

# The Kids to Care Toolkit



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# Acknowledgements

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## **Our Kids to Care community partners**

- Appropriate Revival Initiative for Strategic Empowerment (ARISE) - Uganda
- Community Health Alliance Uganda (CHAU)
- Global Network of People living with HIV (GNP+)
- Health Need Uganda (HNU)
- National Forum of People living with HIV/ AIDS Networks in Uganda (NAFOPHANU)
- N'Weti Comunicação para a Saúde - Mozambique
- Paediatric Adolescent Treatment Africa (PATA) – South Africa
- SFAIDS - Zimbabwe
- Society for Family Health – Nigeria
- Zoelife – South Africa

# About this Toolkit

## Toolkit overview

### Who is this for?

If you are a community actor - a civil society organisation, community-based organisation, a network of people living with HIV, or any community-based group - this toolkit is for you. The resource has been developed to support those who want to implement a community-based model that is based on evidence and best practice to strengthen paediatric HIV care. It aims to provide practical guidance to implement community-based interventions throughout the continuum of care for children living with or most vulnerable to HIV infection.

**We hope you find what you need here!**

### How to use this toolkit

This toolkit will guide you through the Kids to Care model, using a four-stage approach. It can be used to either implement individual interventions at a community level, a collection of interventions focused on one particular stage of the process, or used in its entirety to create a holistic and comprehensive community-based approach to paediatric HIV in a specific context.

Look out for these icons to help you to navigate the toolkit:



**Laying the groundwork** - this icon highlights steps to help you build a strong foundation for your work, increasing effectiveness.



**Best practice** - building on experience from community organisations, this icon points you toward best practices for each stage of the model.



**Tools** - this icon points you to the practical tools you can use for each stage and intervention of the model. We have provided templates and sample tools, but these should be adapted to your context to be appropriate and readily used.

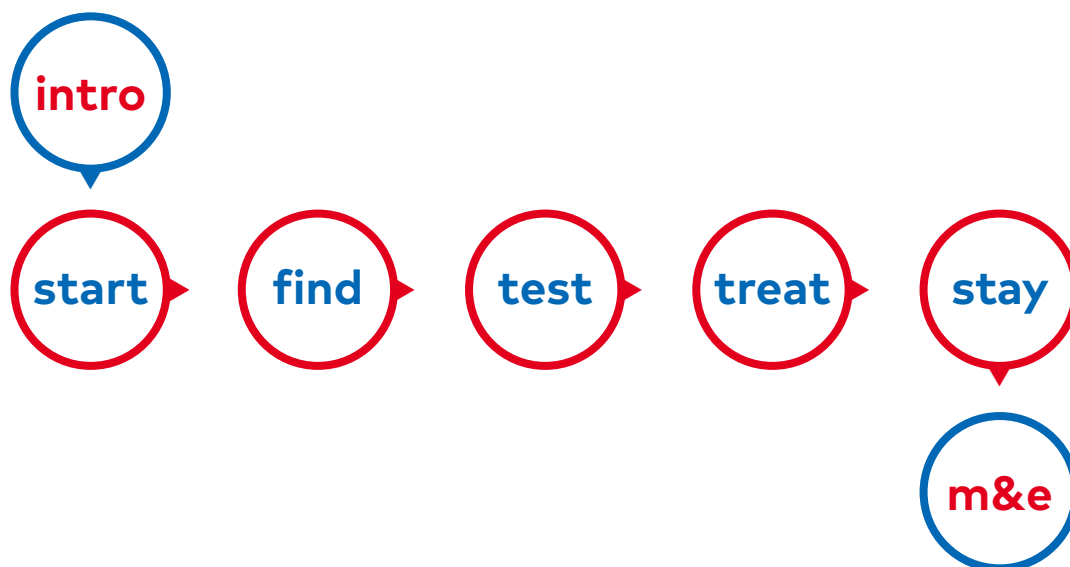


**Case Study** - this icon refers to a particular case based on implementation experience from community organisations

## Toolkit modules

This toolkit has been based on the four key stages of the Kids to Care model. It also includes a start module that explains how to lay the groundwork well before starting to implement the model, as well as sustainability considerations that can be integrated throughout any project. At the end of the toolkit, you will find guidance on monitoring, linking and learning to help you to continuously improve implementation, evaluate your work and share learning.

The toolkit structure is as follows:



# Introduction

## Why children are left behind

### We have a problem

Children around the world are still dying of AIDS — over 300 children every day.<sup>1</sup> Each day 850 new HIV infections occur in children. Worldwide, an estimated 1.68 million children (0-14 years) are living with HIV and 48% of them are not on treatment [2021 estimates].<sup>2</sup> Without treatment, 50% of children born with HIV will die by the age of two.<sup>3</sup>

The international community committed to eliminating vertical transmission of HIV, but coverage of the appropriate services has remained static since 2015.<sup>4</sup> 1.4 million children were supposed to be on antiretroviral treatment by 2020, but this super-fast-track goal was missed.<sup>5</sup> Only 37% of children living with HIV are virally suppressed, compared to 60% of adults.<sup>6</sup> Current global targets aim for 95% of those living with HIV to know their status, 95% of those who know their status to be on treatment, and 95% of those on treatment to be virally suppressed and sustained.<sup>7</sup> These targets must be met if there is any hope of meeting the 2030 sustainable development goals.

HIV care and treatment for children and pregnant women in low-resource settings comes with a number of challenges. These include long distances to health facilities, stock outs of antiretroviral treatment or lack of paediatric antiretroviral treatment, health facility staff shortages and high workloads. These health system challenges are complicated by community challenges - poverty, food insecurity, stigma and discrimination. Those most affected are children.

**This is unacceptable.**

## Our response: The Kids to Care model

Aidsfonds, together with its partners, have created the **Kids to Care model** to respond to this problem. The model uses four stages: find, test, treat, stay to reduce new HIV infections in children and ensure that children who live with HIV are able to have healthy and full lives. The model is effective, evidence-based and rooted in community knowledge, built on the contextual and localised experience of community actors.

Communities know best how to identify children most vulnerable to HIV infection and how to support them to test for HIV, initiate treatment and sustain treatment for the long-term. Building on local knowledge and local community structures, community-based models are effective, sustainable and critical for filling the gaps in paediatric HIV care and treatment to reach global goals.

Aidsfonds, together with community partners, co-created the **Kids to Care model**.<sup>8</sup> The model was based on the TAFU (Towards an AIDS-Free generation in Uganda)<sup>9</sup> and FTT (Find, Test, Treat)<sup>10</sup> models in Uganda and Zimbabwe respectively. These brought together best practice from local communities with evidence-based frameworks, such as the UNICEF Service Delivery Framework<sup>11</sup> and the PATA C3 approach (Clinic-Community-Collaboration).<sup>12</sup>

By bringing care closer to home and using a relational, trust-focused approach to identify and support children, pregnant and lactating women, community-based models build a sustainable support structure for long-term



care and respond to the challenges of stigma and disclosure. In addition, community-based models provide insight into contextual challenges such as drug stock outs, poor nutrition and adherence and effectively link newly diagnosed children and pregnant and lactating women to the services they need in a holistic way (including services at a health facility, centres for responding to gender-based violence or violence against children, nutritional supports, and other services).

Community-based models, particularly where the role of community health workers are prioritised, create a critical link between community and health systems to collaborate on ensuring that children live healthy and full lives. Links work both ways – from facility to community and community to facility, coordinating efforts that are centred on the recipients of care.

Aidsfonds is a non-governmental organisation based in the Netherlands that is working to end AIDS by 2030. Aidsfonds works with community-based partners across Africa to accelerate and strengthen efforts to meet this goal, ending deaths from AIDS and ending new HIV infections. A critical component of this is to improve paediatric HIV and vertical transmission services.<sup>13</sup>

**Community-based models are not new.** The Alma Ata Declaration in 1978 made by the World Health Organization and UNICEF started the movement toward community systems strengthening, recognising the importance of social actors in health outcomes.<sup>14</sup> The Global Fund to Fight AIDS Tuberculosis and Malaria launched their community systems strengthening model in 2010<sup>15</sup> and UNICEF took forward a community-facility linkages model in 2015.<sup>16</sup> Each contribution on the global stage led to refinement in the understanding of community-based models and the critical role that community actors and systems play in the health outcomes of all people, especially children.

However, there are significant gaps in identifying best practice and how-to steps

for implementing effective community-based models for paediatric HIV. The Kids to Care model, and this toolkit, aim to respond to this gap by providing practical step-by-step guidance on how to implement effective community-based interventions to improve paediatric HIV and vertical transmission services.

## What makes Kids to Care unique?

The Kids to Care model is built on a set of core principles. These are critical to the success of the model and inform each of the model's stages.

### Community-owned and community-led

Local community actors must be at the centre of any intervention or programme. They must be meaningfully involved in project design, implementation, monitoring, learning, and evaluation.

### Builds on existing community structures

The Kids to Care model identifies and strengthens community actors and structures to contribute to long-term sustainability and to optimise support for children and pregnant women.

A key component of this is strengthening linkages between community structures and health facilities and building the skills and knowledge of key actors to fulfil their roles effectively.

### Child and family-centred

Responding effectively to paediatric HIV means working effectively with children and families, placing their needs and priorities at the centre of the response and focusing on building trust and rapport.

>>



### **Builds on government policies and frameworks**

Government guidelines, policies and frameworks for paediatric HIV treatment and care are adhered to and community actors are trained on these as part of capacity building.

### **Key stakeholders are meaningfully engaged from the beginning**

Government stakeholders, other implementing organisations and community actors are mobilised and meaningfully engaged from the start of any project or intervention to avoid duplication of activities and to create visibility within the government health system.

### **Interventions are informed by data**

The Kids to Care model and its related interventions are targeted based on available data. This is used to target districts within a country and to target communities within a district. Where data is not complete or not available, additional data collection should be conducted to supplement existing data, in both qualitative and quantitative forms. This can be done by engaging local entities, conducting focus group discussions or planning a needs assessment survey to focus interventions where there is greatest need.

### **Committed to sustainability and long-term support**

To support children living with HIV in the long-term, programme interventions must start with sustainability in mind, embedding capacity and equipping community structures to provide care and retention support throughout the life cycle.

## **Keep in mind: everyone's needs are different**

It is important to remember that the Kids to Care process is not always linear. At times, people living with HIV drop out of care and need to be identified in order to return to care. The barriers that people face to retention in care differ and their reasons for dropping out of care are unique. Community health workers, community resource persons and where relevant, mentor mothers, should provide tailored support for people living with HIV who drop out of care and may return at a later time, adapting their support to respond to the barriers that households and communities face.



**The Start module: Laying the groundwork** is essential for any intervention and provides guidance on how to conduct a situational assessment to target your project, how to embed sustainability from the outset and how to identify key actors to carry out your interventions.

