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## Engaging community and governmental partners in improving health and mental health outcomes for children and adolescents impacted by HIV/AIDS in Uganda

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### Abstract

The African region remains the world's most affected region in the HIV epidemic. A related consequence of HIV/AIDS in sub-Saharan Africa (SSA), including in Uganda, is the high prevalence of children and adolescents who have lost one or both parents to this virus or who have been perinatally infected. Guided by the Practical, Robust Implementation and Sustainability (PRISM) framework, this paper describes the strategies by which we have engaged community and government partners in research using three NIH-funded randomized clinical trials testing an evidence-based combination intervention aimed at improving health and mental health outcomes among children and adolescents impacted by HIV/AIDS in Uganda. We specifically lay out four strategies that have been used to facilitate stakeholder engagement, namely consultative meetings, stakeholder accountability meetings, training of key players (task-shifting), and policymaker engagement. We emphasize that community collaborations and partnerships are especially critical when implementing combination interventions that require a high level of communication and coordination among multiple implementation partners. We underline that building and sustaining long-term relationships and communication with the stakeholders can allow the researchers to successfully design rigorous studies that are responsive to local needs and can make a difference

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especially in low-resource settings. Finally, we highlight that the process of engagement and collaboration can be guided by conceptual frameworks.

### Keywords

Adolescent; mental health; youth; stakeholder; poverty

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### Introduction

The African region remains the region in the world that is most affected by the HIV epidemic, home to 25.7 million people living with HIV worldwide (1). In addition, two-thirds of the new HIV infections globally occur in these regions of Africa. Despite great strides that have been made to address HIV, the HIV/AIDS prevalence rate in Uganda was estimated at 5.7 percent for people aged 15 to 49 years in 2018 (2). A related consequence of HIV/AIDS in sub-Saharan Africa (SSA) is the high prevalence of children and adolescents who have lost one or both parents to this virus. Worldwide, more than 13 million young people are orphaned by AIDS, the majority living in SSA (3). Uganda, one of the countries hardest hit by HIV in SSA, is highly impacted by HIV/AIDS-related orphanhood. Of the ~1.2 million Ugandan young people who are orphans, AIDS orphans account for 45% (4,5). With the free rollout of antiretroviral therapy in 2004 in Uganda, more youth cope with HIV as a chronic, highly stigmatized, and transmittable illness (6).

Too often, adolescents affected by HIV/AIDS, both those orphaned by AIDS and those living with HIV/AIDS, find themselves at the intersection of HIV/AIDS, poverty, and mental health challenges. They face developmental, psychosocial and economic adversities, less social support, fewer opportunities for education, and higher risk for mental health challenges and risk-taking behaviors, compared to the general population (7). In addition to these struggles, adolescents living with HIV in Uganda also experience poor drug adherence, primarily due to poverty and factors associated with it (e.g., limited access to food, unaffordable transport costs), and HIV-related stigma (8).

The intricate relationship between HIV/AIDS, poverty, and mental health underlines the importance of implementing evidence-based combination interventions to effectively address the needs of this vulnerable population. Moreover, these combination interventions require recognition and involvement of key community stakeholders (religious leaders, politicians, parents, youth, and community elders) as partners in the planning and implementation of interventions (9). Hence, this adaptation is critical for effective implementation, dissemination, and potential sustainability of interventions as well as recognizing local knowledge as a resource in science.

In this article, we illustrate how combination interventions can be successfully implemented in close collaboration with community stakeholders by using examples from our multiple studies. These studies test a homegrown combined evidence-based intervention to address the multi-faceted issues experienced by youth and their families impacted by HIV/AIDS and the challenges they face in Uganda. Guided by the Practical, Robust Implementation and Sustainability (PRISM) framework (10), we describe the strategies by which we have

engaged communities and government structures to invest in collaborative, longitudinal studies aimed at improving health and mental health outcomes for these youth.

## Background

### HIV in SSA and Uganda

The AIDS epidemic that swept the African continent during the late 20th century took away loved ones and subjected many children to an orphanhood status (11,12). SSA is home to over 10.9 million AIDS-affected orphans (13), constituting 80% of the orphaned children worldwide (14). The most affected population includes adolescents ages 10–18 and young adults ages 19–24, due to their potential risks and high-risk taking behaviors having unprotected sex, drug injection, sex trade, and others (15). Despite the availability of antiretroviral therapy (ART) and effective prevention strategies, HIV vulnerability among adolescents and young adults has exponentially increased and thus, recent focus has turned the HIV prevention strategies to the youth and adolescents and encourages promotion of youth friendly HIV and sexual reproductive services (16).

