve the lives of people living with or affected by HIV.

The founding group envisioned an organization that would provide a forum for mutual support and empowerment at a time when HIV-related stigma and discrimination towards women were very high. Since then, WOFAK has contributed significantly to national efforts aimed at preventing HIV and providing comprehensive care and support to women, youth and children living with or affected by HIV.

14 https://www.facebook.com/tovmpc.tsumeb/

15 https://www.wofak.org

Expanded community-led and community-based service delivery: **reach and impact beyond HIV**

This report identifies evidence of community-led and community-based HIV service delivery beyond HIV, including but not limited to access to health and advancing universal health coverage.

To ensure everyone has access to good-quality health services, many community-led organizations offer services beyond the health mandate. Their people-centred services take into consideration the conditions in which people live and evolve to address issues beyond HIV, such as access to health care, schools, employment, land, housing, water, working conditions, communities, towns and cities. Services acknowledge social dynamics such as social status, gender, age, ethnicity, and cultural norms and values.

People-centred community-led organizations tend to be fluid and flexible in their responses to change. KELIN has expanded from offering only HIV services to offering services for TB, sexual and reproductive health and rights, and women's access to land and property. UYP has expanded to cover holistic health issues and community development for young people in the urban slums and rural communities of Kenya. With over 18 years of experience working with the Kenyan Ministry of Health, UYP strengthens the voices of people living with HIV.

2 BOX
EXAMPLES OF EXPANDED SERVICE DELIVERY

DEMAND CREATION:
- Adaptation and response during the COVID-19 pandemic.
- Health promotion and health literacy.
- Peer-to-peer support for treatment adherence.

DIFFERENTIATED SERVICE DELIVERY:
- Home-based care.
- Mobile health clinics.
- Mentors and community health workers.

MENTAL HEALTH SUPPORT:
- Prevention of substance use.
- Response to gender-based violence.
- Child protection and trauma counselling.

SOCIAL PROTECTION AND SECURITY:
- Education and skills development.
- Food security and nutrition.
- Community-led innovative financing.

PROTECTION FOR HUMAN DIGNITY AND RIGHTS:
- Challenging stigma and discrimination.
- Women and land rights.

NAVIGATING THE POLITICAL AND FUNDING LANDSCAPE:
- Facilitating agency and participation.
- Tapping into community expert knowledge.

EVOLUTION OF SERVICES BEYOND HIV

The HIV epidemic and responses to it are subject to constantly changing political and resource-constrained contexts. This evolution also shapes community-led and community-based service delivery in the context of shifting political, resource and funding constraints.

This study found that socioeconomic and political environments influence the evolution of community-led services. Community-led organizations grapple with the evolutionary trajectory of health and related social services across different socioeconomic and political contexts over time. A Kulima respondent said: "Packaging health services with community empowerment, nutrition and education will ensure vulnerable communities and populations have more access to everything they need."

Communities expand the reach and uptake of services far beyond formal health facilities and empower people to advocate for their rights while holding governments accountable. To succeed in universal health coverage, services need to be expanded through community-led approaches rather than only through approaches that are public health system-focused, facility-based and doctor-dependent. Community health workers deliver a wide range of services, including counselling, home-based care, health education, adherence, livelihood support, and health services such as screening, referrals and surveillance.

Of the 17 organizations included as case studies in this report, eight (47%) offer outreach health and HIV prevention services.

TASO reached more than 1600 mothers with HIV testing and antiretroviral therapy in one year, increasing the number of people using elimination of mother-to-child transmission services to 20 288. In 2018, TASO tested 3685 babies for HIV.

In Kenya, Ishtar MSM reaches more than 3586 clients a year with HIV services from its wellness centre. The centre encapsulates the holistic approach of services beyond HIV. It offers HIV testing and counselling services, screening for sexually transmitted infections, treatment and referrals. It also distributes information, education and communication materials on health and HIV. Although the centre works mainly with transgender people and gay men and other men who have sex with men, it will serve any member of the community who needs its services.

Ishtar MSM supports community-based organizations to develop HIV prevention strategies based on distribution of condoms and lubricants and programming for sexually transmitted infections. Partners offer services across drop-in centres, clinics and wellness centres, which provide health information through peer-led programmes to mobilize and create HIV prevention awareness at hotspots.

"Packaging health services with community empowerment, nutrition and education will ensure vulnerable communities and populations have more access to everything they need."

KULIMA RESPONDENT

DEMAND CREATION FOR SERVICES

Creating demand for services through community mobilization is a vital service offered by community-led organizations. Health system-centric services often assume, wrongly, that communities are always aware of the services they provide. Demand creation during the COVID-19 pandemic helped to counter vaccination hesitancy *(17)*.

Improved access to services and broader coverage can follow rapid scale-up of interventions through demand creation. Demand creation involves mobilizing communities to shift and adopt healthy behaviours, seek health-care services, and adhere to treatment by increasing awareness for new and existing clients *(17)*.

Most of the organizations in this report create demand for their services. TASO uses peer educators in health literacy groups and one-to-one sessions to create demand for services. Discussion topics have included living with HIV, adopting risk-reduction strategies, treatment adherence, disclosure support, family planning, sexual and reproductive health and rights, domestic relations, gender stereotyping, positive health dignity and prevention of HIV.

Ishtar MSM retains and supports 150 community health volunteers in 10 of the 12 regions prioritized for TB programmes in Kenya. Volunteers facilitate public education to enhance TB treatment and prevention literacy among people living with HIV. Volunteers support directly observed treatment programmes through diagnosis and treatment referrals. They provide counselling, trace clients lost to follow-up, and link them back to facilities for re-treatment. Ishtar MSM works with community health extension workers and includes a school component to reach out to students and teachers with targeted messages around TB/HIV coinfection and multidrug-resistant TB.

Ishtar MSM peer educators work in 117 hotspots to provide essential support and mobilize people to access services. The use of peer-to-peer demand creation and outreach programmes in Nairobi led to a significant number of gay men and other men who have sex with men and male sex workers accessing services *(18)*. Demand creation increases awareness about the availability of services, and peers encourage each other to access services and share their experiences. Including services at all contact points and relevant facilities across communities in Kenya is vital. Ishtar MSM also trained 50 peer educators on community mobilization to reach out to gay men and other men who have sex with men.

DIFFERENTIATED SERVICE DELIVERY

HIV programmes are labour-intensive, which significantly impacts human resources for health and access to health-care services for people in poor communities. In eastern and southern Africa, there is an increasing burden of chronic conditions such as diabetes and hypertension, which has severely overloaded health systems in many countries *(19)*. Clients wait for long periods to receive care due to overcrowding and the resource-constrained operational contexts of HIV clinics. Innovations in HIV service delivery approaches are essential.

Increased demand for health services coupled with a shortage of professional health workers has led to innovations such as task-shifting. The need for differentiated service delivery has elevated the participation of communities in the delivery of health care. Such interventions are likely to be cost-effective from a societal perspective as they offer

a shift of specific tasks from overburdened and high-cost health-care settings directly into communities and community health workers. This has the added benefit of reducing transportation costs for clients by bringing services to the community.

Community-led health services can bring about inclusive, people-centred partnerships between health-care providers and service users by offering differentiated service delivery. WHO and leading global donors such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) and the United States President's Emergency Plan for AIDS Relief endorsed differentiated service delivery in 2016 as a novel evidence-informed HIV approach that relieves pressure on overburdened health systems and reduces frequent visits to facilities *(20)*.