# Start module: Laying the groundwork

The Kids to Care model is built on core principles (outlined in the introduction). Laying down the groundwork for the model contributes to building a strong foundation for interventions by:

- Understanding the context: key stakeholders, barriers to care, and available services
- Responding to where the needs are greatest by using existing and collected data
- Equipping community actors, such as community health workers, to strengthen community structures
- Embedding sustainability from the beginning of the response.

To find out where your project will work best and why, you need to conduct a situational assessment.

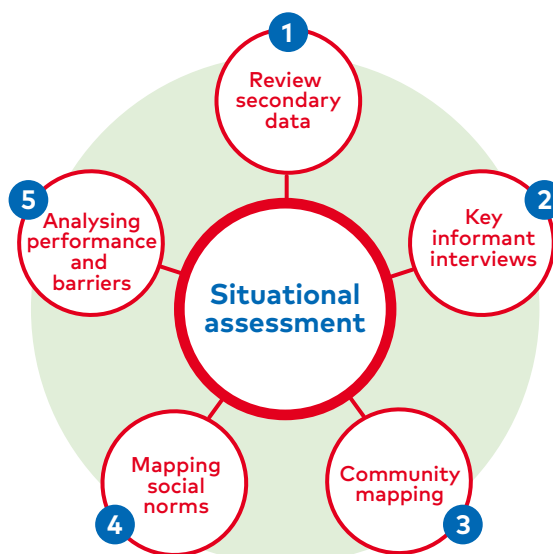


## Top tip!

Tools have been provided in this module for each intervention/step. It is important to adapt these tools to your own context so that they can be used effectively and be relevant for your work.

## What is a situational assessment?

A situational assessment is a process to identify the areas of greatest need so you can target your Kids to Care interventions to respond to those needs.



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## Step 1: Review secondary data

Reviewing secondary data will give you insight into where the needs are greatest and how you can focus your intervention. The checklist

below provides key areas that can be reviewed prior to starting any Kids to Care intervention.

# Secondary Data Checklist ✓

## 1 NATIONAL HIV STATISTICS

- Prevalence rate - national, regional, district, etc.
- Number of children living with HIV; number of pregnant woman living with HIV
- Number of children living with HIV enrolled in antiretroviral treatment; pregnant woman living with HIV enrolled in antiretroviral treatment and prevention of mother to child transmission rate
- National retention and progress data (PEPFAR)
- Vertical transmission rate; availability and timing of early infant diagnosis
- Availability of ART, including pediatric antiretroviral treatment

## 2 REGIONAL HIV STATISTICS

- Areas of highest prevalence
- Lowest uptake of antiretroviral treatment + high numbers of children living with HIV or suspected children living with HIV
- Lowest rates of early infant diagnosis

## 3 COMMUNITY HIV INFORMATION

- Local health facility proximity to community
- Local availability of test kits, antiretroviral treatment, pediatric antiretroviral treatment, early infant diagnosis
- Antiretroviral treatment register data - number of adults, adolescents and children on treatment

## 4 DEMOGRAPHICS

- Household size, family structures (marital status/ age/ gender/ education level of family members)
- Average household income/ socio-economic status

## 5 FRAMEWORKS, POLICIES AND STRATEGIC PLANS

- Guidance on how the government health system is responding to the needs of children living with HIV and policies that you will need to adhere to in your project and strategic plans that your project is contributing to

## Step 2: Key informant interviews

When you have reviewed the secondary data, you will have identified the areas where you can focus your project. It is critical at this stage to engage with stakeholders from the Ministry of Health and the relevant health teams that work in the subnational areas you have identified (i.e. district health teams).

Conducting interviews and holding meetings with representatives from the Ministry of Health will help you work out which communities to focus on in these areas. This will give you a clearer understanding of the context, including the key barriers and quality of services. Then you can see which stakeholders should be engaged in the project to avoid duplication of efforts, promote coordination and encourage buy-in at community level.

Once you understand the context better, You will probably benefit from doing some key informant interviews with key stakeholders, including:

- health care workers
- community and/or faith leaders
- caregivers
- community members
- teachers, representatives from local schools
- others as relevant to your context.

You can share with them the findings from your secondary data and ask them questions to help you assess how to focus your project. This will also help you validate the data you have collected and fill in any gaps.



**Community Services Register<sup>17</sup>:** This tool helps you track what services are available in a community, where they are accessed and how referrals for these services are made. It provides questions you can use to map services for families, those provided by implementing organisations and services available through the government health system. This tool was developed by Health Need Uganda, a Kids to Care implementing organisation.

**BASICS Paediatric HIV Toolkit<sup>18</sup>:** This provides more detailed questions for assessing processes and services for paediatric HIV case identification, referral and care at the community level. The tool was produced by BASICS.

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### Step 3: Mapping the community

In this stage, you want to map the relevant community structures, resources and actors, including other implementing organisations. You can map at a very local level and map an individual community, or you can map at the level of the subnational area that you have identified (i.e. district, state, province, region).

Mapping the community helps you to identify the essential community structures that you can build on in your project. Two of the primary Kids to Care model key principles are that the response is community-based and community-led, and builds on existing community structures. **Community mapping**<sup>19</sup> helps you understand what structures exist, what resources are available in the community and who the key decision-makers are - this can include human resources (community health workers and other actors), community/faith groups, forums and regular meetings.



The easiest way to map the community is to actually draw a map:

- Start with **infrastructure** - where is the nearest health facility and which one do families prefer to go to? What is the most local level health facility available? Consider community health centres, pharmacies, and other places that community members go when they feel unwell. Where do community groups meet? Are there prominent faith groups in this community, where do they meet? Where are the schools? Is there a local market? A government office? Mark all infrastructure and key meeting places on your map.
- Map out **who is doing what** in the area where you want to work. What other civil society, community-based organisations or non-governmental organisations are working here? What are they doing?
- Once you have mapped infrastructure and key stakeholders, you can **review the map** to identify gaps. What gaps are there in service delivery? What challenges do families face in accessing paediatric care and treatment?





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Once you have drawn a map that covers all the different resources in your community, you can meet with different groups to understand more about the map and how the resources function or are utilised.

#### Key groups to meet with

- Groups or networks of people living with HIV
- Caregivers of children living with HIV
- Schools
- Foster homes
- Health care providers
- Community or religious leaders
- Subnational area level officials (i.e. district, region, state, province)

#### Key questions to ask

- Do the elements on the community map accurately represent the resources in the community?
- If not, what is missing or has not been captured well?
- What barriers do you see to these resources being utilised most effectively?
- What opportunities are there to improve use of these resources?

## Step 4: Mapping social norms

Social norms have a significant impact on HIV care and treatment as they can influence willingness to test for HIV, entry into care and adherence to treatment in the long-term. Social norms are the unwritten rules of how a society operates. They vary from one culture to another and influence how people behave and what is seen as normal and acceptable. In all cultures there are social norms that are positive and norms that are negative, such as stigma. Understanding social norms that relate to HIV can help to shape the interventions you use in your project.



**People Living with HIV Stigma Index<sup>20</sup>:** This tool provides insight into how stigma and discrimination impact on the lives of people living with HIV and can be used to advocate for improved rights and access to services. This can support with mapping of social norms within your situational assessment. It provides data compiled by UNAIDS, the Global Network of People Living with HIV (GNP+) and International Community of Women Living with HIV.

## Step 5: Analysing performance and barriers

At this stage, you can start to bring your situational assessment together to analyse performance in service delivery, analysis of barriers and key programme assessment questions.



### **UNICEF Service Delivery Framework**

**(SDF)<sup>21</sup>:** This framework was developed by a group of experts to provide guidance on how to improve service delivery for paediatric HIV care and treatment. There are three parts of the SDF that are helpful in analysing performance and barriers within your situation assessment:

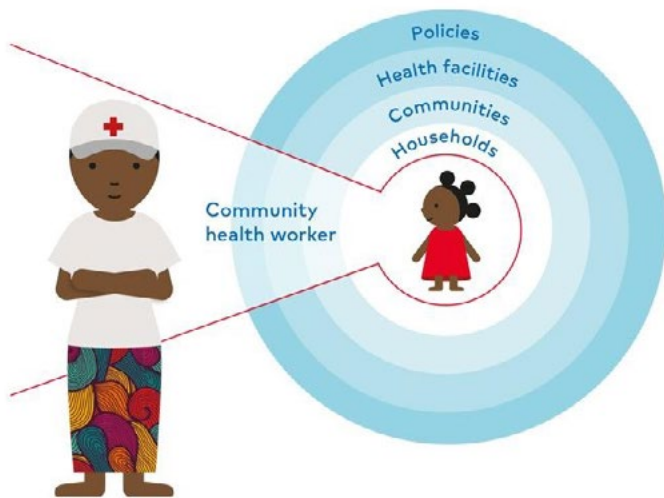
- Performance along the locate-link-treat-retain continuum (key indicators by age group (0-4; 5-9; 10-14; 15-19) - page 20
- Key Programme Assessment Questions - page 21
- Barriers analysis (demand and supply side barriers by age group) - to inform interventions and advocacy - page 22-23



# Identifying your community health workers

## What is a community health worker?

This is a general term that refers to the lowest cadre within the government health service delivery system. In different contexts this role has different names. In Uganda, they are referred to as 'village health teams'. In Nigeria, they are known as 'village health workers'. However, the Kids to Care model implemented in Nigeria also works with traditional birth attendants and 'proprietary and patent medicine vendors', as these are critical cadres within the community system in that context. Each context will have a different name, but for the purposes of this toolkit, we will use the term community health worker. **Community health workers are at the heart of the Kids to Care model.**



Community health workers influence change first at the household level. They are critical in the process of identifying children most vulnerable to HIV infection and in supporting them to remain in care over the long-term. However, they are also well known by the community and act as mobilisers, raising awareness about paediatric HIV and reducing stigma.

Community health workers link with the health facility to support children and pregnant women with access to testing and treatment.

In addition, they influence change in policy by participating in advocacy related to the contextual needs they identify and work with every day.

## Selecting community health workers

The selection of your community health workers is a critical step in the Kids to Care model. It is important to identify the right cadre to work with and to select the best participants for training, capacity building and mentoring throughout your project. In this step, you are establishing the foundation for every other stage of the model and each of the interventions you will implement.

### Roles and responsibilities of community health workers

Community health workers play a critical role within the Kids to Care model. Their role and responsibilities include:

- Conducting household visits with families to provide education on HIV, to dispel myths and reduce stigma and discrimination
- Supporting home or community-based testing in collaboration with local health care workers, where applicable
- Providing pre and post test counselling
- Supporting disclosure and providing psychosocial support
- Establishing and strengthening support mechanisms for treatment adherence such as peer to peer support groups, caregiver support groups, etc.
- Establishing and strengthening retention mechanisms such as Village Savings and Loans Associations and providing nutritional education and support
- Supporting community mobilisation activities such as community dialogues, outreach and sensitisation sessions

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### Identification and selection criteria

Community health workers must have the following characteristics:

- Commitment to improving outcomes for children living with HIV and reducing new infections among children
- Respected by the community and well known by community members
- Good understanding of the health issues that families face in the community
- Willingness to learn
- Commitment to long-term support of children and families
- Basic literacy
- Willingness and intrinsic motivation to work as a volunteer



### Village health teams boost HIV testings

In Uganda, community health workers are known as village health teams (VHTs) and are the cadre in the government health system that is closest to communities. Village health teams in Uganda are responsible for providing health education on a number of health issues, however this does not often include paediatric HIV. The teams develop relationships with families by conducting household visits to provide health education and by linking with health services where needed.