UNICEF estimates that there are about 1million orphaned children ages 0–17 years who have lost either one or both of their parents due to HIV/AIDS in Uganda (17). The Global estimate of the orphans in the same age group is about 14 million orphans. The eastern and Southern African region is the strongly affected region in Sub Saharan Africa in terms of HIV prevalence. This includes countries like, South Africa, Nigeria, Mozambique, Uganda, Tanzania, Zambia, Zimbabwe, Kenya, Malawi, and Ethiopia, all together, accounting for almost 80% of all people living with HIV globally. Yet, Africa as continent accounts for less than 15 percentage of the world's general population.

### HIV-impacted youth and mental health

Orphaned children face several challenges related to parental loss and poverty that may interfere with their physical and emotional growth and development Loss of parents makes orphaned children susceptible to mental disorders due to the grief and sadness that is associated with parental death (18). Studies have found that orphaned children often deal with anxiety and tend to isolate themselves in social situations (19). Besides, they also experience other challenges like higher levels of depression, and post-traumatic stress compared to their counterparts who are orphaned due to other causes (20). Such conditions are worsened when these children are separated from their siblings and forced to live apart from each other (21).

While efforts to make ART available to adolescents have been largely successful over the years, research about the mental health functioning of adolescents living with HIV (ALHIV) has not received as much attention in low resource settings. A study by Mutumba and colleagues (22) found that adolescents living with HIV still struggled with internalized, anticipated, and experienced stigma from both friends and family. HIV stigma is associated with poor medication adherence, emotional adjustment, and disclosure status (23). Gaughan and colleagues (24) found that psychiatric hospitalizations were more likely to occur for children living with HIV compared to the general pediatric population. Kinyanda and

colleagues (25) found that psychological and social factors accounted for major depressive disorder among people living with HIV/AIDS in Uganda.

Mental health is receiving increased recognition from major health regulatory bodies such as WHO through their Mental Health Gap Action plan and Sustainable Development Goals (SDGs) that include prevention, treatment, and promotion of mental health as one of the targets (SDG 3.3) for SDG #3 “Ensure healthy lives and promote well-being for all at all ages” (26–28). These calls come at a time when 10–20% of children and adolescents worldwide experience mental health challenges and many of whom live in low and middle-income countries (18). Several factors trigger mental health problems in children and adolescents, including interactions with family members, peers, community members, and social determinants of health such as poverty, culture, access to care and local and international policies (29). Failure to address mental disorders during childhood presents a public health problem in low-resource settings such that most affected individuals are unable to attain basic development goals and productivity, leading to poor quality of life in adulthood (18,30).

Poverty-related stressors contribute to mental health challenges among children and adolescents. A systematic review of studies among children aged 4–18 years found that children coming from families with low socioeconomic status were three times more likely to exhibit behavioral challenges compared to their counterparts from families with high SES (31), due to high parental stress, limited social support (32–34). Consistent with other studies (35,36) low SES has been linked to poor mental health outcomes. Children who are orphaned due to AIDS experience higher risk of mental and psychological challenges as a result of the pressing needs for education, access, food security, household employment and the overall struggle for survival (37). For example, Cluver and colleagues (38) studied South African households and found that household poverty is significantly associated with child mental health and compromises the quality of life of children. Additionally, orphanhood and the HIV status of a caregiver also place children at risk of mental health challenges. Severe poverty is significantly associated with caregivers living with HIV and exacerbates child mental health, educational, and HIV-infection risks. Besides, children whose mothers are infected with HIV also find it hard to cope with the situation, which negatively impacts their emotional well-being (39,40).