Community-led and people-centred services reach people through outreach services, mobile services, drop-in centres and home-based testing. People are empowered to participate and lead in their own and their communities' health. Community-led mobile health clinics are an essential model for delivering health services to people from vulnerable populations and are impactful when providing differentiated, tailored and client-centred preventive health services *(21)*. Outreach mobile health clinics are often used in low- and middle-income countries to offer a wide range of health services closer to where people live, including for mental health (e.g. Dlalanathi, TASO, TNU), diabetes, HIV, sexual and reproductive health and rights (e.g. RMU, TASO, TNU), maternal and child health, nutritional assessment and counselling, and growth monitoring *(22)*.

In South Africa, Philani demonstrates the critical role played by community-led organizations in reaching marginalized communities with essential health services. Philani uses innovative human resources approaches such as a peer-led workforce. Philani engages trained mentor mothers living with HIV as community health workers in the Eastern Cape and Western Cape provinces to deliver maternal and child health services. Through a task-shifting approach, Philani deploys community health workers to six flexi-clinics in Cape Town to provide services in mothers' homes. A digital application provides real-time data on maternal and child health indicators and outcomes in the metropolitan areas of Cape Town. The mentor mother model has been adopted in other countries, including Egypt, Ethiopia and Swaziland, and a pilot study is operating in a refugee community in Malmö, Sweden.

A Philani informant said: "The mentor mother programme is to engage capable women to improve the lives of families within their communities, prioritizing mothers and children. In this way, the programme takes family health, including the nutrition and rehabilitation of children, beyond clinics and institutions and directly into people's homes."

In Mozambique, Ahitipaluxene provides Government hospitals with volunteers. In turn, Government hospitals provide nurses for Ahitipaluxene's home-based health-care services.

Community-led organizations in eastern and southern Africa positively impact the direct communities they serve. They are shifting the norms in health systems by expanding care models through community innovation and differentiated models of care and social inclusion within their settings. Community health workers and volunteers receive training, equipment and commodities to provide high-quality services at the community and health facility levels. The expansion of community-led HIV-related service delivery models that employ community health workers in Africa significantly impacts health-care services for poor communities *(22)*. In Kenya, Mozambique, South Africa and Uganda, community health workers and volunteers are connected to health facilities' social protection agencies and are directly accountable for their services to community structures.

To meet the needs of marginalized communities, health system efficiencies must be improved. People-centred approaches tailor their services to the needs of individuals, families and communities, rather than offering a one-size-fits-all undifferentiated model. It is well documented that community-led services improve HIV-related knowledge, attitudes, intentions, self-efficacy, risk behaviours, risk appraisals, health literacy, adherence and viral suppression *(14, 15)*.

For example, Ishtar MSM, SWEAT, TASO and UYP provide HIV testing and counselling for infants and adults, screening for sexually transmitted infections, treatment for opportunistic infections, and HIV adherence support groups as part of their services for hard-to-reach communities at outreach facilities such as drop-in centres and wellness and mobile clinics. Services include basic HIV care programmes, antiretroviral therapy initiation and adherence support, laboratory services (e.g. viral load monitoring) and CD4 monitoring.

UYP offers ongoing peer-to-peer support groups and counselling for young people living with HIV, covering youth-led treatment literacy, peer support and peer relationship-building.

Using mentor mothers, TASO offers routine HIV testing, retesting of all pregnant and breastfeeding women, early infant diagnosis, dry blood sample collection, staff training and mentorship, family planning, and HIV care and treatment services at 11 centres of excellence and 162 supported facilities. This has increased retention in HIV care at every step along the prevention of the mother-to-child transmission cascade *(24)*.

> "The mentor mother programme is to engage capable women to improve the lives of families within their communities, prioritizing mothers and children. In this way, the programme takes family health, including the nutrition and rehabilitation of children, beyond clinics and institutions and directly into people's homes."
>
> PHILANI INFORMANT

LINKING HEALTH, SOCIAL PROTECTION AND RIGHTS

Many health programmes do not integrate social protection services, but the community-led and community-based organizations in this report deliver services in a holistic way. Community-led organizations may essentially be funded to deliver health services—but because they are people-centred, they also offer services related to social protection. Health inequity often lays bare other inequalities that affect the same communities. Community-led organizations cannot limit their services to HIV and ignore the other needs of people in their communities.

WOFAK in Kenya and Dlalanathi in South Africa target their services to improve the psychological and emotional well-being of communities beyond HIV care. These organizations provide overlapping services, including services for health, social protection, education, economic empowerment, land rights, and basic needs for children and elderly people.

WOFAK was initially founded to provide Kenyan women with psychosocial support and a voice to deal with HIV-related stigma and discrimination. The organization has evolved to include youth and children living with or affected by HIV. WOFAK supports families with legal referrals, provides social inclusion for marginalized people, and advocates to hold policy-makers accountable.

MENTAL HEALTH SUPPORT

Mental health support is an essential service. The Ishtar MSM wellness centre for gay men and other men who have sex with men engages community members to understand and deal with issues around mental health. In Uganda, TNU offers mental health services to sex workers who use drugs and alcohol. Group sessions allow sex workers to share and cope with their challenges, including drug and alcohol use, risks of violence and disease, and antiretroviral therapy efficacy and adherence.

RESPONDING TO GENDER-BASED VIOLENCE

TNU provides sexual and reproductive health and rights services and promotes the acceleration of the Sustainable Development Goals (SDGs) to incorporate gender-based violence, mental health and economic empowerment into HIV programming. The TNU leader said: "[If] we can integrate mental health, economic empowerment, prevention of gender-based violence and HIV for sex workers, then our services will be comprehensive. Because we realize that many sex workers are not adhering to treatment, not because they do not want the treatment or do not know that they must take their medicines."

CHILD PROTECTION AND TRAUMA COUNSELLING

Death and loss are familiar experiences for many children in the region due to poverty, HIV, violence and other social issues. At the family or home level, Dlalanathi in South Africa focuses on building families through improved parent-led communication with youth

on sexual and reproductive health and rights. Dlalanathi links children with families and uses child-centred methodologies to provide psychosocial support services through the playmat model.

The Dlalanathi website states: "Play for healing is central to our work. We train local caring community members to run bereavement groups for children and caregivers who use play to reflect on death and loss, strengthen coping and improve relationships."

For children, play is essential for leisure, recreation, learning, communication, forming relationships and attachments with caregivers and other people, and developing social skills and awareness. Play offers access to freedom of expression, thought and opinion. Play is the language in which children express themselves and make meaning of lifechanging events, and a critical factor in learning to cope with difficulty and develop resilience *(25)*.

Dlalanathi child protection work includes sensitization on the risks facing children, safeguarding, and prevention of neglect, abuse and harm. It empowers parents and children with knowledge about their rights, including building community capacity to facilitate child participation processes, safety and remedies where needed. It uses participation processes that create safe spaces for children to talk about child protection and family support processes that focus on prevention and coping with use of alcohol and other substances.

Dlalanathi offers essential healing and psychosocial support to more than 265 bereaved children through weekly bereavement support groups in KwaZulu-Natal province. It also supports 237 caregivers and 733 children through family-based bereavement services.

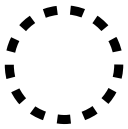
By increasing participation of children and youth within crucial structures in the community, GDX increases access to services for vulnerable children and youth in the KwaZulu-Natal province of South Africa. GDX creates an enabling environment for youth and children and engages parents and stakeholders to come together to talk openly about transgender and gender-diverse issues.

At the family level, Dlalanathi focuses on building family resilience through improved parent-led communication on sexual and reproductive health and rights among young people. Dlalanathi supports young people to prioritize and achieve their vocational and career goals, delay sexual debut, and access sexual and reproductive health and rights services through open communication with their parents.