Within the Towards an AIDS-free Generation in Uganda (TAFU) programme, community-based organisations selected village health teams and provided training on paediatric HIV so it could be integrated into the services they were already providing. In Uganda, village health teams have been critical to increasing testing of children and to supporting long-term retention in care. Community-based partners in the TAFU programme have engaged with village health teams from the design stage through implementation to evaluation. Without meaningful involvement of village health teams in each stage, the programme would not have been successful.



## Laying the groundwork for sustainability

Building a community-based model means supporting existing structures and strengthening them to more effectively reach and care for children living with HIV. Embedding sustainability from the beginning ensures that the structures can continue to support children and families long-term. Children living with HIV become adolescents and eventually adults living with HIV and need support throughout their lifespan to adhere to treatment and remain virally suppressed.

### Building relationships

Sustainability is built on relationships. It is important to focus on relationships that you need to strengthen within the community.

- Consider first the government stakeholders from within the government health system. This might be officials from the Ministry of Health, health care workers, district health teams or other structures depending on your context.
  - Who do you need to connect with to support sustainability of the Kids to Care model?
  - What do you need from them?
  - How can you develop a relationship with them?
  - What policies, frameworks or strategic plans did you identify in your situational assessment that would be helpful to emphasise in your meetings with stakeholders? Try to explain how your work contributes to the government goals and aligns with these frameworks.
- In addition to government stakeholders, what other implementing organisations did you identify in your community mapping? What are they doing and how does it align with your plans? Forming partnerships with other implementing organisations can avoid duplication of services and ensure that you respond to gaps in service delivery.



To build sustainability into the programme, community organisations implementing the Kids to Care model need to engage with government stakeholders and other implementing organisations from the design and inception stages. This can be part of the situational assessment or during the selection of interventions for your particular project. Many community-based organisations also invite government stakeholders to participate in co-creation of the project design, as well as joint monitoring. Consider the following:

- How will you capture the results of your work and showcase this to other organisations and stakeholders? Plan for how you will monitor and evaluate your work and when and where you will share learning.
- How can you engage stakeholders in joint monitoring and coordination meetings to collaborate and ensure ongoing participation? Are there technical working groups that you can join to share your work and engage with stakeholders?
- Community health workers are vital to the sustainability of the Kids to Care model. They should receive fair compensation for their work. Consider how you will integrate their support into your project, and how you can make that sustainable in the long-term. This could mean engaging in advocacy to promote compensation of community health workers within the government health system.

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### **Working with the government to find – test – treat children exposed to HIV**

The FTT (Find, Test, Treat) project, based on the Kids to Care model, is implemented by SAfAIDS in Zimbabwe. When the project was started, it was designed to respond to a gap in health service delivery by building the capacity of community health workers to provide case identification, testing and linkage to care services at the community level.

The project worked with community health workers to first identify children who were not already included in the continuum of care for the elimination of mother to child transmission, and to support early infant diagnosis and dry blood spot sampling. The project used a risk profile to identify households who had a high likelihood that the mother and/or child had not been tested and worked to engage families from a holistic perspective.

To build sustainability and cost-effectiveness into the project, the FTT project held monthly meetings with district and ward level representatives to coordinate services and avoid duplication. This resulted in more effective service delivery, but also strengthened relationships for sustainability with government stakeholders.

## **Planning for sustainability**

Each stage of the Kids to Care model – from establishing the groundwork to retention in care – includes sustainability considerations to help you build sustainability in from the beginning of your work. What follows are the sustainability objectives for each stage. As you work through the different stages and interventions, building in advocacy and implementing your project, these objectives can help set the benchmark for what to aim for in terms of sustainability in each stage.

### **Laying the groundwork**

First set the foundation for your project, establishing relationships with those who will contribute to the sustainability of the model in the long-term. By the end of this stage, you should be working toward:

- Established relationships with implementing partners for collaboration and coordination of services
- Established relationships with government stakeholders and engagement in the project through regular meetings and joint monitoring
- Alignment of project activities with government policies, frameworks and guidelines
- Identifying community health workers who are committed to the Kids to Care model and to providing long-term support to children, adolescents and pregnant women living with HIV

## Stage 1: Find

Community health workers are critical to the Kids to Care model, especially in case identification. By the end of this stage, you should be working toward:

- A sustainable structure for community health worker stipends and/or salary
- Integration of stipends and/or salary into government health system expenditure

## Stage 2: Test

In this stage, the community structures and health facilities begin to link and work together. Sustainability in this stage is built on advocacy and clear referral mechanisms. By the end of this stage, you should be working toward:

- Consistent supply of HIV test kits for community-based testing
- Consistent supply of HIV test kits for confirmatory testing at the health facility
- Consistent supply of early infant diagnosis materials with quick turnaround of results (within 4 weeks)
- HIV testing consistently provided within antenatal care

## Stage 3: Treat

This stage involves the introduction of children and pregnant and lactating women into treatment for HIV and requires advocacy and continued linkage between the community structures and health facility to build sustainability. By the end of this stage, you should be working toward:

- Consistent supply of antiretroviral treatment at health facilities, including paediatric antiretroviral treatment
- Established support groups for adults, adolescents and children living with HIV, caregivers, and pregnant women with clear governance structures and group agreements for meetings
- Nutrition education provided regularly and emergency nutrition support available for vulnerable families
- Ongoing household visits provided by community health workers and mentor mothers

## Stage 4: Stay

In this final stage, community structures are strengthened so they can endure long-term. You need to build a strong foundation through support groups, household economic strengthening and food security to reduce the barriers for retention in care that exist in low resource settings. By the end of this stage, you should be working toward:

- Strong support groups established with self-governance capacity for long-term psychosocial and adherence support
- Household economic strengthening established through savings and loans groups with clear governance structures and constitutions for meetings
- Nutrition education provided regularly and emergency nutrition support available for vulnerable families
- Ongoing household visits provided by community health workers, community resource persons and mentor mothers
- Households integrated into government support programmes

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**The next module is Module 1: Find.** This provides guidance on how to identify children and pregnant women for HIV testing, including how to build relationships and trust, and how to strengthen relationships between health and community systems.

# Module 1: Find

## What will you learn in this module?

### This module will help you understand:

- what barriers children and pregnant women face to accessing HIV care and treatment;
- how the Kids to Care model responds to those challenges;
- what interventions you can use and how to build on best practice for case identification.

### **Mary's story: concerns about her son**

There is a family in your community with a child who has been unwell a lot recently. His mother Mary has tried to take him to the local health facility, but it's far from their home. She tried to get him some medication from the local pharmacy, but he doesn't seem to be getting better. Her mother-in-law was telling her about another child in the community who has recently been diagnosed with HIV and that it was passed on during delivery when he was born. She knows that HIV can make a child sick, but she is scared to think that it could be HIV. Does that mean she is also HIV positive? What about her husband? She feels overwhelmed even thinking about it. She's worried her husband would be angry and force her out of the house, which is just too much of a risk. She goes back to the pharmacy to try again to get some kind of medication. She really hopes that this time it will help.

### This module will help you take action to:

- lay the groundwork for case identification through training of key cadres;
- identify children and pregnant women who need to be tested for HIV.

Children living with HIV face a number of barriers to care. Many parents are afraid to test their children - afraid of what a diagnosis would mean for their child and what it could mean for them. Poverty, risk to livelihood or economic security are often driving forces behind stigma and fear. In addition, distance to the health facility and the cost of transport mean spending precious resources on a trip that may not offer a solution.

### **Here's where the Kids to Care model starts.**

Community health workers conduct household visits to help dispel myths about HIV and break down stigma. They mobilise people in the community to create awareness about what HIV is, that it is important to know your own and your child's HIV status, how it can be treated and to understand what services are available for children. By building relationships with families, community health workers build trust and over time are able to support families to have their children tested for HIV.



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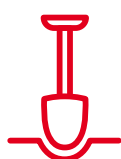
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In this module, you will build a foundation for case identification by doing two things:

- Identifying community resource persons who can support mobilisation and social norms change
- Training community health workers and community resource persons on case identification, stigma reduction and basic HIV knowledge



### Top tip!

Tools are provided in this module for each intervention/step. It is important to adapt these tools to your own context so that they can be used effectively and be relevant for your work.

## Training of community health workers and community resource persons

### What are community resource persons?

**Community resource persons are not health workers.** Community health workers are part of the government health service delivery system, situated at the community level. Community resource persons are people in the community who have an influence over social norms, particularly those relating to children and pregnant women. Such social norms can include the freedom a woman has to choose her healthcare provider or to access antenatal care and family planning; or the freedom a caregiver has to take their child for testing or treatment. Social norms can also influence how family resources are utilised and what is prioritised, which can influence costs of

healthcare and nutrition. Social norms are the unwritten rules of how a society operates. They vary from one culture to another and influence how people behave and what is seen as normal and acceptable. In all cultures there are social norms that are positive and norms that are negative. Community resource persons can be mobilised to generate support for paediatric HIV by working to shift negative social norms that act as barriers to care and treatment.

Community resource persons vary from one context to another, but they can include:

- Religious leaders
- Community leaders
- Teachers
- Chiefs or other traditional leaders
- Mentor mothers or expert clients

Negative social norms that community resource persons address include: stigma and discrimination, fear of HIV, decision-making about health within the family, how treatment is sought for health issues, and how children's health is understood.

Community resource persons are part of the lives of children and pregnant women in a social space. They have pre-existing relationships with families and are usually in a position of influence. They may be leaders of a local faith centre like a mosque or church, or they might teach a child at school.