### **Importance of engaging communities to ensure successful implementation, dissemination, and sustainability**

Community engagement is defined as the process of working with groups of people connected by either geographic location, special interest, or affiliation to identify and address issues related to their wellbeing (41). Community engagement is critical in ensuring the success and sustainability of intervention implementation (42,43) and leads to a sense of ownership by local stakeholders (42,44). Additionally, it increases the acceptability, efficacy, cultural and contextual sensitivity, and capacity for wider-scale use (44,45). Community collaborative research emphasizes the intensive and ongoing participation and influence of community members in building knowledge (46). Collaboration with community members

facilitate the identification of concerns and acknowledge the importance of community-level knowledge and resources (47,48).

Community engagement and partnerships for intervention have been explored more across study groups and have shown positive outcomes for dissemination and sustainability. Holzer *et al.* (49) found that community engagement produces more context-specific projects and shows respect for communities, which adds to trust in the project activities and outcomes. Johnson *et al.*'s (50) study showed a 78% increment in enrollment rate and 100% participant retention and drug adherence with a community engagement approach. Dubois *et al.*, highlight the importance of training and continuously engaging community members in advisory boards and planning activities to cater for ethical issues and promote successful implementation and sustainability of research (51).

### **Theoretical framework: using the PRISM to understand contextual influences on implementation**

Interventions developed in academic isolation are limited in addressing the real-world constraints of settings in which they will be used—insufficient resources, limited workforce capacity, and failure to partner with key funders and policymakers (45). We draw upon PRISM, which is a practical and comprehensive implementation framework that integrates aspects of the diffusion of innovation and models for quality improvement (10,52). PRISM emphasizes (I) organizational perspectives on an intervention (e.g., feasibility, adaptability, barriers from the perspective of schools); (II) external environment (e.g., community resources, policy context); (III) recipients' characteristics (intervention facilitator and caregiver responses); and (IV) implementation and sustainability infrastructure (training and supervision support for intervention facilitators). PRISM provides a framework to study the interaction of interventions with the characteristics of multi-level contexts and factors that may influence uptake, implementation, integration and youth outcomes (youth and adult caregiver response, provider preparedness, motivation and fidelity, community-level support)

Glasgow and colleagues (52) present 5 dimensions including reach, efficacy, adoption, implementation, and maintenance at the individual, organizational, and community levels to establish intervention impact with maximum resource utilization. To successfully implement sustainable interventions, we have been collaborating with different stakeholders within the country, including communities and institutions that play vital roles in not only influencing policy but also the uptake of our evidence-based combination interventions.

### **How to engage community stakeholders and policy makers for sustainable and impactful child-focused research in SSA context: Uganda as a case example**

In this paper, we draw from our various NIH-funded randomized control trials housed within the International Center for Child Health and Development (ICHAD) to illustrate how community stakeholders and policymakers can be extensively involved throughout the process of conducting intervention studies. ICHAD studies are the first to test the impact of

a combination intervention focused on alleviating poverty as a social determinant of health and improving health and mental health among HIV-impacted youth and their families in Uganda. This combination intervention is informed by the asset theory which posits that assets can lead to wide scale benefits, including expectations for more resources in the future, optimistic thinking, feelings of safety and security (53), and future planning (53–55). Asset-building is increasingly viewed as a critical factor for reducing poverty, positively impacting attitudes and behaviors, and improving psychosocial well-being, including mental health (56–61). ICHAD's combination intervention includes: (I) Financial Literacy Training Workshops; (II) Mentorship; (III) Income Generation Activities, (IV) Youth Development Accounts; and (V) Multiple Family Groups. A description of these interventions is shown in the Table 1.

The following studies (Table 2) will be used as case examples to illustrate how ICHAD has engaged policymakers and community members at different levels of intervention implementation.

Bridges to the future and Suubi + Adherence interventions have resulted in improved mental health outcomes among adolescents in the intervention group. Specifically, in the Bridges project focused on adolescents who are orphaned by HIV/AIDS, there was decreased levels of depression and hopelessness and improved self-concept and self-efficacy among adolescents in the intervention group 24 months after the intervention initiation (55,58,62). The Suubi + Adherence project among adolescents living with HIV, adolescents receiving the intervention reported significantly lower hopelessness score at 24 months following the initiation of the intervention and lower scores of depression at 36 months following the initiation of the intervention compared to those who did not receive the intervention (57).

In all these studies, we have engaged a range of stakeholders at different levels, right from project planning to the dissemination of the results. These stakeholder engagements have informed our project design and field activities, allowed us to have sustained engagement within the communities where we work, and work closely with policymakers.