> "[If] we can integrate mental health, economic empowerment, prevention of gender-based violence and HIV for sex workers, then our services will be comprehensive. Because we realize that many sex workers are not adhering to treatment, not because they do not want the treatment or do not know that they must take their medicines."
>
> TNU LEADER

Parental and family care is critical for children, particularly during the early child development phase. Parenting in the context of HIV, poverty, violence, loss and trauma is complicated by a high burden of care, the psychosocial and emotional impact of grief and loss, and caring for children originating from other families. GDX works to strengthen relationships for the optimal care and development of children in the home environment. Parents, grandparents, extended families and other adults in the household are encouraged to provide love and praise. Acknowledgement is the base on which all learning and positive parenting are built.

SOCIAL PROTECTION AND SECURITY



Health inequity overlaps with other socioeconomic rights injustices that affect the well-being of marginalized people. Service delivery by community-led organizations connects health, economic and social protection services to improve the conditions that cause ill health. Initially, Ishtar MSM and WOFAK offered HIV services to LGBTQI people and people living with or affected by HIV. They broadened their HIV service offerings to include other social protection services such as income generation, housing, employment and skills development to empower people's agency, power and choice in negotiating safer sex. Social protection services include public provision of essential utilities (e.g. water, sanitation, electricity), housing, education, health and social welfare. The provision of public goods and services comprises the building blocks of a fair and just society.

Ishtar MSM shifted its focus to encompass the entire well-being of gay men and other men who have sex with men, offered as one package of community development. The organization meets immediate needs for HIV treatment, protection from violence, housing assistance, counselling and therapy. It offers further assistance by promoting positive living, access to education, income generation and food security.

EDUCATION AND SKILLS DEVELOPMENT

Good-quality education and skills development are critical structural enablers for health and addressing social and gender inequalities. The school environment is meant to offer a common ground for improved livelihoods, but lack of resources in and out of school puts many children at a disadvantage *(26)*. In recognition of the role of education and skills development, some community-led organizations pay for school fees, uniforms, books and pens; offer training in business entrepreneurship skills and writing resumés; and run workshops to produce and sell handicrafts.

The case studies from Kenya, Mozambique, Namibia and South Africa demonstrate that community-led and people-centred organizations contribute to universal health coverage and address the SDGs.

UYP delivers its services beyond HIV for its community, including training on group dynamics and youth exchange visits. It offers skills development on entrepreneurship, creates platforms for young people to sell their products, helps young people register their enterprises, and runs training sessions on small grant and project proposal development.

UYP supports orphans and vulnerable children with its Big Brother Big Sister initiative, with referrals and linkages to school bursaries, legal support, treatment and career guidance.

Ishtar MSM, Philani and TNU provide skills development services. All Ishtar MSM staff receive training to build their resumés and work portfolios. In 2018, TNU provided life skills development services, including entrepreneurship and business skills, for more than 2000 people in Uganda, targeting sex workers, plantation workers, uniformed personnel, anglers, out-of-school youth, and community peer educators. Train-the-trainer courses are provided to people from key populations who are community health workers in the Ugandan districts of Jinja, Manafwa, Masindi and Tororo.

Philani began a development centre to teach women silk screen printing, weaving, linoleum printing, fresco painting, collaging and beading to provide them with income-generation skills to look after their families and come out of extreme poverty. Revenue is generated through sales of the handicrafts, with 65% paid to the women who produce the crafts and 35% retained by Philani to cover production costs.

WOFAK directly supports retention in school of orphans and vulnerable children, encourages their learning and enhances their self-esteem. It provides support with school fees, learning materials and uniforms. It offers psychosocial support, counselling, and follow-up home and hospital visits to households headed by grandmothers.

Ishtar MSM carries out home visits to encourage adolescent and teenage orphans and other vulnerable children to develop vocational skills such as embroidery, mechanics and tailoring. The women's groups in the programme raise funds and resources to support community members' needs and programmes, such as children's educational and socioeconomic needs *(27)*.

TOV supports 80 vulnerable young children with school fees, uniforms and equipment every month. TOV has strong links with the police, social welfare and child protection units. It offers incentives to reduce school dropouts, including offering payments for children to stay in school and pass their exams. The money is used to pay for food or books.

FOOD SECURITY AND NUTRITION

Some community-led organizations address food insecurity of families affected by poor health and HIV services. In Mozambique, Kulima demonstrates that expanding services to support children with basic needs is as critical as providing health services. Kulima supports vulnerable children with feeding programmes, providing meals for up to 250 children a day. Some Kulima volunteers sacrifice their stipends to pay for children's school fees.

In South Africa, the evolution of Philani was driven by the changing needs of the community. Philani adapted to offer holistic maternal and child health services as its primary focus. Through its Integrated Nutrition Programme, Philani offers five nutrition centres throughout Khayelitsha in South Africa. Poverty, food security and ill health are interconnected, so the organization also supports educational opportunities for women and children and income-generating opportunities as a logical evolution. The Educare programme is the primary focus of its nutrition centres. This aligns with the mission of promoting good child health and development, knowing that children who play enjoy developmental benefits and recover faster from illness and malnutrition.

In 2019, the Integrated Nutrition Programme offered medical care and nutrition support to 392 malnourished children, and 119 new clients entered the Programme. The Programme has eight peer counsellors who offer antenatal and postnatal breastfeeding support and guidance to new mothers through one-to-one and group sessions. The nutrition centres are located near government clinics for immunizations—Philani can refer children to the clinics through mentor mothers, and clinic counsellors can refer to Philani.

Philani provides children aged under 6 years with high-quality preschool education in a safe environment that supplies nutritious meals daily. In 2019, it ran 13 preschool classes in six centres in the Western Cape province and 10 classes in the Eastern Cape province, serving over 600 children *(28)*.

COMMUNITY-LED INNOVATIVE FINANCING

HIV and health problems have deep economic origins, with potentially severe implications for poor people. Inequalities in the context of education and income earning opportunities exacerbate risks and vulnerabilities of populations and households *(29)*. Even in its most basic form, access to microfinance services gives households a way to prepare for and cope with crises *(30)*.

Access to education, skills and jobs for women and girls is essential to redress gender inequities, particularly in Africa. Improving economic well-being by supporting and empowering women and young people with skills in microenterprise development and entrepreneurship for income opportunities helps to close poverty gaps *(31, 32)*.

WOFAK provides a microcredit services programme for poor women. It offers start-up for income-generating projects. At the time of this study, it had reached and supported 50 000 women through training and microcredit to run small-scale businesses, contributing to their well-being and reducing their vulnerability.

Ahitipaluxene offers group microcredit for people to start and maintain businesses. The organization maintains a database of the people it trains and their businesses and undertakes regular site visits to evaluate whether the strategy works. It also mobilizes young people through HIV treatment adherence support and post-testing clubs to encourage them to start income-generating activities to maintain their livelihoods.

Kulima supports people to rebuild their rural communities after natural disasters. It offers rural microcredit at 16 centres, annually benefiting 1 500 people.

TNU sells shoes to sex workers at a subsidized rate so the sex workers can then sell them to generate income. The organization recovers the original costs, and the sex workers keep the profits. Many sex workers have benefited from this scheme. TNU also runs a lubricants sales business, facilitating sex workers to be involved as agents to make an income.

Dlalanathi focuses on training communities on budgeting skills and offers savings loans. Through a partnership with social protection services, Dlalanathi has explored self-help saving and loans groups with young people in Cape Town while responding to critical development and health issues.

Community-led and people-centred service delivery addresses underlying factors to ill-health due to economic disempowerment and lack of financial resources for survival. There are few data on the details and impact of self-help savings and loans initiatives—this could be an area for future research.

Another way community-led service delivery organizations evolve is to include activities to raise revenue, which in turn sustains the support offered to their communities.