#### **Characteristics of a community resource person**

- Holds a position of influence in the community
- Has a pre-existing relationship with families
- Is respected by people in the community
- Understands the unique challenges faced by children and pregnant women in accessing testing, care and treatment for HIV

#### **Roles and responsibilities within the Kids to Care model**

Community resource persons play a role in championing the Kids to Care model. While community health workers mobilise and raise awareness, the role of a community resource person is to reinforce that work through their leadership and influence. A community resource person is responsible for:

- Championing mobilisation efforts in the community to raise awareness about HIV
- Endorsing community health workers and linking them to families who they do not already have a relationship with
- Sharing information and key messages about paediatric HIV through their own spheres of influence
- Supporting retention efforts by reducing stigma and discrimination and offering space for peer and support groups to meet
- Speaking out against harmful social norms such as gender based violence that act as barriers to accessing HIV care and treatment
- Using their leadership and influence to join advocacy efforts to improve the quality of services available for children and pregnant women

#### **Identification and selection criteria**

Identifying community resource persons often comes through Laying the Groundwork, where you conducted a situational assessment and community mapping to identify influential stakeholders in the community. The following criteria can be helpful for identifying and selecting community resource persons to participate in your project:

- Commitment to improving the outcomes of pregnant women and children and the quality of paediatric HIV services
- Understanding their own influence in the community and how that can be leveraged to change social norms
- Strong relationships with families and respected by people in the community
- Able to act as a role model in the community and to lead by example



## Training

To effectively identify children and pregnant women in need of HIV testing, community health workers and community resource persons must be trained. In many contexts, community health workers receive training from the government health system. It is important to build on this training within the Kids to Care model to ensure that all community health workers and community resource persons receive a standard package of training to effectively conduct case identification. This may be in partnership with government stakeholders, other implementing organisations or independently. The training for community resource persons and community health workers should include at a minimum:

- Basic facts about HIV
- Overview of HIV in the country where your project is being implemented (provide regional and district context from your situational assessment also at this stage)
- Understanding community mobilisation
- Roles and responsibilities of community health workers and community resource persons
- Identifying the needs of children living with HIV
- Referring children with HIV and their caretakers for services
- Vertical transmission services in your context
- Addressing stigma and discrimination of HIV positive children
- Understanding the linkages between social norms and HIV
- Disclosure of child's HIV status
- Data management and reporting
- Planning for case identification of children and pregnant women



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**TAFU training manual**<sup>24</sup>: This provides training materials for community health workers and community resource persons within 14 sessions in the areas of: understanding of HIV among children, pregnant and lactating women; identifying children who needs support; referral systems and coordination with health facilities; addressing stigma and discrimination; disclosure support; treatment adherence; prevention of vertical transmission; planning for activities; data and monitoring.

**Caregiver guide**<sup>25</sup>: This provides additional support for community health workers working with caregivers. It goes beyond the TAFU training manual by providing indepth support on disclosure; understanding antiretroviral treatment and adherence; stigma and discrimination; child abuse and protection; sexual and reproductive health and family planning; loss, grief and bereavement; transition in care (adolescent to adult); child/adolescent mental health; tuberculosis; and nutrition for children living with HIV. The guide was produced by the Elizabeth Glaser Pediatric AIDS Foundation.

**Training/mentoring report template**<sup>26</sup>: This template can be used to keep track of training conducted, topics covered and participants.

## Linking community health workers with the local health facility

A critical step towards equipping community health workers to work in the community is to link them with the health facility. This creates a relationship between community health workers and health care providers that facilitates regular follow up, case management and individual advocacy to ensure that children and pregnant women receive the best possible care.



- Every child and pregnant woman enrolled on antiretroviral treatment should immediately be linked with a community health worker. This creates a health facility to community linkage and provides local support for recipients of care.
- As new children and pregnant women are identified and referred for testing (see [Module 2: Test](#)), community health workers should be linked with health care providers at the health facility who are providing care for that particular person.
- In many contexts, it is helpful to set aside a particular day each month when community health workers are at the health facility for coordination meetings. These meetings can be used to follow up on the needs of recipients of care and to support case management. Health care providers should be available on this day to meet with community health workers and discuss any issues that are arising in care.
- Community health workers and health facility staff can work together on outreach testing in the community. This helps to build the relationship between them and offers additional support for community members. [See Module 2: Test](#) for more information on how to do this.



**Guidance for conducting coordination meetings with stakeholders**<sup>27</sup>: this guidance outlines the key steps for conducting coordination meetings with stakeholders as part of implementation and planning for long-term sustainability. This guidance has been developed by Kids to Care implementing partners.

**Clinic-Community Collaboration Toolkit**<sup>28</sup>: this toolkit goes into more depth about how to form an effective partnership between clinic and community within paediatric HIV programming and how to strengthen the collaboration between stakeholders in implementation. The toolkit was produced by PATA.

**Memorandum of Understanding template**<sup>29</sup>: this template for a memorandum of understanding between clinical and community partners working on paediatric HIV was produced by PEPFAR.



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## Key interventions

### Deciding which interventions to use

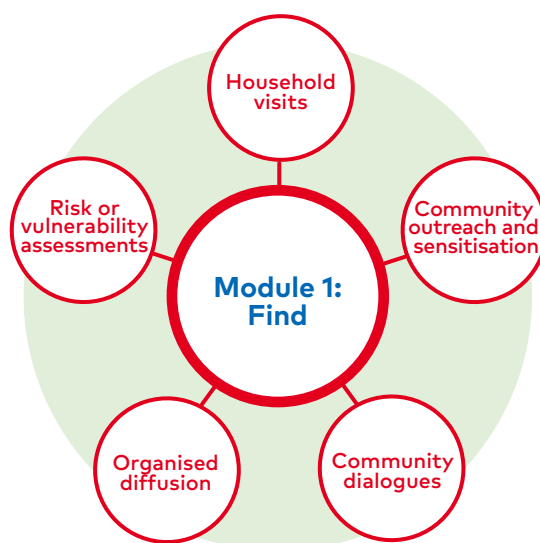
When designing your project, you can choose from any of the interventions in this toolkit that are most relevant to your context. As you work through the different modules and refer back to your situational assessment and community mapping, as well as issues that may have emerged in training, you can select the most appropriate interventions for the needs you are responding to. Each of the key interventions for this stage is outlined below along with best practices for that intervention and suggested tools that can be used in implementation.

A key consideration before implementing any intervention to identify children and pregnant women in the community is to understand the government guidelines on who is eligible to be tested for HIV and how vulnerability to HIV infection is assessed. This may not exist in your context, but if the government health system has created these guidelines, it is important that your project follows them.

To effectively identify children and pregnant women to be tested for HIV, there are several interventions you can implement at community level. You will find a summary of each below, along with best practices and recommended tools.

### Household visits

Household visits are the foundation of the Kids to Care model and used during each stage. Within [Module 1: Find](#), community health workers conduct household visits with families to build relationships and rapport and then begin to increase their understanding of HIV, help reduce stigma and fear and discuss HIV testing. Household visits help create trust, support privacy and confidentiality and allow openness in discussion around topics related to HIV.





Most community health workers have additional responsibilities within the government health system and it is helpful for paediatric HIV to be one of the topics they discuss when conducting household visits. This helps reduce the stigma of a community health worker visit', avoiding it being associated specifically with HIV.

Community resource persons can be helpful in initiating household visits and introducing the community health workers if they are not already known to the family or community. Community resource persons often already have a relationship with families as a community leader, pastor, imam, teacher, etc.



**Home visit tool**<sup>30</sup>: This resource provides a template for tracking information during home visits and guidance on topics to discuss with household members. It can be used by community health workers and has been adapted from a tool produced by ARISE Uganda, a Kids to Care implementing organisation.

## Risk or vulnerability assessments

Risk or vulnerability assessments help identify children or pregnant women who are most likely to test positive for HIV. This makes more efficient use of limited resources, such as HIV test kits, and targets support to those who need it most.



You may have guidelines from the government health system for how to conduct risk or vulnerability assessments, in this case you can use these.

Community health workers should engage with the health facility to create a link with every child on antiretroviral treatment for ongoing support. This can help identify families and other children who may need to be tested for HIV and encourage use of an index testing model (See Module 2: Test for more on index testing).



**Risk/vulnerability assessment**<sup>31</sup>: This document provides guiding questions for a risk/vulnerability assessment and support for community health workers to conduct the assessment during household visits.

**Community-based paediatric/adolescent HIV testing screening checklist**<sup>32</sup>: This was produced by the Ministry of Health in Nigeria and provides additional questions that can be used in assessing risk/vulnerability to screen for HIV testing.

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## Community outreach and sensitisation

Community health workers and community resource persons work together to mobilise the community and conduct outreach and sensitisation. This can take many forms and might involve discussing paediatric HIV at a community event; hosting an event solely focused on paediatric HIV; sharing information, education and communication materials in the community or other strategies.



Mobilisation raises awareness about HIV, the importance of testing and where to access support. Experience in the Kids to Care model has shown that integrated sensitisation activities on HIV with other health information can increase participation and openness of communities to engage, especially where HIV stigma and discrimination are challenges.



**Community mobilisation module<sup>24</sup>:** Module 4 of TAFU's training manual for community health workers and community resource persons provides content on community mobilisation. It includes participant handouts to increase understanding of how to do community outreach and how to sensitise communities on HIV.

## Community dialogues

Community dialogues are structured discussion forums where topics related to health and social norms can be explored. These groups should be led by a local facilitator with a good understanding of HIV and the barriers that children and pregnant women face in accessing care and treatment. Facilitators are often supported by community health workers to run community dialogues.



- Community dialogues provide a space for discussion on health-related topics and should be led by a facilitator who is local to the community and respected by community members.
- Select topics that are relevant for the group who will be participating. Insight into what topics to choose can come from your situational assessment and from qualitative data you gathered at the project start. As an example, N'weti in Mozambique ran community dialogues within their Kusingata project, based on the Kids to Care model and had sessions on the following topics:
  - Gender norms and equality, and communication within the family
  - Rights and responsibilities related to health and health care, focusing on sexual and reproductive health
  - Prevention of HIV and sexually transmitted infections, HIV counselling and testing
  - Family planning and planning for pregnancy, including use of contraception
  - Elimination of mother-to-child transmission and adherence to antiretroviral treatment
  - Delivery and taking care of a child exposed to or living with HIV, including the importance of early infant diagnosis
  - Participation in community-based monitoring of the quality of health services

- Following discussion sessions, one-to-one follow ups should be conducted with each participant as an opportunity to conduct a health assessment. HIV testing can be one of many areas assessed within that assessment.
- Consider how you will capture data from community dialogues. Tracking the number of participants and disaggregating by gender, age, and other factors is important. So you can follow up effectively, keep a record of what has been discussed, commitments that are made by participants and how people engage with the topics.



#### **Guidance for conducting community dialogues**<sup>34</sup>:

This document provides foundational principles, top tips from implementing organisations and practical questions for how to organise a community dialogue and how to follow up on outcomes from the discussions.

#### **Example summary of community dialogues**<sup>35</sup>:

This summary of community dialogues topics was produced by N'weti, a Kids to Care implementing organisation operating in Mozambique. It can be used to support the development of a community dialogues intervention.

### **Organised diffusion**

Organised diffusion is where paediatric HIV, the importance of testing and key messages to reduce stigma and discrimination are integrated into other social spaces, such as within church sermons or regular community meetings. Organised diffusion is primarily the responsibility of community resource persons. It can involve expert clients sharing testimonials of their experience in testing for HIV and accessing care or can be promoting messages within other meetings or gatherings.



- Identify appropriate social spaces where there is already trust and relationship and where you can intentionally share information and experience.
- Work with community resource persons to share key messages about paediatric HIV and vertical transmission within spaces of influences (i.e. faith groups, community meetings, community groups).
- Work with community resource persons to develop these key messages with input from community health workers, to ensure accurate and relevant information is shared.