Community stakeholders involved in ICHAD's project include but are not limited to public schools, both primary and secondary, hospitals and clinics, community members, policymakers, and NGOs. Primary and secondary schools, hospitals, and clinics are our recruitment sites and we work closely with leadership and staff at these institutions to coordinate our recruitment activities. Two health facilities (Rakai Health Sciences Program and Mildmay Uganda) provide support in the collection and lab testing of biomarkers. Community members may be parents, local leaders and elders or local health care system supports (i.e., community health workers) selected and trained to deliver study interventions. Other community partners include NGOs (e.g., Reach the Youth Uganda, ChildFund Uganda, and Blessing Basket among others). These organizations support project design and implementation, help with the planning of activities, and act as liaisons with other potential collaborators in the community and political leaders. Collaborations with the church—Masaka Diocese have also been pivotal in granting access to public schools and some of the health facilities for project engagement, given that most of the schools and some of the clinics we collaborate with are church-founded or supported by the church.

Collaboration with policymakers has taken place both at the local and national levels. ICHAD involves the local government officials including District Health Officers and Educational Officers, given their role in policy formulation and the services they offer to the participants and the general community. District Health Officers and Educational Officers are also concerned with overseeing the operations of the clinics and schools respectively at the district level so their collaboration is critical to the success of the projects. Specifically, presentations of study objectives to all the district local leaders are done to ensure the study goals fit well into the existing clinic and school activities. This ensures that district leaders can support and follow the progress with their community members participating in ICHAD studies. National-level policymakers are equally critical to engage as they determine policy priorities.

Invitations to attend and participate in project launches, conferences, and accountability meetings are extended to community collaborators and stakeholders at all levels. Information about progress, findings, and next steps are shared at these meetings. How to overcome any challenges that the project team may have experienced is also discussed during those meetings. Stakeholder engagements have been helpful to build strong relationships over time, with the church, schools, and health facilities/clinics where we work, local leaders, and the ministries (both the ministry of Health and the Ministry of Education). Through these engagements, ICHAD has built trust and local buy-in from communities, which has made the implementation of ongoing and new projects a smooth process. The close collaborations with stakeholders have also made ICHAD's work in the region unique and impactful.

### **Consultative meetings with community partners and stakeholders**

ICHAD formally launches all its projects by inviting different stakeholders to attend the study launch events. Financial institutions, selected schools or clinics (depending on the study), and study participants, the local and national policymakers, religious leaders, and collaborating organizations among others come together to discuss field plans. Different activities carried out on these functions include accounts opening, consenting, and assenting of participants and their guardians among other activities.

Launching projects is yet another opportunity for ICHAD to inform the public and different stakeholders, most especially the policymakers and community partners about the study goals and expectations from the partnership. These events further strengthen community relationships and trust.

Following project launch, meetings are initiated with stakeholders who work with our target populations and would support our study implementation. These consultative meetings are always part of ICHAD's implementation process. In these meetings, teachers, healthcare workers, and other school administrators are invited depending on the project to provide feedback on the project design and implementation aspects of the project. For example, consultative meetings for the Suubi + Adherence project were conducted with the healthcare workers and peer counselors working at the health care centers or serving as village health teams in their communities. They provided feedback on the content and illustrations of the cartoon-based intervention manual that was used in the project. In the meeting with health

care workers, and VHTs, the main character names (Kamperempe and Mabebbere) were chosen. These names are commonly used in folk tales in the community and used in children songs to talk about hygiene. Given their prominence and wide use, the team found it ideal to adopt both names for the illustrations. During the same meetings, the community members provided several contextual examples that were included in the manual to depict, stigma, interaction between parents and children, activities done within families and interaction between healthcare workers and adolescents living with HIV. For example, expert clients/VHTs recommended the use of evening local news on a prominent radio station as a way to remind adolescents to take their medication since most of the adolescents do not have a functional watch.