TOV began a poultry farm in 2020. Through a partnership with the private sector, the farm has 2000 chickens with the capacity to produce 1300 eggs a day. As well as using the eggs and meat to feed orphans and vulnerable children, TOV raises funds through the farm and creates jobs for the local community. TOV has developed six fishing ponds with the assistance of the Ministry of Fisheries and Marine Resources. It aims to harvest up to 25 000 African catfish and Nile tilapia a month, which will enable it to pay for school transport and washing machines.

Kulima supports its women's group to manufacture and sell a traditional Zambian drink to raise funds. The money is used to sponsor orphans and vulnerable children through school, buy food for the children's feeding programme, and pay rent for the building where the drink is manufactured.

Kwasha Mukwenu Women's Group purchased and converted a house into an office space and skills training centre for women and youth. The premises give prominence to the organization and provide a clean, safe environment for children to learn. The centre offers the community daily access to participate in income-generating activities, such as cooking, sewing and tie-and-dye. The cooking project has contracts with several local schools. The group makes clothes and uniforms and sells its cloth through local shops, conferences and special events.

In addition to the income-generating activities, Kwasha Mukwenu's youth wing helps orphaned adolescents to support themselves and their siblings and to learn as apprentices. At the time of the study, the feeding programme had stopped because the group had run out of funds.


MY
HEALTH
MY
RIGHT

PROTECTION FOR HUMAN DIGNITY AND RIGHTS

CHALLENGING STIGMA AND DISCRIMINATION

Stigma and discrimination are barriers to HIV-related health services and social inclusion for people living with HIV and people from key populations. UNAIDS defines HIV-related stigma as negative attitudes, feelings and beliefs towards people living with HIV, groups, families associated with people living with HIV and other key populations who are at high risk of HIV, including sex workers, transgender people, gender-diverse people, people who inject drugs, and gay men and other men who have sex with men *(33)*.

Discrimination is defined according to international human rights law as intent to nullify the recognition, enjoyment or exercise on an equal basis of others of all human rights and fundamental freedoms, in the political, economic, social, cultural, civil or any other field. HIV-related discrimination is therefore any distinction, exclusion or restriction (sometimes referred to as acts or omissions) based indirectly or directly on a person's real or perceived HIV status *(33)*.

Many transgender women, for example, are isolated, rejected and stigmatized in their communities, with no safe spaces. This may lead to homelessness, barriers to completing secondary or tertiary education, and unemployment. In addition to key populations being socioeconomically vulnerable, they are also excluded in health policies. Discrimination can be institutionalized through existing laws, policies and practices that focus negatively on people living with HIV and people from marginalized groups, including criminalized populations *(33)*.

A key informant from RMU said: "Culturally and politically in Uganda, transgender people are not recognized. They are not in any legal document apart from the health management document that recognizes us and puts us in the national strategic plan."

Despite the prioritization of key populations in national HIV plans and strategies, there is often insufficient budget allocation and programme implementation to address the needs of marginalized communities *(34)*. Stigma is a persisting barrier for many people living with HIV in accessing HIV and health services. Many people living with HIV and people from key populations face intersections of marginalization, including gender identity, sexuality, sex work and race, but few health programmes focus on structural change outside of community-led responses. Community-led approaches show promise in addressing stigma that manifests in HIV health services settings *(35)*.

In some countries, networks of people from affected communities are emerging, and regional networks now exist, such as for female sex workers and gay men and other men who have sex with men, to challenge these exclusions. For example, GDX, Ishtar MSM, RMU and TNU deliver services to gay men and other men who have sex with men and male sex workers who may not otherwise access services due to stigma, punitive laws, or the attitudes of health-care workers untrained in dealing with people from key populations.

Since 2015, UYP has undertaken human rights advocacy to demand decriminalization of sex work. It also supports actions by the network of sex workers to challenge the structural discrimination that excluded sex workers from accessing to comprehensive HIV, TB, and

sexual and reproductive health and rights services. UYP provides services and demand creation for viral load suppression and pre-exposure prophylaxis for sex workers and young women across Uganda, despite the hostile environment against sex workers.

The case studies demonstrate common challenges facing marginalized communities. In many African countries, same-sex sexual acts, sex work and gender identity are criminalized, culturally unacceptable, and socially and legally discriminated against—and therefore emerged as common themes *(36)*.

Of the countries in this study, Namibia, Uganda and Zambia criminalize same-sex sexual acts, and Kenya has a bill before Parliament that threatens to criminalize the LGBTQI community *(8)*. Other studies have found that in countries where same-sex sexual acts are criminalized, the number of people who know their HIV-positive status is 11% lower and viral suppression levels are 8% lower *(37)*. A study in 10 sub-Saharan countries found that HIV prevalence among sex workers is 11.6% in contexts with partial legalization, 19.6% within contexts without legal specification, and 39.4% within criminalized settings *(38)*.

The case studies demonstrate that community-based and community-led organizations can facilitate solidarity and challenge the laws and policies that stigmatize, discriminate and criminalize people from marginalized populations. Community-based and community-led organizations build agency and increase participation and power to influence policies and challenge toxic cultural norms and legal barriers.

UYP works primarily with adolescent girls and young women aged 15–24 years who identify as sex workers and their children to overcome the stigma and discrimination that arise from sociocultural attitudes and criminalization of sex work in Uganda. They engage with local leaders to shift cultural norms and attitudes around sex workers.

In South Africa, a GDX key informant said: "Health providers add to the problem because they have personal prejudices, such as not considering gender-affirming health care as essential. In instances where we offer health provider training, there is uptake. We have had to provide training for surgeons because we could not find any surgeons that are interested in the training."

Promoting gender-affirming health-care services is critical to realizing universal health coverage, because health-care workers lack the knowledge to prescribe and manage hormone therapy for transgender and gender-diverse people.

Most of the case studies demonstrate that structural barriers to health service delivery cannot be ignored. Some of their work targets cultural, gender and religious practices that negatively influence people's health. Examples from Botswana, Burundi, Kenya and South Africa make the case that people from affected populations can actively lead efforts to challenge structural barriers.

> "Culturally and politically in Uganda, transgender people are not recognized. They are not in any legal document apart from the health management document that recognizes us and puts us in the national strategic plan."
>
> KEY INFORMANT FROM RMU

Female sex workers bear a disproportionate burden of HIV and high levels of sexual and reproductive health morbidity *(39)*. Sex workers are highly vulnerable to HIV and other sexually transmitted infections due to multiple factors, including multiple sex partners, unsafe working conditions, and barriers to negotiating condom use. Sex workers often have little control over these factors due to social marginalization and the prohibitive legal framework under which they work. Evidence from 10 peer-reviewed articles between January 2000 and August 2015 indicates that HIV care and treatment outcomes are below par for female sex workers *(20)*. UNAIDS reports that female sex workers have 30 times greater risk of acquiring HIV than adult women aged 15–49 years in the general population, and female sex workers are less likely to access treatment than adult females in the general population *(40)*.

In South Africa, GDX has been organizing, advocating for, and delivering services to sex workers for 20 years. SWEAT empowers sex workers to explore and voice their experiences and realities using a human rights-based approach.

> Health providers add to the problem because they have personal prejudices, such as not considering gender-affirming health care as essential. In instances where we offer health provider training, there is uptake. We have had to provide training for surgeons because we could not find any surgeons that are interested in the training."
>
> GDX KEY INFORMANT, SOUTH AFRICA

In Kenya, WOFAK reacted to increasing levels of poverty, gender-based violence, stigma and discrimination against women living with HIV by empowering them to become human rights champions. Through community dialogue, peer groups and participation, WOFAK provides a platform for cooperation, supporting joint community action to address barriers to access to services, and challenging gender inequality practices. WOFAK supports women and youth to advocate for greater state accountability in delivering good-quality, gender-responsive services. Champions' roles include educating people on their right to inherit and own property, their right to education and training for employment, and their right to have children. WOFAK addresses harmful cultural practices and structural challenges and covers health issues such as living with HIV and prevention of vertical transmission.