#### **Paediatric HIV Advocacy 'talking points'**<sup>36</sup>:

These provide a starting place to develop key messages on HIV for use in organised diffusion (sharing of messaging through community structures). The paediatric HIV advocacy toolkit (see P16 for talking points) was produced by UNICEF and WHO.

**Children Treatment Literacy Booklet**<sup>37</sup>: this provides detailed guidance on treatment literacy for children and targets caregivers. The messages in provided can be used to develop key messages for organised diffusion. It was developed by the Elizabeth Glaser Paediatric AIDS Foundation.

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## Sustainability considerations

During this stage of the Kids to Care model, the key sustainability consideration is the longevity of the work of community health workers. This cadre is critical to the success of the Kids to Care model and through your project you will invest time and resources to build capacity and strengthen this vital community structure. Community health workers will form relationships with families and build trust to be able to discuss sensitive topics like paediatric HIV, testing and stigma.

### Key questions for community health workers' longevity:

- Are community health workers in your community provided with any stipend or salary through the government health system? Is this consistently provided?
  - If they do, is it sufficient for their family's needs and for the number of hours they work?
  - If not, what additional stipend or salary support is needed?
  - Where could this be resourced from?
  - If they do not receive a stipend or salary, how could you raise this issue with government officials? What relationships have you developed during the laying the groundwork stage that might be helpful?
  - What mechanisms could be in place in the short term to provide them with a stipend?



Some organisations enrol community health workers into Village Savings and Loans Associations (more information on how to create and support VSLAs is available in [Module 4: Stay](#)) where they can meet to contribute to savings and take loans to support their income. This works best when they meet at the health facility as it increases their visibility and provides opportunity for follow up on client referrals and care. Many organisations provide a start-up grant for the community health worker group to initiate individual or group business ventures and provide training on small business startup.

The ideal situation is for the government to provide a continuous salary for community health workers. Village Savings and Loans Associations can provide an interim solution while advocacy is ongoing toward this goal.



## Advocacy considerations

The key advocacy considerations that emerge from this stage of the Kids to Care model include:

- Promoting the role of community health workers as a key resource within the health system for finding and linking mothers and children with HIV to care and encouraging the government to support a stipend or salary support
- Linking community health workers with the lowest level of health facility available for ease of referral and building of relationships with health care workers
- Coordination of the community-health facility linkage with support from community-based or civil society organisations in a particular geographical area. This can provide support to the local government and strengthen the coordination mechanisms.



### Traditional birth attendants and proprietary and patent medicine vendors

In addition to community health workers, two other actors are part of the Kids to Care model implemented by the Society for Family Health in Nigeria. These are traditional birth attendants and proprietary and patent medicine vendors. Both these actors are influential in local communities and are the main resource for health information and health care. Proprietary and patent medicine vendors are local level pharmacists who can prescribe medication after consultation and traditional birth attendants support pregnant women through labour and delivery. Traditional birth attendants are often left out of community-based programmes as they have been linked with traditional practices, however, they proved to be influential and effective in the Lafiyan Yara project in Nigeria.



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Within the project, all three cadres support case identification and are referred to as 'community mobilisers'. The project developed research protocols to test the effectiveness of each actor in case identification. Community members were informed about HIV testing services by either a traditional birth attendant, a village health worker, a proprietary and patent medicine vendor, or a combination of all three. These cadres carried out sensitisation in schools, within places of worship, at healthcare facilities and at other public meeting spaces.

The percentage of women referred for HIV testing increased significantly at the endline assessment of the project compared to baseline. Where traditional birth attendants provided sensitisation, referral for testing increased from 16.9% to 87.7%; for village health workers the increase was from 17.3% to 79.7% and for proprietary and patent medicine vendors, the increase was from 25.9% to

36.4%. However, when a combined approach was used, the increase was from 9.3% to 80.0%.

Using a combined approach proved to be the most effective but also the most cost-efficient. Other models cost USD 342.10 per pregnant woman to refer for HIV testing services (ICER), but with a combined approach, this reduced to only USD 38.35 per pregnant woman.

Community mobilisers use the national re-stratification tool provided by the government health system to assess the level of risk of HIV for children. When the project started, cases that were identified for testing were referred to the health facility, but the project invested in building capacity of community mobilisers to both identify clients and conduct testing at home. Referral was then made for a confirmatory test at the health facility.



**The next module is Module 2: Test.** This module introduces interventions for increasing HIV testing and embedding support mechanisms for testing into community systems.

# Module 2: Test

## What will you learn in this module?

### This module will help you understand:

- How testing can be done within community-based models
- How to build capacity within key cadres for community-based testing

### Mary's story: a visit at her home

You have recently started visiting a new family in your community. You have been sharing some health information with the husband and wife who have been quite open to your visits. One of the challenges they face is their son's health. He is eight years old and continues to have bouts of ill health but medications from the pharmacy don't seem to help. You explain to the parents what HIV is and explain that it is possible for HIV to pass from mother to child. You explain that this can be managed with medication if any of the family test positive and there are things that they can do to stay healthy and strong. The mother is nervous to test for HIV and doesn't want to go to a health facility to do it. She is afraid someone will see her there and she doesn't have the money for transport to get there.

### This module will help you take action to:

- Choose a community-based testing model that suits your context
- Create links with the health facility for effective referral and follow up

Long distances and lack of transport to health facilities, staff shortages and lack of resources in health facilities, as well as stockouts of test kits are primary challenges with testing for HIV. In addition within families, lack of accurate information, stigma and fear remain some of the most pervasive barriers to testing.

Community-based testing that is used within the Kids to Care model can help alleviate the financial and logistical burdens of transport to the health facility, bringing testing into the home or community. It can also resolve some of the challenges with overworked healthcare workers and test kit stockouts. Pre and post test counselling can be provided by properly trained community health workers who have already developed a relationship of trust with the family.

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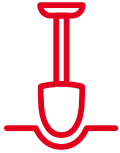
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In this module, you will build a foundation for effective testing by thinking through the following questions:

- Which government policies must be adhered to for maternal and paediatric HIV testing services, and what are the protocols for testing?
  - It is critical to follow health system guidelines for testing and ensure community health workers are trained on these
- What training is needed to provide HIV testing at community level? What training is needed to provide pre and post-test counselling?
- Who will do the testing? Where will it be done?
- How will confirmatory testing be done? How will you link community health workers to the health facility for confirmatory tests?



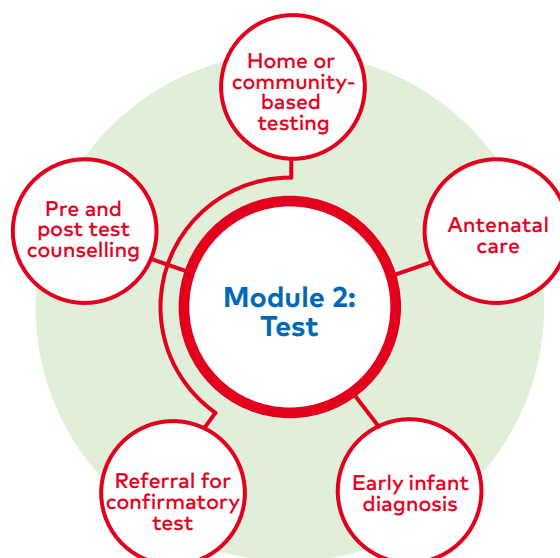
#### Top tip!

Tools have been provided in this module for each intervention/step. It is important to adapt these tools to your own context so they can be utilised effectively and be relevant for your work.

## Key interventions

Testing for HIV is a standardised process and each government health system has guidelines and standard operating procedures for how this should be done. **It is essential that these guidelines are followed and community health workers are trained on them.**

There are key interventions in this stage that can support a community-based model of testing for HIV. This stage requires strong linkages between community health workers and the health facility so they can work together to test those who have been identified in [Module 1: Find](#).



## Continuous intervention: Household visits

Household visits are a foundational intervention that continues throughout all stages of the Kids to Care model. It is important that community health workers continue to conduct household visits to support the interventions in [Module 2: Test](#), which are outlined below.

### Home or community-based testing

Home or community-based testing moves HIV testing from the health facility to either a family's home or a community location. This helps address the barriers faced by many families including long distances to the health facility, test kit stock outs or staff shortages and lack of resources in health facilities.

When HIV testing is done in the home or community, it is essential that those providing the testing, most likely community health workers, are trained to conduct testing effectively, but also to provide good quality pre and post test counselling.

Home or community-based testing is done in the context of a relationship with the family, which is developed during household visits conducted by a community health worker or through community mobilisation and outreach. These activities are foundational parts of [Module 1: Find](#) and precede home or community-based testing.



HIV testing must be done in a confidential setting to protect the privacy and anonymity of children or adults who are being tested. In many places where the Kids to Care model is implemented, community health workers are trained to provide testing and are supported by a health care worker to provide quality assurance. Community health workers can either be trained on pre and post test counselling or supported by a lay counsellor who has experience in this area.

In most settings, index testing is used to target resources and identify those who are most in need of testing. Index testing is an approach whereby the exposed contacts of an HIV-positive person are notified and offered an HIV test. It can be done at home, in the community or at the health facility, and involves testing the biological children and sexual partners of an adult who tests positive for HIV. Index testing requires that one person in the family system has tested positive for HIV, which can occur following interventions in [Module 1: Find](#) such as community dialogues, household visits or community sensitisation sessions. Once an adult in the family has tested positive for HIV, children and sexual partners can be tested.

In some cases, this is reversed and the child is identified to be most vulnerable to HIV infection and testing is recommended based on health status or other risk factors. This can emerge from the risk or vulnerability assessments conducted in [Module 1: Find](#). From this point, parents and other biological siblings can be tested using an index testing approach.

As mentioned in laying the groundwork for [Module 2: Test](#), it is important to be aware of and adhere to government regulations around home and community-based testing and to ensure that all required protocols are observed.

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Intervention 1 is divided into three parts: home or community-based testing (1a), pre and post testing counselling (1b) and referral for confirmatory testing (1c). When conducting home or community-based testing, index testing is considered best practice in most contexts. The tools below can be used to facilitate index testing and adapted to your particular project. Tools for pre and post test counselling and referral for confirmatory testing are provided under Intervention 1b and Intervention 1c.

**Index testing tool**<sup>38</sup>: This tool was produced by ARISE Uganda, a Kids to Care implementing organisation. It provides a template for tracking key contacts for index testing.

**Index client information form**<sup>39</sup>: This form provides more in-depth questions for index testing, tracking of key contacts, partner information, intimate partner violence assessment, and space to document the outcomes of testing for the individual, partner and family members. This form was produced by PEPFAR.

**Index testing for children working tools**: these two working tools outline the key steps for index testing with children and can be used by community health workers to ensure that all steps are followed. They were produced by PEPFAR:

- [Working tool 1](#)<sup>40</sup>: 6 Steps for Providing Index Testing to Children;
- [Working tool 2](#)<sup>41</sup>: Paediatric Index Testing Job Aid for Orphans and Vulnerable Children and Community-Based Staff.

**TB screening tool**<sup>42</sup>: this can be used with index testing to integrate TB screening into HIV testing services. It was produced by ARISE Uganda, a Kids to Care implementing organisation.