In addition to the adaptation process, health care workers and village health teams were critical to the project success because they supported the referral, follow up and, retention of the participants. For example, health care workers informed project participants about the project and referred them to the project team. In the same way, health care workers provided us with appointment records, medication refill data, and special adolescent day appointments at their clinics, which facilitated the recruitment and follow-up of the project participants. For those participants who transferred from the project clinic, health care workers would get information about the new clinic, and the contact information of the new caregiver/guardian—if applicable, all of which, minimized attrition. The village health teams played critical role in the home visits of the project participants for pill counts. They provided knowledge about the medication and since they live in the community, they helped research assistants to locate and visit participants' home. They also organized all project participant files to facilitate data capture at the clinic level. Thus, the involvement of stakeholders helped to fit project programs into hospital settings without much disruption of already existing organizational schedules.

### **Stakeholder accountability meetings**

Stakeholder accountability meetings are important to keep the partners and stakeholders updated about project progress. ICHAD's stakeholder accountability meetings occur through annual meetings with the school/health facility leadership and contact people, participants, implementation partners, and local policymakers (Mayor, LCV Chairman). The intervention team uses this opportunity to inform the community stakeholders and collaborators about the next steps and answers any questions that the attendees may have about the project, its findings, or the next steps.

Annual accountability meetings are a platform to present preliminary findings from project work. During these meetings, selected participants, local and national political leaders, and key stakeholders are also invited to contribute to presentations and discussions about the research project work or outcomes experienced. For example, in the Suubi + Adherence study, health care workers, District Health Officers, local leaders, and village health teams met once a year during the study duration (5 years) to discuss the study progress, challenges, and also advise on the direction and components of the intervention. Particularly, village health teams shared their experience working with the project. Participants also shared their experiences with the intervention. Additionally, field challenges the team encountered and



potential solutions were discussed during these accountability meetings. For instance, initially, the team had experienced problems locating some of the participants. The healthcare workers from collaborating clinics advised the team to work with village health teams to locate participants' homes since they lived in the same communities. During these meetings, members from partner banking institutions presented on their relationship with the projects, how the interventions have created a strong market base for them and their optimism that the participants would continue banking after the end of the projects. As per PRISM recommendations, the team solicits continuous feedback from organizations and individuals, as well as additional checks on project alignment with external resources and infrastructure. These meetings also have allowed us to raise awareness around adolescents' health and mental health in communities and among local policymakers.

### **Training of key players (task-shifting)**

Task shifting is the process through which tasks are transitioned from specialized or well-trained providers to health workers or a new group of workers with shorter training and fewer qualifications (63). The goal of task shifting is to make efficient use of existing human resources and ease bottlenecks in service delivery (63). Task-shifting is promising as a cost-efficient and feasible model for SSA countries since it strengthens the capacity of lay workers already embedded within health and education systems and trains them to implement the intervention for parents and their children. In the Ugandan context, community health workers/village health teams are the community's initial point of contact for health and considered an integral part of the national health structure. Community health workers tend to be stable members of their communities, residing in the same community for many years (64), and hence, are well integrated within the communities with social ties. For the Suubi4Her project, we have used community health care workers we trained in the delivery of the multiple family group intervention (see Table 1; see McKay *et al.* (65) for more details on multiple family group intervention used in Uganda).

We have also worked with extension workers—these are public servants at the sub-county levels with skills to support crop and animal husbandry at the community level. In Uganda, extension workers are experts who advise farmers on their agricultural practices. They operate on a sub-county level, which comprises different villages and are recruited by the Ministry of Agriculture, Animal Industry and Fisheries (MAAIF). Extension workers' responsibilities include, but are not limited to mobilizing and registering farmers into production and marketing groups; assessing their needs and designing training sessions accordingly; training farmers in technical and leadership skills for improved production and productivity of crops, livestock, and fisheries; demonstrating land preparation and management of crops and livestock; and advising farmers on how to harvest water for livestock and crop production (66).

We have worked with and trained extension workers for the vocational training component of our projects, including Suubi4Her, Bridges to Future, and Suubi + Adherence. We have worked with over 50 extension workers and provided workshops that introduced them to the particular study and focused on income-generating activities and delivery modalities of this intervention component. The involvement of extension workers is key to the sustainability of

the program because they live close to the community and participants can easily contact them if questions arise.