Delivery of health services to achieve universal health coverage must deal with complex barriers to health, such as sociocultural, economic and political factors. Structural barriers impact the way people experience stigma, discrimination, criminal legislation, toxic gender norms, and out-of-pocket health costs. The case studies show that people-centred and community-led organizations challenge unconducive environments in which they deliver health services. BONELA and SWEAT have advocated through the courts to compel governments to deliver services to people from marginalized communities.

Some organizations challenge sociocultural beliefs about the rights of people from vulnerable communities, such as sex workers, transgender people, and gay men and other men who have sex with men. The case studies show that various intersecting factors shape

who has access and who will be left out. Where access to services and respect for human rights require lobbying—often through litigation—high legal costs can be a barrier for people from poor and marginalized populations. KELIN in Kenya and SWEAT in South Africa mitigate against this barrier by providing legal and support services for people from marginalized and criminalized populations.

Given the high levels of stigma and discrimination experienced by people living with HIV and other people from key populations when accessing health-care services, training and sensitization of health-care providers is a critical component of community-led service delivery. In people-centred service delivery, clients play a central and active role. In South Africa and Uganda, the law does not officially recognize the rights of people from some key populations. Community-led and people-centred organizations seek to change and challenge discrimination in social, cultural, legal, gender and age policies.

TASO provides rights and legal services to the sex worker community. It has provided policy frameworks for guaranteed equal access to good-quality HIV and sexual and reproductive health and rights services for sex workers and young women. TASO worked on the Ugandan HIV and AIDS Prevention and Control Act with other HIV human rights organizations to improve access to antiretroviral therapy services for sex workers and their children.

In addition, TASO reaches more than 17 000 people through stage shows and community dialogues focused on addressing gender norms that negatively affect people's access and adherence to treatment. In 2017, TASO screened more than 29 000 people and found 79% were survivors of gender-based violence. Health-care workers referred survivors for post-exposure prophylaxis, emergency family planning and counselling services.

Case studies in this report show that task-shifting in the legal support context is possible. BONELA, GDX, KELIN and SWEAT have demonstrated that peer-to-peer human rights models can be used in health-care delivery. Peer-to-peer models empower communities to assist in human rights awareness, training, and paralegal services. They can create community-led human rights clubs, law clinics and legal advice centres to increase access to legal services for vulnerable communities that cannot afford lawyers.

GDX advocates to improve access to health care, legal and policy reform. Its international advocacy work assists regional organizations to prepare and present shadow reports for the United Nations Universal Periodic Review.

BONELA provides direct services such as drop-in centres offering legal services for its partners to ensure their cases are addressed across six health districts in Botswana. BONELA has human rights clubs in most districts and has created a cadre of human rights champions within schools to provide leadership in addressing rights violations for children. BONELA empowers young people to be human rights champions through two projects focusing on disability rights and children's rights. The human rights clubs work with youth and educational institutions to advocate for children's rights and develop leadership skills. Providing legal services to children in need is essential to ensure their lives are valued, supported and protected.

In Kenya, KELIN community outreach and legal aid clinics support sex workers facing health rights violations and barriers to accessing HIV-related services. These community-led and people-centred clinics identify human rights cases for possible mediation, arbitration or litigation.

SWEAT provides legal advice, including a 24-hour legal helpline, for sex workers who wish to challenge human rights violations. Trained peers offer advice on human rights, paralegal awareness, education and health. SWEAT peers conduct basic screening on violence, drug and alcohol use, and psychosocial wellness. SWEAT offers free training and education on health, legal education, and human rights-based training for sex workers and their partners to increase awareness and knowledge on human rights and the legal remedies available. It uses participatory methods and offers services in safe, nonjudgemental spaces. SWEAT makes submissions for legislative reform processes at the national and local levels to challenge human rights violations against sex workers.

Ishtar MSM, SWEAT and TASO have trained services providers because stigma and discrimination often occur in places where health care is meant to be delivered. TASO facilitates dialogue around issues facing sex workers by bringing together sex workers and community leaders, human rights activists, other stakeholders and implementing partners from across Uganda to engage with the ministries of health, gender and internal affairs and other institutions. This allows sex workers to directly interface with public officials, peers and other stakeholders. Through this process, sex workers access information about grants and collaboration opportunities. These meetings play an essential role in bridging the link between rural and urban sex worker movements, civil society and the Government.

GENDER AND HEALTH

In many countries, the health sector does not fully recognize the implications of gender inequalities as a social determinant of access to health services for people from marginalized groups. Punitive laws and violence exacerbate inequalities in access to health. Creating safe and welcoming physical environments that are inclusive for people from marginalized groups is essential. Significant health disparities persist, with stigmatization and discrimination, indicating the need for human rights-centred universal health coverage.

An Ishtar MSM key informant said: "Creating safe spaces is key because there was much fear for my community members." Ishtar MSM creates safe spaces and mobilizes communities in Kenya to access services such as condom and lubricant distribution in their local networks and provides gay men and other men who have sex with men and transgender people with symposiums and mentoring programmes.

GDX developed university-based life orientation for university staff and LGBTQI student interest groups. It facilitates community dialogues in partnership with social protection services such as the police, educators, religious leaders, community development and political leaders at various levels.

TASO engages the community through ongoing dialogues around gender norms that contribute to stigma, violence and discrimination, and advocates for survivors to access legal protection from the Ugandan police.

Burundi MenEngage offers services to women, men, adolescents, gay men and other men who have sex with men, LGBTQI people and sex workers as groups facing gender-related oppression and human rights violations due to cultural norms. It facilitates workshops and community-based initiatives to build awareness on gender equality among men and boys in Burundi. It collaborates with other HIV organizations to deliver its services and health service referrals. It demonstrates various pathways to influence HIV prevention behaviours, including strengthening knowledge and skills, promoting community education, fostering coalitions and networks, changing organizational practices, and influencing policy and legislation.

When women have secure access to land, their family's health, education and security improve. In Kenya, KELIN developed a partnership with the family division court to facilitate the referral of cases relating to succession to ensure vulnerable widows obtain documentation that they otherwise could not afford.

Homabay County in Kenya has an HIV prevalence of 27% *(41)*. Elderly women bear a significant burden of caring for orphaned children after the death of the parents. This leaves women vulnerable after the erosion of their families' resources and assets. Women and their grandchildren are exposed to opportunistic diseases such as malaria, TB, pneumonia and jiggers. Using participatory approaches and working together with local villages, WOFAK has constructed permanent housing from locally available building materials. The houses have roof gutters to harvest rainwater, which is then used in farming. WOFAK is also training villagers to offer psychosocial and emotional support.

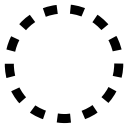
The promotion of land rights is fundamentally linked to the right to health. Without land, communities cannot produce food; and without food, they will have poor health outcomes. KELIN promotes women's land and property rights as a pathway to food security for communities. Property rights are at the core of securing the future of women's land tenure; protecting these rights contributes to protecting the entire family.

Some of the challenges encountered in improving health service delivery to people from vulnerable populations are stockouts of antiretroviral medicines and nutritional support for people living with HIV. The ecological systems approach recognizes that community cultural norms can be both enablers of and barriers to well-being *(10)*. Community-led organizations connect social protection and health for better outcomes.

> "Creating safe spaces is key because there was much fear for my community members."
>
> ISHTAR MSM KEY INFORMANT

NAVIGATING THE POLITICAL AND FUNDING LANDSCAPE

FACILITATING AGENCY AND PARTICIPATION



The case studies in this report demonstrate facilitation of social inclusion through building agency to participate in health policy and challenge discrimination through the courts and social structures. Social inclusion is facilitated by the agency of people affected. People living with HIV who are open about their status and have accumulated health literacy and organizing in their community have expert knowledge.