## Pre and post test counselling

Pre and post test counselling is an essential component of home or community-based testing, but requires a unique skill set and understanding to be effective.

As with home or community-based testing, it is important that community health workers are trained in the relevant government policies on pre and post test counselling and where possible, that government training materials are used.



The WHO guidelines on HIV testing services recommend that all forms of HIV testing services adhere to the 5Cs - confidentiality, counselling, consent, correct results and connections to care.

Pre-test information should include, at a minimum:

- the benefits of testing for HIV
- the significance of an HIV-positive and an HIV-negative diagnosis
- services - including provision of antiretroviral treatment - that are available should the recipient of care test positive
- a brief description of prevention options and encouragement of partner testing
- confidentiality of the test result and any other information shared by the recipient of care
- the right to refuse to be tested and that declining testing will not affect the recipient of care's access to HIV services or general medical care
- potential risks of testing, particularly in instances where there are legal implications for those who test positive and for those whose sexual or other behaviour is stigmatised

Pre-test information for pregnant women should also include, at a minimum:

- the potential risk of transmitting HIV to the infant
- infant feeding practices
- how to reduce mother-to-child transmission, including the use of antiretroviral treatment to benefit the mother and prevent HIV transmission to the infant
- benefits of early HIV diagnosis for mothers and infants
- benefits of partner testing

Post-test counselling should include, at a minimum:

- an explanation of the test results and diagnosis
- clear information on antiretroviral treatment and its benefits
- where and how to access antiretroviral treatment. Make an active referral for a specific time and date
- how to prevent transmission of HIV and viral suppression
- how to encourage and offer HIV testing to sexual partners, children and other family members of the recipient of care. This can be done individually, through couples testing, index testing or partner notification

An HIV positive test result is often a shock. The counsellor should provide emotional support by:

- giving the recipient of care time to consider the results
- helping cope with emotions arising from the diagnosis of HIV infection
- discussing immediate concerns and helping decide who in her or his social network may be available to provide immediate support
- discussing barriers to linkage to care, same-day enrolment and antiretroviral treatment eligibility assessment and arrange for any follow-up
- discussing possible disclosure of the result and the risks and benefits of disclosure

- assessing the risk of intimate partner violence and discussing possible steps to ensure the physical safety, particularly women, who are diagnosed HIV-positive
- assessing the risk of suicide, depression and other mental health consequences of a diagnosis of HIV infection and providing additional appropriate referrals for prevention, counselling and support
- encouraging and allowing the recipient of care to ask additional questions

### Testing of children for HIV requires a different approach.

When testing a child under the age of 14 years, the parent/guardian should be thought of as the client and the child should not be present when the initial results are discussed. It is important to maintain confidentiality and to reassure the parent/guardian that you will not share the results of the test with the child until they are ready.

- Use the guidance above to support the parent/guardian after sharing the results of the test. Allow time for emotions that may arise and shock that a parent/guardian may feel if the results of the child's test are positive.
- Discuss any fears that the parent/guardian may have
- For more information on disclosure of HIV status with a child, see [Module 4: Stay](#)





**Pre and Post Testing HIV Counseling for Children**<sup>43</sup>: this booklet can be used to support caregivers and children themselves with pre and post HIV testing counselling support. It was produced by UNICEF.

**Pre and Post Testing HIV Counselling QA/QI checklist**<sup>44</sup>: this can be used by community health workers and implementing organisations to provide quality assurance and quality improvement support for pre and post HIV test counselling. The checklist was produced by FHI360.

## Referral for confirmatory testing

When HIV testing is done at home or in the community and the test result is positive, it is important that the person who received the positive test result is referred to a health facility for a confirmatory test. This avoids the result being a false positive, but also helps to begin the linkage into care.



Linkages between community health workers and health facilities should be established during the setting the groundwork phase of the Kids to Care model. This relationship can be reinforced through coordination meetings or regular visits to the health facility by community health workers to follow up on recipients of care who have been referred and to promote visibility.

Referral for confirmatory testing can be passive or active. A passive approach would be to give a recipient of care who has just tested HIV positive a referral letter, and to recommend that they go for a confirmatory test. An active approach would be to explore what support the recipient of care needs to attend the clinic for their confirmatory test and to provide that support, where feasible, to increase the likelihood that they will attend.







### **Sample referral form for confirmatory testing**<sup>45</sup>:

This tool was produced by Community Health Alliance Uganda, a Kids to Care implementing organisation. The referral form provides an example that can be used by community health workers to refer individuals for confirmatory HIV testing at a health facility.

If a pregnant woman tests positive for HIV within antenatal care, it is recommended that she starts treatment as soon as possible and is linked with a mentor mother for follow up support.

If a pregnant woman tests negative for HIV within antenatal care, it is recommended that she is provided with HIV prevention messages and tools (this could include PreP) and she is followed up and re-tested during pregnancy and breastfeeding.

## Antenatal care

In addition to identifying children, community health workers are also responsible for identifying pregnant women. Referring pregnant women to antenatal care and providing support to assist them in overcoming barriers to attending antenatal care visits, provides an opportunity to link pregnant women into care and to facilitate HIV testing as part of eliminating vertical transmission of HIV.



**Breastfeeding and HIV**<sup>46</sup>: this advocacy brief provides guidance on breastfeeding and HIV that can be used during household visits by community health workers or mentor mothers with pregnant and lactating women. It was produced by the Global Breastfeeding Collective.



According to the WHO, pregnant women should attend at least four antenatal care visits during their pregnancy. Antenatal care visits should include, at a minimum:

- Counselling on nutrition and healthy eating during pregnancy, including iron and folic acid supplementation
- Screening for gestational diabetes, hypertension, anaemia
- Advice about alcohol and tobacco use, malaria prevention and vitamin supplementation (iron and folic acid at a minimum)
- HIV testing services
- Ultrasound scan before 24 weeks to determine gestational age or symphysis-fundal height measurements

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## Early infant diagnosis

Early infant diagnosis is the process of testing an infant that has been exposed to HIV. It is a critical step in reducing new infections among children and preventing mother to child transmission of HIV.



- Infants who have been exposed to HIV should be tested at the earliest opportunity, ideally between 4-6 weeks of age
- Test results should be provided within four weeks of testing and sooner if possible. If available, same day point of care tests should be used
- Antiretroviral treatment should be initiated immediately on confirmation of a positive test result
- HIV testing services should continue to be offered for infants, especially once the breastfeeding period has ended



### **HIV-exposed infants service delivery tool**<sup>47</sup>:

this provides a template for tracking services provided to new mothers with HIV-exposed infants. It was produced by ARISE Uganda, a Kids to Care implementing organisation.

**Strategic framework for supporting point-of-care early infant diagnosis**<sup>48</sup>: this resource provides support for implementing organisations to understand early infant diagnosis, to increase demand for this service within the community and to advocate for improved quality of service delivery for infants in a variety of contexts. The framework was produced by the Global Network of People Living with HIV (GNP+).

## Sustainability considerations

HIV testing requires effective collaboration and linkages between community health workers and the health system. A positive test result is the entry point into a continuum of care for a person living with HIV and is a critical opportunity for optimising access to care and likelihood of retention and optimal treatment results.

Effective collaboration is needed to:

- Access test kits that are used in home or community-based testing
- Collaborate on in-home or community on-site testing
- Support quality assurance in testing and pre and post test counselling
- Refer for confirmatory testing at a health facility
- Refer pregnant women to antenatal care where HIV testing is a consistent part of antenatal care services
- Refer women who test negative during the first antenatal visit throughout their pregnancy and lactating/breastfeeding period

## Advocacy considerations

- Are HIV test kits consistently available?
- Are trained cadres available to provide testing, pre and post test counselling, and referral for confirmatory testing?
- Is early infant diagnosis consistently available? How long do test results take? Are point of care early infant diagnosis devices available?
- Is HIV testing a consistent component of antenatal care?



### Scaling up HIV testing services through effective follow up

Within the Kusingata project implemented by N'weti in Mozambique, the aim was to use index testing for HIV testing services within the Kids to Care model. Within this approach, testing would be conducted for sexual contacts and biological children of pregnant women and other adults who tested positive for HIV within the health facility. However, early on in the project, N'weti realised there was greater need for testing than an index testing model would allow for.

In response, the project decided to utilise two approaches for HIV testing services : 1) within community dialogues facilitated by community health workers; 2) through 'medical brigades' (mobile outreach teams) to remote communities.

Once an individual has been tested for HIV, they are referred for a confirmatory test at the health facility and linked into treatment and care. The community health workers who provide testing also provide follow up through reminder calls, visits and accompaniment, which has resulted in a 99% linkage success rate.

Community health workers support HIV positive individuals to accept their status through post test counselling and encourage them to disclose their status to family members and sexual contacts. From this point, community health workers can support index testing for household members.

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The next module is **Module 3: Treat**. This module provides guidance for supporting children and pregnant women to initiate treatment and overcome any barriers to accessing the treatment.

# Module 3: Treat

## What will you learn in this module?

### This module will help you understand:

- Treatment protocols in your context
- How to improve adherence and treatment literacy and provide psychosocial support
- The importance of viral load suppression

### This module will help you take action to:

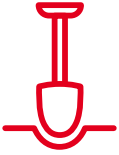
- Advocate for improved access to treatment for children and pregnant women
- Establish and strengthen support mechanisms for optimal treatment outcomes

#### **Mary's story: financial struggles**

One of the families you've been visiting decided to test for HIV. Both the mother and child have tested positive. You visit the family and sit with the mother to explain the test results and what she can do to live a full and healthy life despite this diagnosis. You explain that each month, she will have to travel to the health facility to refill medications and to take them regularly. She is worried because she has heard that the health facility does not always have enough of the medications and especially not those for children. You explain that nutrition is important and that having access to sufficient and nutritious food will help keep them both well. The mother is concerned that she doesn't earn enough to always have enough food at home, and especially the right food for their nutritional needs. She is also worried about the cost of travelling to the health facility every month. She is a farmer and sells tomatoes in the market and her husband works as a day labourer, which means sometimes they have money but other times don't.

Lack of transport to the health facility, food insecurity, together with stigma and fear of HIV are all factors that prevent children and their caregivers from continuing to access treatment and take their medication as prescribed in low resource settings. These factors are further complicated by lack of access to accurate information or understanding of treatment adherence and its importance. Systemic challenges such as stockouts of antiretroviral drugs or the lack of specific paediatric treatment regimens for optimal and child-friendly treatment create additional barriers to treatment and adherence.

The Kids to Care model works to respond to these issues through advocacy, setting up support mechanisms for children, adolescents and adults living with HIV and for caregivers, and by providing education on treatment literacy and nutrition.



There are a few key considerations that help to lay the groundwork for this stage. Some answers to the questions below will come from the situational assessment you conducted in the Laying the Groundwork module, particularly the analysis you conducted of health system performance and barriers.