### **Policymaker engagement**

Beginning with the project launches, as stated in the previous sections of this paper, ICHAD has widely engaged local policymakers at every step of the way. During the launch of the Bridges to the Future study, the Minister for Higher Education represented the central government. In the same way, the local districts in the study area were represented by the Local Councilor Chairman (LCV), the District Health Officers and District Education Officers from the four geopolitical districts (Rakai, Masaka, Kalungu, and Lwengo), teachers from all the participants schools, the Rt. Rev. Bishop John Baptist Kaggwa of Masaka Diocese, church leaders as well as children and their caregivers. Similarly, local district leaders including the Mayor, the Chairman, the DHO, DEO, the presidential representative in the area, and religious leaders embraced the recent launch of the Suubi4Her study. The Commissioner for private schools in the Ministry of education represented the central government. During the launch, the research team, together with the Mayor and the Chairman, distributed the school textbooks to all schools participating in the project.

Local government leaders and national level policy makers have also been invited to participate in our conferences, including the annual “Child Behavioral Health in sub-Saharan Africa” conference organized by ICHAD and SMART Africa Center (U19110001, PIs: Ssewamala, McKay). For instance, the First Lady and Minister of Education and Sports officiated the 1st Annual Conference on Child Behavioral Health in SSA on July 12, 2016. This event brought together policy makers, practitioners, researchers, and community members to begin to collaboratively develop and test theoretically informed culturally appropriate, evidence-based, youth- and family-focused service models. In her remarks, the first lady highlighted the importance of addressing child mental health in health programming and voiced the government’s commitment to developing a solid policy framework for the betterment of Ugandan children. The 4th Annual Conference was attended/officiated by Her Royal Queen mother of Buganda and the Honorable Minister for Primary Health Care. Both underscored the importance of addressing the behavioral health needs of children in Uganda and the SSA region at large. At each of the conferences, ICHAD has organized policymaker panels to discuss strategies to increase collaborations between project staff/initiators and policymakers. In addition to in-country conferences in Uganda, ICHAD also organizes bi-annual conferences in the United States that focus on adolescent health and economic empowerment. These conferences are also attended by local and national policymakers from Uganda. The 3rd bi-annual conference *Global Perspectives on Adolescent Health and Economic Strengthening* held in the United States was attended by Ugandan officials including the Chairman of the Health Care Committee (Parliament of Uganda), and local leaders from Masaka district including the Mayor of Masaka Municipality and the Masaka District Local Council (LCV) Chairman. In addition to the role of local governments and media in influencing policy, their presentations focused on the policy-making context, policy priority areas, the policy making process and ways to influence health and asset building policy in Uganda.

The ICHAD leadership, along with our collaborators Reach the Youth and ChildFund, held various meetings with top policy leaders including the Speaker of Parliament and the Prime minister of Uganda to present study findings. These meetings are in addition to the regular meetings with local leaders from the cities and municipalities where we work including District Education officers, District Health officers, Chief Administrative officers, Mayors, and other leaders at the district levels who have always been engaged in our work.

Beyond the annual meetings and conferences, ICHAD, in collaboration with SMART Africa Center, was invited to make child-specific recommendations to the Mental Health Bill 2014. The bill that was assigned to the Health Care Committee was formulated in 2014 when Uganda government officials decided that it was necessary to revise the outdated Mental Health Act passed in 1964. The team proposed the following three amendments to the bill in the form of 3-part policy brief: (I) include specific interventions and preventative measures to address mental health issues among youth and adolescents; (II) outline how mental health care could be further integrated into existing health care systems to increase access; and (III) include poverty prevention supports such as Child Savings Accounts (<http://ichad.wustl.edu/wp-content/uploads/2020/01/Combined-2018-Policy-Brief.pdf>). The Principal Investigator (PI) of the studies -the Founder and Director of ICHAD, appealed to the Uganda Parliament in an effort to generate more child-specific laws within the Mental Health Bill of 2014 during the Mental Health Bill Parliamentary Meeting in March 2018. The 3-part policy brief was also distributed to members of the Uganda Parliament. The PI met with the Speaker of Parliament in her office regarding the Bill along with the Chairperson of the Health Committee of Parliament, Country Director of ChildFund International and the Executive Director of Reach the Youth Uganda. The team also submitted a formal proposal to parliament to guide the amendment process and detail scientific evidence on effective interventions. This is an example of how project findings may potentially influence the external resource environment, a pillar of the PRISM framework.