GIPA promotes self-determination and participation in decision-making as a universal right for people living with HIV. It acknowledges people's agency, especially when engaging with systems and structures with barriers *(1)*. It recognizes that people are active shapers and receivers of care.

Social inclusion is critical to meet the health needs and rights of all people living with HIV and people from key populations. Health systems and services are often shaped by sociocultural and legal values that are not always inclusive or do not respect human rights of all people *(40)*. In eastern and southern Africa, people from key populations are often excluded from accessing essential health services and participation in critical decision-making processes that affect them. The United Nations Development Programme definition of social inclusion includes improving the terms of participation in society, particularly for people from populations disadvantaged based on age, sex, disability, race, ethnicity, origin, religion or economics *(42)*.

In the case of Ishtar MSM, SWEAT, TASO, TNU and UYP, peer-to-peer engagement facilitates voice for concerns to be raised over the services received. These organizations support people to gain skills to deliver services to their peers, thereby informing and improving health-care service delivery for their communities. This demonstrate that community-led organizations facilitate agency, voice and active participation of all communities in their diversity. Community action and influence result in improved social, physical and material conditions, and enhanced service provision. Such communities can participate in broader decision-making processes and challenge decisions.

In Uganda, TNU brings together stakeholders, leaders, Government representatives, human rights lawyers and activists once a year with the sex worker movement in urban and rural districts to discuss the challenges facing sex workers.

In Botswana, BONELA works with traditional and religious leaders. For specific policies and attitudes to change in the community, these leaders must be involved, sensitized and lobbied. BONELA also targets other audiences such as parliamentarians, local authorities and public service providers, including police officers, social workers, teachers, nurses and community health workers. BONELA has worked with influential community leaders and key stakeholders who influence community services.

The case studies of Bonela, GDX and TNU illustrate the work of community-led organizations to promote and advocate for inclusion of marginalized people in policy and health service delivery.

In Kenya, WOFAK promotes the participation and social inclusion of women and young people in public policy- and decision-making processes that affect their health and livelihoods.

In Uganda, UYP carries out policy review and reforms; advocates for policy implementation, provision of good-quality services, and protection of human rights of young people; and participates in key national events to highlight the needs of young people living with HIV. UYP works in schools through Green Leaf Clubs, which teach young people about sexual and reproductive health and rights and create platforms for knowledge exchange and debates. UYP trains teachers as mentors and trains young people living with HIV as ambassadors for a stigma-free generation. UYP holds parents' and teachers' debates on challenges facing young people, such as managing sexuality and responding to the challenges of HIV.

The prioritization of youth participation within fundamental community structures aims to improve access to sexual and reproductive health and rights services for vulnerable youth. Youth participation seeks to sensitize key community stakeholders such as teachers, nurses, community leaders, clinics and schools to be more youth-friendly. This enables youth to take responsibility for their own sexual and reproductive health and rights.

The critical work of UYP supports disengaged youth and links them back to care. It offers support with follow-up appointments and has an active referral system to health facilities, aiming to reduce the number of AIDS-related deaths due to late diagnosis, barriers to access to antiretroviral therapy, poor treatment adherence and stigma, which still exist despite universal access to antiretroviral therapy *(43).*

GDX creates an enabling environment for youth and engages parents and stakeholders to come together to talk openly about transgender and gender-diverse issues. It uses participation processes that create safe spaces for young people to talk about child protection and family support processes that focus on prevention and coping with substance and alcohol abuse. Its work includes discussing what families can learn to do for themselves, youth participation, emerging relationships, and responsive networks of caregivers that give rise to hope, love, respect and courage. By increasing child and youth participation within crucial structures in the community, GDX supports their agency and voice.

Being part of policy-making and community decision-making processes is not enough. Community collective actions can result in improved social conditions and enhanced service provision. Participating in collective actions builds solidarity among affected communities to hold governments accountable.

Many communities have increasing health needs as the burden of chronic lifestyle-related conditions is rising. Human rights violations that have excluded some populations from access to care and the consequences of COVID-19, Ebola and yellow fever underscore the further need for services.

> "Empower women and girls and involve men to defend their rights and participate in debate and discussion for decision-making"
>
> AHITIPALUXENE KEY INFORMANT

TAPPING INTO COMMUNITY EXPERT KNOWLEDGE

People-centred health services appreciate the active contribution of the populations they serve. Clients are not passive services users—they actively shape and influence service delivery approaches. Communities bring their lived experiences and contribute to increasing human resources to deliver health services to their peers and other people in the community. Task-shifting may also be envisaged to achieve the GIPA principles *(23, 44)*.

The organizations in these case studies engage expert clients as community health workers. Clients are actively engaged through differentiated service delivery models, as community antiretroviral therapy support agents, community-led antiretroviral therapy delivery leaders, mentor mothers and adolescent peer educators, and by sharing experiences during clinic days. Some community health workers are employed by civil society organizations and others by national governments to provide critical linkages between state-run health systems and community responses *(23)*.

Community-led and people-centred organizations are embedded in community structures and systems. This implies that services delivered through community-led and people-centred approaches are beneficial not only to the populations served but also to broader health and social systems *(2, 45)*.

Community responses are diverse, dynamic and contextual. The people that health services are meant to reach should influence the ecological systems of health delivery through policy avenues and processes and ensure duty-bearers are accountable.

TASO streamlined the community medicine distribution point model through ongoing orientation and training of groups to effectively carry out mobilization, peer counselling, adherence monitoring, and distributing and accounting for medicines on behalf of community members.

Philani in South Africa trained 200 mentor mothers in core skills to provide comprehensive services such as monthly counselling and support to medically stable clients who are unable to travel to Philani nutritional centres due to distance or financial constraints *(28)*. Philani focuses on maternal and child health and nutrition. It deploys 200 mentor mothers in geographical areas aligned to health facilities and works with a digital system to facilitate referrals. Communities of people living with HIV work synergistically with health systems to bring into and retain in care people from marginalized populations, who are often difficult to reach without the specific experience and expertise that only community-led services can provide.

NAVIGATING THE POLITICAL AND FUNDING LANDSCAPE

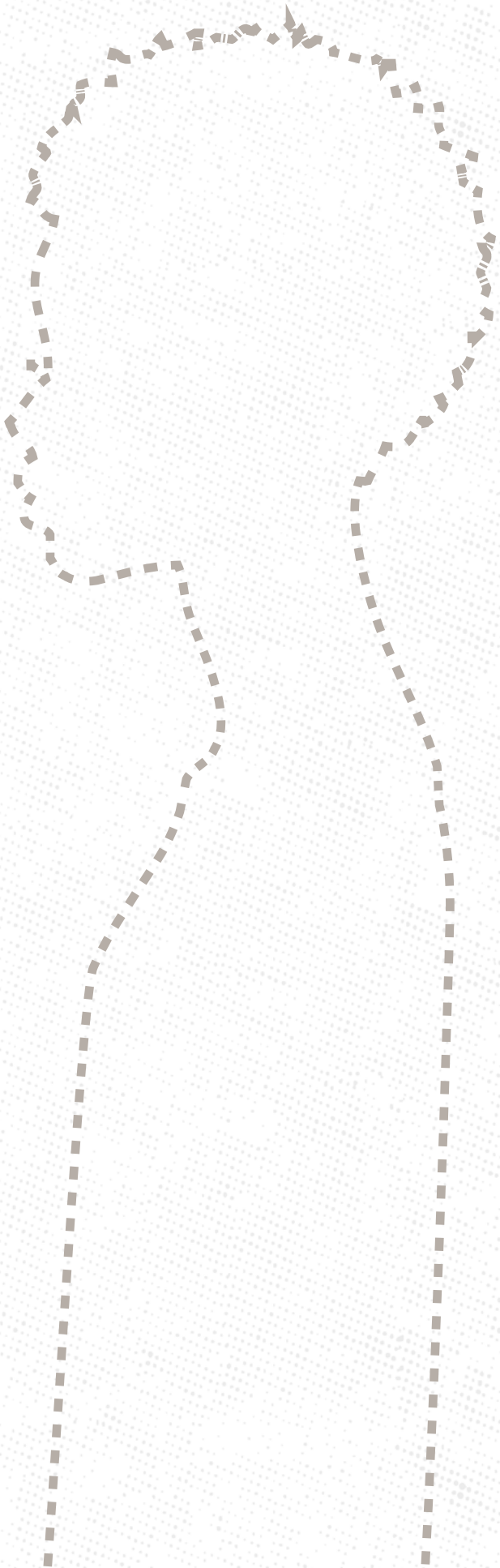
Political and funding barriers remain threats to achieving universal health coverage. Equity and human rights-centred approaches are fundamental to HIV-related health services. This implies transforming laws, policies, norms and governance mechanisms that increase risk and impede access to services.