Key questions to consider include:

- What policies are in place for treatment initiation in this context?  
The WHO recommends a test and treat model where treatment is initiated as soon as a child or adult tests positive for HIV. It is important to understand what policies are in place in your context and how treatment is initiated.
- Is paediatric antiretroviral treatment available for children? Is there consistent availability of these medications?
- Is viral load testing done and if so, how is this done?
- What support systems are already in place at the community level for people living with HIV?
- What barriers do people face to starting treatment?

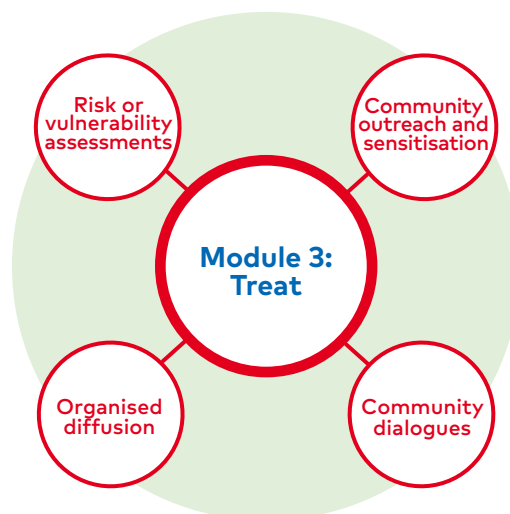


#### Top tip!

Tools have been provided in this module for each intervention/step. It is important to adapt these tools to your own context so that they can be utilised effectively and be relevant for your work.

## Key interventions

Treatment for HIV starts at the health facility and requires consistent access to medications and early initiation of antiretroviral treatment. Supporting treatment adherence to reach viral suppression is the core work of the Kids to Care model in this stage. Community structures are critical to support children and caregivers to take their medication as prescribed and ensure that children and adults living with HIV can reach viral suppression.



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## What is viral load suppression?

Viral load suppression is having very low or undetectable levels of HIV in your blood, defined as having **less than 200 copies of HIV per millilitre of blood**<sup>33</sup>. Viral suppression helps to keep a person healthy and prevents transmission. HIV medicine can keep viral load low.

Interventions in this stage of the Kids to Care model aim to provide the support to reach viral suppression.

## Peer to peer support groups

Peer to peer support groups are a critical support mechanism for treatment adherence. Support groups provide a space where children, adolescents and adults living with HIV, as well as caregivers, can meet together with others who are in similar situations. Group members can share experiences and provide emotional support to each other. Groups also create a unique opportunity for community health workers and community resource persons to provide training on treatment literacy and follow up on health services.



In most contexts, community-based organisations and non-governmental organisations can help you organise support groups in the community. They can mobilise community members to join groups; provide training and support with establishing groups through a group constitution or setting ground rules, and can provide follow up to ensure groups are visited regularly and supported by community health workers.

**Step 1:** The first step for organising peer to peer support groups is to identify and select group leaders, who are ideally from the same demographic as the group and living with HIV. This provides trust and connection with group members.

**Step 2:** Peer to peer support groups should be organised first by age to facilitate connection and understanding between group members.

- Children's clubs
- Adolescent groups
- Adult/caregiver groups

After organising by age, it can be helpful to also divide by sex in some contexts. This is particularly relevant for groups of pregnant or lactating women. In some cases, adolescent girls and adolescent boys feel more comfortable in single-sex groups.

Group leaders will need to think through how they invite and welcome members to join the groups. This can be through household visits by community health workers, in community spaces by community resource persons or through health facility staff who recommend the groups.

**Step 3:** Establishing leadership and providing support to groups.

- In most cases, group leaders are identified and selected by community-based organisations and provided with training on how to facilitate support groups (resources for training are provided below in the Tools section).
- Peer to peer support groups should establish a process for their meetings.
- Groups should also create their own agreements and ground rules for how group meetings will operate and how they will protect confidentiality of group members. It is recommended that groups create their own constitution that everyone agrees to follow.
- Groups for children should be led by an adult.
- Community health workers and community resource persons can be invited to visit groups and provide training on particular topics or follow up on care at regular intervals.
- Caregivers of children living with HIV often form their own group to access support around the unique needs of caregivers.



#### CHILDREN'S CLUBS:

**The Happy Made by Zed book**<sup>49</sup> was created by the Happy Made By Foundation. TAFU, a Kids to Care implementing organisation, utilised this book within their Kids to Care programme in Uganda. It can be used within children's support groups and clubs to share information on HIV and reduce stigma and fear.

The **KidzAlive Talk Tool**<sup>50</sup> was created by ZoeLife, a Kids to Care implementing partner organisation. It is a job aid that can be used by healthcare workers, community health workers, and children's club facilitators to provide child-friendly HIV information.

#### ADOLESCENT GROUPS:

**Tiwale**<sup>51</sup> is a comic book created for young people living with HIV to help to reduce self-stigma. It can be used within adolescent support groups.

**CAYA Cartoons**<sup>52</sup> is a resource designed for young people living with HIV to sparking conversations around treatment literacy. The cartoons were created by AVERT.

**Positive Voices, Positive Choices**<sup>53</sup> is a toolkit providing activities and training resources for supporting adolescents living with HIV to become peer educators of support groups. The toolkit was created by ICAP.

#### ADULTS LIVING WITH HIV:

**Guidelines for establishing and operating successful support groups for people living with HIV**<sup>54</sup> provides guidance on group formation, leadership and activities that can be conducted within groups for people living with HIV. The resource was produced by Catholic Relief Services.

**Scaling Up Positive Prevention**<sup>55</sup> provides guidance on how groups can be formed and structured as well as suggestions for health information topics that can be discussed within the group. The resource was produced by FHI360.

#### PREGNANT AND LACTATING WOMEN LIVING WITH HIV:

**Positive Health, Dignity and Prevention for Women and their Babies**<sup>56</sup> is a guide for pregnant women and mothers living with HIV which can be used by networks of women living with HIV, peer educators, women's groups or others who want to help women navigate the decisions they need to take before, during and after their pregnancy. This guide was produced by GNP+, IATT and ICW.

#### CAREGIVER SUPPORT GROUPS:

**Children Treatment Literacy Booklet**<sup>37</sup> provides detailed guidance on treatment literacy for children and targets caregivers. It can be used to develop key messages for organised diffusion (sharing of messaging through community structures). The booklet was developed by the Elizabeth Glaser Pediatric AIDS Foundation.

**Caregiver guide**<sup>25</sup> provides additional support for community health workers working with caregivers. It goes beyond the TAFU training manual by going into more depth on disclosure; understanding antiretrovirals and adherence; stigma and discrimination; child abuse and protection; sexual and reproductive health and family planning; loss, grief and bereavement; transition in care (adolescent to adult); child/adolescent mental health; tuberculosis; and nutrition for children living with HIV. The guide was produced by the Elizabeth Glaser Pediatric AIDS Foundation.

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## Household visits

Household visits are a core intervention within [Stage 1: Find](#) and [Stage 2: Test](#) of the Kids to Care model, and continue to be key in this stage. Household visits can be conducted by community health workers, community resource persons or mentor mothers (see intervention 3 below) to continue building relationships and trust with families; follow up on care and offer referral support; provide one-to-one counselling and information on treatment literacy; reduce stigma and fear; and provide psychosocial support to enhance adherence.

Household visits with community health workers also offer an opportunity for HIV status disclosure support. Disclosure support for children means sharing their HIV status with them and helping them to understand the implications of it. Community health workers can support caregivers to disclose HIV status to children in an age-appropriate way and to do this gradually by providing information and emotional support to the child as and when they are ready to receive it.



Community health workers should visit households at least once a month to follow up on children, pregnant women and caregivers.

A household visit should involve the following, at a minimum:

- Follow up on health status and how the child or other household members are feeling
- Follow up on mental health and any fears, concerns or difficulties faced
- Follow up on antiretroviral treatment refills and whether the client is able to consistently refill and take medications according to the health care worker prescription

- Education on treatment literacy and adherence, as needed
- Education on nutrition, as needed (see below intervention 4)
- Disclosure support, as appropriate



**Home visit tool<sup>30</sup>:** This provides a template for community health workers to track information during home visits and guidance on topics to discuss with household members. It has been adapted from a tool produced by ARISE Uganda, a Kids to Care implementing organisation.

**Care and Treatment Plan<sup>57</sup>:** this guideline can be used by community health workers during household visits to support access and retention to treatment. It was produced by HealthNeed Uganda, a Kids to Care implementing organisation.

**Viral load monitoring tool<sup>58</sup>:** This template can be used by community health workers to track viral load for HIV positive individuals during household visits. It was produced by ARISE Uganda, a Kids to Care implementing organisation.

**Example child protection referral form<sup>59</sup>:** This serves as an example of a referral form for child protection and support services if these are needed by children who are being supported by community health workers. It can be used as it is or adapted to the context.



## Mentor mothers

Mentor mothers are women living with HIV who support pregnant women and lactating mothers who also live with HIV to reduce vertical transmission of HIV. Mentor mothers are one type of community resource person that provides household visits, focusing mainly on pregnant women. Mentor mothers are linked with a pregnant woman after she tests positive for HIV during antenatal care, and can provide support for early infant diagnosis after birth, guidance on breastfeeding safely and adherence support for mothers living with HIV. Mentor mothers also provide psychosocial support and nutrition education (see Intervention 4).

Mentor mothers are useful to include in a Kids to Care programme when you are working with pregnant women and supporting them to adhere to treatment during their pregnancy; attend their antenatal care visits; and provide support with breastfeeding and early infant diagnosis after their baby is born.



- Mentor mothers should be 'expert clients' - women living with HIV who understand prevention of vertical transmission, treatment literacy and adherence and have navigated this system personally. This creates connection and trust between women and increases the likelihood that a pregnant woman will attend antenatal care and be tested for HIV.
- Pregnant and lactating women, with their consent, should be linked with a mentor mother after a positive diagnosis within antenatal care. This provides access to support for adherence and retention for the woman and reduces the risk of vertical transmission. Mentor mothers also provide support for women to access early infant diagnosis for their children and breastfeeding support.



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**Mentor Mothers Training Manual**<sup>60</sup>: this manual can be used by implementing organisation to train mentor mothers to provide support to pregnant women and lactating mothers living with HIV. The manual was produced by 4M Mentor Mothers and the Salamander Trust.

## Nutrition education and support

Malnutrition is one of the main causes of poor viral suppression among children and a critical factor in health outcomes for both children and pregnant women living with HIV. In contexts where poverty is high, malnutrition is a common and significant problem. In addition, when many paediatric antiretroviral drugs are prescribed, it is advised that they be taken together with food. Some caregivers are not able to provide adequate food for their children at the time they need to take their medication and this has a negative impact on their adherence. The Kids to Care model therefore prioritises nutrition education and support and improving food security to increase the likelihood of taking antiretrovirals as prescribed and to reach viral suppression.