Another policy brief was prepared by ICHAD, SMART Africa Center in partnership with the Clark-Fox Policy Institute at the Brown School at Washington University in St. Louis, ChildFund Uganda and the AfriChild Centre. This brief presented the role of asset-based family economic empowerment in Uganda, with three main recommendations, including: (I) Strengthening asset-based interventions through a family economic empowerment perspective; (II) combining asset-based interventions to adopt a much more holistic approach and (III) providing space in Uganda's national budget to address asset-based interventions with language that marries early childhood development policies ([http://ichad.wustl.edu/wp-content/uploads/2020/01/Asset-based-Family-Economic-Empowerment-Policy-Brief-2019\\_FINAL.pdf](http://ichad.wustl.edu/wp-content/uploads/2020/01/Asset-based-Family-Economic-Empowerment-Policy-Brief-2019_FINAL.pdf)).

## Discussion

In this paper, we described the strategies ICHAD has used to systematically engage with communities and government structures, using examples from our ICHAD studies in Uganda. We specifically laid out four strategies that have been used to facilitate stakeholder engagement, namely consultative meetings, stakeholder accountability meetings, training of

key players (task-shifting), and policymaker engagement. These strategies, while not an exhaustive list of possible strategies for community engagement, have been effective in successfully creating and maintaining relationships with communities and government structures.

Collaborative and sustained engagement of stakeholders in interventions increases the likelihood of success in implementation. (41,42) Collaboration also allows for a sense of ownership by local stakeholders (41,43) and improves the potential for acceptability, efficacy, cultural and contextual sensitivity as well as uptake and scalability (43,44). Creating and sustaining community collaborations and partnerships are especially critical when implementing combination interventions that require a high level of communication and coordination among multiple implementation partners (e.g., banks, clinics, schools, NGOs). Through close partnerships with schools and clinics from the start, the project staff was able to ensure active engagement of participants and high retention rates (~90%).

ICHAD has been engaged in the Greater Masaka region of Uganda for more than 15 years and has carefully established and nurtured relationships with community stakeholders, implementation partners, and policymakers. The case examples provided here illustrate the time, effort, and commitment that community and policy engagement require. ICHAD has continuously expanded its reach and engaged families, teachers, clinic staff, religious leaders, parent-teacher associations, and community members. The team has also systematically engaged local and national-level policymakers. Project staff committed to engage communities in the process need to invest in relationships, maintain trust, work with both the formal and informal leadership, and sustain the commitment of community organizations and leaders in order to effectively mobilize the communities (43,44,67). It is through these sustained community engagement efforts that ICHAD has been able to create community support that allowed multiple innovative interventions to address the mental health needs of thousands of children and their families who live in resource-limited communities in Uganda.

Community-engaged intervention also necessitates that the staff engages in projects that meet the needs of the communities where it is conducted. This requires staff to be flexible while maintaining the scientific rigor of their studies in order to best respond to the local context. When communities and governments feel that the research project aligns with their priorities and needs, they are more likely to endorse and remain engaged in the process (44), utilize research findings to inform policies and programming; and adopt or scale up the tested intervention. Building and sustaining long-term relationships and communication with the stakeholders can allow the researchers to successfully design rigorous studies that are responsive to local needs and can make a difference (67). This is especially critical when working in low-resource settings with communities that have already been made vulnerable due to structural barriers and inequities. It is also important for researchers to be able to effectively and rapidly translate and present their research findings in accessible and actionable language for policymakers and communities to further encourage evidence-informed policies and programs. The policy briefs presented in section 4.4 are an attempt to communicate research findings to local and national policymakers as well as non-

governmental organizations focused on youth at the intersection of HIV/AIDS, mental health, and poverty.

Finally, community engagement and collaboration need to be informed by frameworks to enable a systematic approach, and increase the likelihood of successful implementation, sustainability and replication. Frameworks, such as PRISM (described above) emphasize multi-level alignment and contextual influences that have challenged many attempts to meet the serious mental health needs of children in resource scarce country contexts.