All the organizations in the case studies are externally funded. Funding challenges have forced many community organizations to shift their focus, reduce their services or discontinue altogether.

The World Bank classification of Botswana as an upper-middle-income country came with a significant and rapid loss of external donors *(46)*. With 17 of its projects externally funded, BONELA had to shift its work. Instead of directly providing services through its projects, BONELA shifted its role and subgranted to another community-led organization that focused strongly on gay men and other men who have sex with men to remove legal barriers to funding from the Global Fund.

To advocate for people from populations whose human rights are violated, BONELA works to engage politicians and lawmakers. Over the past 12 years, the human rights space in Botswana has changed, and some issues that could have been resolved amicably have had to use the courts. BONELA believes the current administration in Botswana is more open to engagement with civil society organizations and more willing to provide the requisite support for them to work.

In the context of climate justice, Kulima promotes awareness and develops training manuals that link environmental justice with the health of communities. This includes climate change, reforestation, rainwater collection, biodiversity and soil conservation, use of firewood and charcoal, introduction of improved stoves in rural and peri-urban areas, and introduction of improved lavatories and their proper use. Attention is paid to programmes promoting the establishment of environmental protection laws, primarily due to the high number of multinational organizations in the country actively participating in discussions on environmental advocacy *(47)*.



Conclusion

For over 30 years, communities of people living with HIV have played a crucial role in reaching people with HIV treatment, prevention, care and support services. In such contexts, communities are both providers and users of services delivered through local and trusted health systems that respond to community needs and preferences in humane and holistic ways.

This study has explored community-led and people-centred delivery of HIV-related health services and social inclusion in eastern and southern Africa, and their potential contribution to achieving universal health coverage. Ecological systems theory was foundational to analysing health-care approaches by communities of people living with HIV. Mixed methods such as desktop review, document analysis and key informant interviews were used to document the case studies of 17 community-led and people-centred organizations with significant experience in delivering HIV, COVID-19 and other health services.

The findings demonstrate that community-led service delivery places affected communities at the centre of interventions. The impact beyond HIV is exemplified through HIV-related health services and social inclusion.

The case studies came from a mix of community-led and community-based organizations engaged in service delivery to reach their communities. Of the organizations studied, 47% offer direct services for HIV, TB, sexually transmitted infections, sexual and reproductive health and rights, wellness, maternal and child nutrition, gender-based violence, mental health screening, and economic empowerment of adolescent young girls; and 43% offer direct human rights services, legal services, training of service providers on human rights, partnership building, and referrals for communities affected by punitive laws.

The case studies demonstrate diverse and differentiated approaches to services organized around the needs, contexts and expectations of individuals, families and communities. They use people from the community as community health workers, offer home visits and mobile services, and have flexible hours for services to expand their reach and increase access.

Community-led and people-centred service delivery promotes a healthy population by fostering a sociocultural, economic, and political environment conducive for health. The case studies show that these approaches facilitate inclusion through agency, voice and active participation of all communities in their diversity. Their service delivery has an impact beyond HIV, and their outcomes are vital for achieving universal health coverage.

Of the organizations studied,
47% OFFER direct services for HIV, TB, sexually transmitted infections, sexual and reproductive health and rights, wellness, maternal and child nutrition, gender-based violence, mental health screening, and economic empowerment of adolescent young girls; and
43% OFFER direct human rights services, legal services, training of service providers on human rights, partnership building, and referrals for communities affected by punitive laws


TAYOA YOUTH CENTRE
'Tujenge Pamoja'

ANNEX 1

KEY INFORMANT INTERVIEWS FROM SELECTED CASE STUDIES

ORGANIZATION	AREA	COUNTRY	INTERVIEW CODE
Ahitipaluxene	Southern Africa	Mozambique	SAMOZ03
Botswana Network on Ethics, Law and HIV/AIDS (BONELA)	Southern Africa	Botswana	SABOT1
Dlalanathi	Southern Africa	South Africa	SAZAR13
Gender DynamiX (GDX)	Southern Africa	South Africa	SAZAR14
Ishtar MSM	Eastern Africa	Kenya	ESAKEN02
Kenya Legal and Ethical Issues Network on HIV and AIDS (KELIN)	Eastern Africa	Kenya	ESAKEN03
Kulima	Southern Africa	Mozambique	SAMOZ01
Kwasha Mukwenu Women's Group	Southern Africa	Zambia	SAZAMO1
MenEngage Burundi	Eastern central Africa	Burundi	ESABUR01
Philani	Southern Africa	South Africa	SAZAR11
Rainbow Mirrors Uganda (RMU)	Eastern Africa	Uganda	ESAUGA02
Sex Workers Education and Advocacy Taskforce (SWEAT)	Southern Africa	South Africa	SAZAR04
The AIDS Support Organization (TASO)	Eastern Africa	Uganda	ESAUGA07
TOV HIV/AIDS Orphans and Vulnerable Children Organization (TOV)	Southern Africa	Namibia	SANAM01
Tranz Network Uganda (TNU)	Eastern Africa	Uganda	ESAUGA03
Uganda Young Positives (UYP)	Eastern Africa	Uganda	ESAUGA04
Women Fighting AIDS in Kenya (WOFAK)	Eastern Africa	Kenya	ESAKEN01

ANNEX 2

QUESTIONNAIRE AND KEY INFORMANT INTERVIEW GUIDE

My name is Vuyiseka Dubula-Majola, principal investigator of the study "People-centred community-led HIV-related service delivery: civil society case studies in eastern and southern Africa", run in collaboration with UNAIDS. This questionnaire will take approximately 30–45 minutes to complete.

It is made up of three sections. Section 1 collects demographic information. Section 2 covers the service types delivered. Section 3 collects information on political, cultural, social and economic contextual factors.

If you have questions during any part of the interview, please ask the principal or co-principal investigators or research assistants.

Please note the following:

- All identifying information will remain anonymous and will not be linked to you directly.
- Responses to the questionnaire will remain confidential.
- Participation is voluntary, and you have the right to withdraw at any time without prejudice.
- You are free not to disclose some personal information.
- You are entitled to view the results of this study upon completion. If you have questions, please feel free to contact me at vuyiseka@sun.ac.za.

Questionnaire identification code:
Organizational code:
Location code:
Date (DD/MM/YYYY):
Notes:

SECTION 1: BACKGROUND INFORMATION

[Ask only if information is not available in existing literature]

1 What are the main organizations or initiatives involved in the community response to HIV in the community (e.g. community initiative, community-based organization, nongovernmental organization, faith-based organization, rights-based organization, mass organization, network, private-sector organization)?

2 Does the community organization or initiative mainly operate:
[tick to indicate your response]

- ☐ Locally
- ☐ Nationally
- ☐ Regionally
- ☐ Internationally

3 Is the community organization or initiative informal or formal?

4 What does the community organization or initiative consider itself as (e.g. AIDS organization, human rights organization, faith-based organization)?

5 How long has the community organization or initiative offered these services in the community, and how has its structure or ways of delivery changed or evolved during this time?

6 What is the primary focus of the community organization or initiative (e.g. is the primary focus HIV, or has HIV been added to an existing portfolio of activities)?

7 What are the institutional arrangements and capacity of the community organization or initiative (e.g. mission, management structure, membership, governance, systems for planning, finance, monitoring and evaluation, implementation approach, paid staff and volunteers)?

8 How did COVID-19 affect the community organization or initiative, such as staff, financial resources and capacity to adapt to alternative ways of working (e.g. using digital means or restricted contact with communities)?

9 What are the budget, funding sources and funding channels of the community organization or initiative (direct or through an intermediary)?

10 How dependent is the work of the community organization or initiative on external funding?

11 What type of external support is provided to the community organization or initiative to deal with COVID-19 (e.g. funding, capacity-building, technical assistance, support for networking and coordination), and how effective are different types of external support?

POPULATION AND BENEFICIARIES OF THE SERVICES, ACTORS, AND COMMUNITY PARTICIPATION

[Ask only if information is not available in existing literature.]

12 What population groups does the community organization or initiative provide services to? *[choose all that apply]*

- ☐ Women
- ☐ Men
- ☐ Adolescents [specify age range]
- ☐ Children [specify age range]
- ☐ Gay men and other men who have sex with men
- ☐ LGBTQI people
- ☐ Sex workers
- ☐ People who use drugs
- ☐ People in prisons and other closed settings
- ☐ Transgender people
- ☐ Migrants
- ☐ People living with HIV

13 What are some of the challenges you see in meeting the needs of the populations that the community organization or initiative provides services to?

ACTORS

[Ask only if information is not available in existing literature]

14 Did actors within the community (e.g. individuals, existing community structures or groups) or external actors (e.g. local, national or international nongovernmental organizations or faith-based organizations, multilateral, bilateral or United Nations agencies, national government) start the initiative?

15 Have the drivers changed (e.g. services started by communities but subsequently supported by external actors)?

16 Who leads the initiative (e.g. started and led by community, started and led by external actors, started by external actors and led by community, volunteers or paid staff)?

17 Do the community-based activities receive external support?

18 If so, what are the sources of external support (e.g. donor agency, United Nations agency, government, international nongovernmental organization, national or local nongovernmental organization, private-sector organization, faith-based organization)?

19 How has external support influenced the community response?

20 What type of external support is provided (e.g. funding, capacity-building, technical assistance, support for networking and coordination), and how effective are different types of external support?

21 When did external support start, and what is the duration of external support?

22 What monitoring and evaluation does the organization undertake, and are there any lessons to share about how effective responses can be managed?

COMMUNITY PARTICIPATION

[Ask only if information is not available in existing literature]

23 To what degree is the community involved (e.g. community leads, actively participates, supports, is informed, is co-opted)?

24 To what degree is the community involved in COVID-19 service delivery (e.g. community leads, actively participates, supports, is informed, is co-opted)?

25 What activities or interventions is the community involved in (e.g. identifying problems, needs and priorities; planning and design; implementation and service delivery; monitoring and evaluation)?

26 Has the involvement of the community been sustained over time (e.g. ongoing relationship, involved occasionally, one-off consultation)?

27 To what degree are target groups or intended beneficiaries involved?

28 What are the characteristics of the community (e.g. incentives, capacity, skills, social capital, shared norms and values and social networks)?

PARTNERSHIPS AND COLLABORATION

[Ask only if information is not available in existing literature]

29 How are the activities of the organization linked to community organizations?

30 How are the activities of the organization linked to and aligned with government services (e.g. local government, local AIDS committees, health facilities, social welfare services, health, education or justice departments)?

31 Are referral systems in place between community-based organizations and service providers?

32 What partnership arrangements are in place (e.g. formal partnerships and memorandums of understanding, informal partnerships, collaboration, shared networks)?

33 How do actors in the community participate in coordination mechanisms, networks, umbrella organizations or coalitions?

34 Which actors are driving partnerships and collaboration (e.g. internally or externally?

SECTION 2: SERVICES AND INTERVENTIONS

[Ask only if information is not available in existing literature]

1 What are some of the challenges posed by COVID-19 in meeting the needs of the populations the organization provide services to?

2 What are the main COVID-19-related activities you are delivering?

3 What activities or interventions are the community involved in during COVID-19 (e.g. identifying problems, needs and priorities; planning and design; implementation and service delivery; monitoring and evaluation)?

4 What monitoring and evaluation does the organization undertake, and are there any lessons to share about how effective community-led COVID-19 services can be managed?

5 What are the main HIV areas of activity (e.g. prevention, testing, treatment, demand creation, service uptake, task shifting and sharing, care and support, rights and legal services) and specific activities and services provided?

6 What services does the organization provide to the community? *[choose all that apply]*

- ☐ HIV prevention
- ☐ Confidential and voluntary HIV testing and counselling
- ☐ HIV treatment
- ☐ Demand creation and service uptake
- ☐ Task shifting and task sharing
- ☐ Care and support
- ☐ Rights and legal services

7 What are some of the things that the organization is doing well and should be highlighted regarding meeting the health needs of the community affected by HIV or coinfections?

8 What are the scale and reach of activities?

9 Does the organization play a leading, supporting or enhancing role in different areas of activity?

10 Have activities evolved over time (e.g. in response to external actors, availability of funding or local need)?

11 How did COVID-19 affect the services the organization provides, and why?

12 Has geographical coverage evolved over time (e.g. in response to external actors, availability of funding or need)?

13 Who is the target audience (e.g. whole community, specific target groups)?

14 What is the perception of beneficiaries about the quality of services provided? Are there data to assess the quality of the services provided?

15 What data are available about the health-related services of the organization for vulnerable populations?

16 Are there any data or other information to show how COVID-19 affected the services the organization provides? Kindly share details or email examples and information (e.g. unpublished or published reports, internal feedback, lessons learned).

17 How does the organization report results from services rendered in the community? *[choose all that apply]*

- ☐ Quarterly, biannual or annual reports
- ☐ Publications (e.g. journal articles, white or grey papers)
- ☐ No formal reporting
- ☐ Interested in learning how to formulate data collection and analysis methods
- ☐ Social media platforms:
  - ☐ – Facebook
  - ☐ – Instagram
  - ☐ – Website
  - ☐ – WhatsApp
  - ☐ – Other *[please identify]*

18 Can we have access to this information? *[seek permission to use the data if unpublished]*

SECTION 3: CONTEXTUAL FACTORS

[Ask only if information is not available in existing literature]

1. How have political, cultural, social and economic contexts influenced the community COVID-19 service delivery response?

2. How have political, cultural, social and economic contexts influenced the community response?

3. How has the epidemic context influenced the community response?

4. Have activities changed as the epidemic or the national response to it has evolved?

5. How has the location (e.g. urban, rural) influenced the community response?

6. How have the organization's activities been influenced by national plans?

7. How have the organization's activities been influenced by local or district-level plans or strategies?

8. If you could make changes to improve the health service delivery to your community and vulnerable populations, what would those changes be?

9. Is there anything we have not discussed that you would like to share to help us understand how services are delivered to the communities, or what needs to happen to improve services?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