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**Table 1**

Description of intervention components

Intervention component	Description
Financial literacy training workshops	Participating children/adolescents and their caregivers receive six 1–2-hour workshop sessions that cover components on saving and financial management. The sessions: a) introduce participants to the notion of saving; saving strategies; discuss career planning and help participants begin utilizing financial institutions, including saving in banks
Mentorship	Each child/adolescent has a mentor who would visit with them monthly for the duration of the intervention. The one-to-one mentorship program is intended to help children/adolescents overcome a variety of challenges they face in daily life by fostering meaningful and lasting relationships with near-peer/adult role models. Mentors are high school and university students trained by the schools or NGO staff depending on intervention conditions.
Income generation activities	Participants are trained on investing in income-generating activities (IGA)—during the FLT workshops and are allowed to use up to 30% of their matched savings to invest in an IGA intended to benefit children/adolescents and their caregiving families. The IGA portion is intended to promote economic stability
Youth/Child development accounts	Each child/adolescent in the treatment arm receives a youth development account (YDA), which is a matched savings account held in the child/adolescent’s name in a financial institution under the Central Bank (Bank of Uganda). JCHAD partners with four national banks operating in the study area: Centenary Bank, DFCU Bank, DTB, and Stanbic to host the YDAs. Any of the AY’s family members, relatives, or friends are allowed and indeed encouraged to contribute towards the YDA. The account is then matched with money from the program (at 1:1 or 1:2 match rate), with a cap. A savings account statement is generated monthly for every AY. Each AY, with his or her primary caregiver as a co-signer, has access to the money in his/her account (excluding the matching funds) for emergency purposes. When an AY is ready to pay for school fees, the check for the matching funds is written in the name of “the school” which the AY is attending. The AY then contributes his/her portion of the total cost for the academic term. The approximated matched amounts should be enough to pay for about 4 years of adolescents’ secondary education in a public school under Universal Secondary Education. AY’s access to the matching funds is conditional on an AY having completed the 6 sessions required for FLT workshops within 24 months of enrolment in the program
Multiple family group (Amaka group Amasanyufu)*	Multiple Family Group (MFG) intervention is a 16-session manualized evidence-based intervention for families of children with disruptive behaviors and focuses on family strengthening. The targeted skills and processes are referred to in the curriculum as the 4Rs (Rules, Responsibility, Relationships, and Respectful Communication) and 2Ss (Stress and Social support). The MFG involves up to 20 families. At least two generations (child/adolescent and caregiver -parent, aunt, grandparent) of a family are present in each session. Content and practice activities foster learning and interaction both within the family and between families

\*Happy Families in Luganda—the local language in the study area.

Table 2

## ICHAD studies

Study	Description
Bridges to the future study R01HD070727 (2011–2018)	Funded by the Eunice Kennedy Shriver National Institute of Child Health & Human Development (NICHD), the Bridges study focused on evaluating the efficacy and cost-effectiveness of our family-based economic empowerment intervention for orphaned and vulnerable children affected by HIV in Uganda. It comprised 1383 participants from 48 government-aided primary schools in Uganda. Participants in this study were randomly assigned to one of the three study conditions: 1) Usual care, 2) Child Development Account (CDA) with a 1:1 matching rate, and 3) CDA with a 2:1 matching rate. Participants in the two treatment arms also received mentorship and financial literacy training
Suubi + Adherence study R01HD074949 (2012–2018)	Funded by NICHD, Suubi + Adherence examined the impact and cost associated with an innovative economic empowerment intervention to increase adherence to HIV treatment among adolescents living with HIV on antiretroviral therapy (ART) in Uganda. This study included 702 participants from 39 HIV clinics in southwestern Uganda. Participants in this study were assigned to either bolstered control or treatment arms. Bolstered control arm included the usual care and a cartoon-based curriculum focused on family communication around HIV, ART, and ART adherence. The treatment arm consisted of a savings account in addition to bolstered care). Adherence to ART was measured by wise pill device use, pill counts, clinic records data, and biomarkers (CD4 and viral load tests)
Suubi4Her study R01MH113486 (2018–2023)	Funded by the National Institute of Mental Health (NIMH), the study examines the impact and cost associated with Suubi4Her, an innovative combination intervention that aims to prevent HIV risk behaviors among 14–17-year-old girls living in communities heavily affected by poverty and HIV/AIDS in Uganda. This study follows 1260 adolescent girls from 47 secondary schools in southwestern Uganda. Adolescents girls are randomly assigned to one of the three study conditions: 1) Usual care, 2) Youth Development Accounts (YDA), and 3) YDA + Multiple Family Groups

ICHAD, International Center for Child Health and Development.