Eating well is critically important for children, adolescents and adults living with HIV. People living with HIV require adequate nutrition, a varied diet and sufficient safe and clean water. When a person is living with HIV, they should have their weight monitored regularly and have the capacity to adapt their diet when they are feeling unwell or struggling with food-drug interactions, while maintaining energy and nutrient intake. Weight monitoring is especially important for children living with HIV as the antiretroviral treatment they are prescribed is based on their weight. In

addition, tracking weight is a good indicator of healthy growth and thriving and provides opportunity for additional support if a child's weight is not increasing as it should.

Food availability or food security is often the biggest challenge for people living with HIV in low resource settings. In contexts where food insecurity is a challenge, kitchen gardens can provide high-nutrient foods with low cost and low energy inputs. Where families do not have the means to maintain a kitchen garden, nutritional support can be offered with high-energy and nutrient-dense supplements. However, this is not possible to sustain in the long-term and families must graduate to alternative models over time.



### Top tip:

In Uganda, Aidsfonds partners developed a nutrient-dense porridge formula using locally available ingredients. This formula was shared with all clients so that they could make the porridge at home to support their nutrition and that of their children.

In addition, food insecurity is often the result of income insecurity. Interventions to improve household income are critical to improving the food security of a household. In [Module 4: Stay](#), you will find more information on interventions such as Village Savings and Loans Associations that can support improved income for families.



**Caregiver guide**<sup>25</sup>: this gives additional support for working with caregivers and includes content on nutrition for children living with HIV. It was produced by the Elizabeth Glaser Pediatric AIDS Foundation.

**Nutrition care for people living with HIV**<sup>61</sup>: this provides insight into nutrition requirements for people living with HIV, how to support improved food quality, nutrition counselling and drug-food interactions to be aware of. This can be used within peer-to-peer support groups, household visits, community dialogues or other forums. It was produced by FHI360.

## Sustainability considerations

- Long-term support from community health workers is critical for sustained adherence and to avoid treatment fatigue. It is critical therefore that the government provides stipends or salaries for community health workers
- Peer-to-peer support groups create are vital to long-term psychosocial support for adherence and stigma reduction. They must be developed with a clear governance structure and group agreements to enable long-term sustainability
- Nutritional support provided to recipients of care in a vulnerable situation is a short-term solution and it must be developed into alternative models to avoid resource drain. Alternatives include kitchen gardens, community farming plots, and establishment of savings and loans groups (See Stage 4: Retain for more on these groups)
- Cash transfers and social protection programmes can also provide valuable support for the most vulnerable recipients of care.

## Advocacy considerations

This stage of the Kids to Care model has some of the most pressing advocacy issues that arise. Without consistent and reliable stocks of antiretroviral treatment, including child-friendly paediatric antiretroviral treatment regimens, viral suppression is impossible.

Key considerations for advocacy in this stage include:

- Is antiretroviral treatment consistently available, including paediatric antiretroviral drugs?
- Is viral load testing done? If so, are reagents consistently available? What is the turnaround time of viral load tests?
- Are test and treat policies in place?
- Is treatment available and initiated immediately for children, pregnant women and infants who test positive for HIV?
- Are there strong links with networks of people living with HIV and/or a national forum of people living with HIV to monitor and raise advocacy issues related to treatment?
- How are people living with HIV accessing refills for medications? Are there community-based delivery systems available?
- Are there differentiated service delivery models available for children living with HIV? If so, what do these models include?

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**Advocacy training guide**<sup>62</sup>: this training manual can be used with networks of people living with HIV to identify issues that need to be addressed through advocacy and to raise them effectively with decision-makers. It was produced by NAFOPHANU, the National Forum of PLHIV Networks in Uganda, a Kids to Care implementing organisation.

**Paediatric HIV Advocacy Toolkit**<sup>36</sup>: this provides guidance on key advocacy messages related to paediatric HIV, how to mobilise support for paediatric HIV through Ministries of Health and practical resources for presenting facts and key messages to decision-makers (slide decks, info sheets, videos, etc.). The toolkit was produced by UNICEF and WHO.



### Addressing malnutrition with nutritious porridge

Within the TAFU project implemented by Health Need Uganda in Soroti, Uganda, when a child is referred for confirmatory testing at the health facility, treatment is initiated and the child is referred back to the community health worker who provides adherence counselling and psychosocial support. Each child has a treatment plan which includes schedules for clinic appointments, appointments for household visits by the community health worker, schedules for treatment refills and follow up on treatment adherence. Community health workers support children and caregivers to follow the treatment plan and provide follow up and support to make this possible.

Many children within the project were not getting nutritious food, which was affecting their ability to adhere to antiretroviral treatment. Health Need Uganda developed a formula for a nutritious porridge made from locally available ingredients. Community health workers provide the formula to caregivers and show them how to prepare the porridge. This has created a locally available supplementary nutrition source for children in a vulnerable situation and has led to improved nutrition and better adherence to HIV medication.



**The next module is Module 4: Stay.** This module includes guidance on interventions that can help support long-term retention in care, improving the likelihood of healthy lives for children living with HIV.

# Module 4: Stay

## What will you learn in this module?

### This module will help you understand:

- How to support children to remain in long-term treatment and care, often referred to as retention in care
- How to support children and caregivers to bring back children who have dropped out of care or have interrupted their treatment

### Mary's story: frustration and guilt

One of the families you are visiting has started treatment after positive HIV tests. The mother has been trying to set aside money to travel to the health facility every month to refill medication and to make sure that there is sufficient and nutritious food at home, but it has been hard. You have begun the process of disclosure with her eight-year-old son, explaining to him what HIV is and how it can be managed, but he is frustrated and feels guilty for putting this extra pressure on his mother when he can see how difficult it is for her. Sometimes the drugs make him feel unwell and he wants to stop taking them.

### This module will help you take action to:

- Strengthen community support mechanisms for enabling retention in the long-term

Retention in care is a critical component of positive treatment outcomes. Dropping out of care or "loss to follow up" is a significant problem and contributes to poor treatment outcomes such as high viral load, leading to opportunistic infections. Community health workers play an important role in retention by continuing to visit households regularly to follow up on care and provide support to go for refills, treatment monitoring appointments and take medication. Support groups that were set up in [Stage 3: Treat](#) are strengthened by community health workers through mentoring and coaching, as well as with support from implementing partners. In addition, household economic strengthening is introduced to reduce the burden of the financial costs of good nutrition and transport costs to visit the clinic for health monitoring and drug refills.

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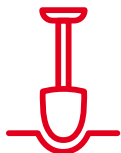
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In this module, you will learn to understand the key barriers to retention in the context you are working in. You may want to reflect on your situational assessment and mapping of social norms to identify any issues that may act as barriers to long-term retention.

### Key questions to consider when exploring barriers to retention

- Consider social norms that relate to stigma, gender, and decision-making power
  - Are people living with HIV facing discrimination based on their status?
  - Are women able to make decisions about their own health care?
  - Are partners able to disclose their status to each other?
  - Who is making decisions on children's health care?
- What medications are available for children and are they consistently available?
- What existing groups and community structures have been established to support adherence and retention, and provide support to children and mothers living with HIV and caregivers of children living with HIV?
- How does poverty and household economic status affect retention?

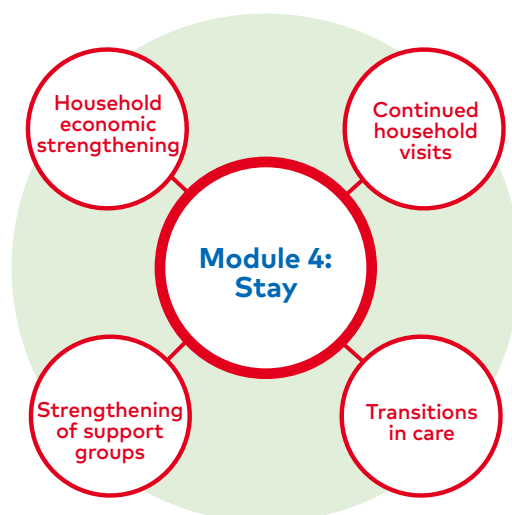


### Top tip!

Tools have been provided in this module for each intervention/step. It is important to adapt these tools to your own context so that they can be utilised effectively and be relevant for your work.

## Key interventions

The Kids to Care model is built on a principle of strengthening existing community structures. This principle is particularly important in Module 4: Stay where the focus is on strengthening these structures to provide continued support in the long-term and to reduce the barriers faced to long-term retention by recipients of care.



## Household economic strengthening

A Village Savings and Loans Association (VSLA) is a transparent, democratic and structured group for the purpose of savings and loans. The Village Savings and Loans Associations methodology emphasises accountable governance, standard procedures and simple accounting that everyone can understand and trust. The Kids to Care model uses Village Savings and Loans Associations as a key component of household economic strengthening. These are one type of savings and loans group that has been successfully implemented by Aidsfonds partners, but any savings and loans group methodology can be used to strengthen the household economy.

Setting up Village Savings and Loans Associations creates an opportunity for adults living with HIV (including pregnant women and lactating mothers), caregivers and community health workers to save money and access loans for small business ventures and income-generating activities. These savings schemes also have a social fund that members contribute to and loans can be taken from this to cover the cost of transport to the health facility or other medical needs - without paying interest. These groups will require training on how to develop their own constitution and group agreements, electing leadership, keeping track of savings and loans, and how to plan for a small business or income-generating activity. Some groups participate in group income generating activities and others start individual projects.

Involving your community health workers in Village Savings and Loans Associations can be a helpful way for them to support their own household economic strengthening. This can help them continue their community work after the project ends, if no stipend or salary is available. In some situations, community health workers have their Village Savings and Loans Associations meetings at the health facility to increase their visibility and provide the opportunity for regular follow up on client care. This is also a chance to discuss and align their work with health care workers at the facility. It can be helpful to involve community resource persons in Village Savings and Loans

Associations too, to help to raise awareness about the needs of children living with HIV in the community.

Many savings groups that involve people living with HIV or caregivers also become a supportive space for discussion about the challenges faced and sharing experiences to address stigma and discrimination.



- When groups are first established, external organisations often provide the training and materials for the group to operate effectively. This includes training on how to run the group, the roles and responsibilities of leadership, how to develop a constitution and how to keep records of savings and loans. Materials include a safe box for storing savings, ledger books and notebooks for keeping records. Some organisations provide seed money to groups to start off their savings or to support group initiatives for income-generation.
- Groups should hold annual elections to establish leadership and elect five positions of leadership each year.
- Each group should be composed of 10 to 25 self-selected individuals. Groups meet weekly and members save through the purchase of shares. The price of a share is decided by the group. At each meeting, every member must buy between 1 and 5 shares. The share price is set by the group at the beginning of the annual cycle and is fixed for that cycle.
- Savings should be deposited to a loan fund from which members can borrow in small amounts, usually up to three times the value of their savings but this varies depending on the context. Loans are for a maximum period of three months and may be repaid in flexible instalments at a monthly service charge determined by the group.
- Village Savings and Loans Associations should have a social fund, which is a simple

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form of insurance. Everyone pays the same amount at each meeting. The social fund is used to pay expenses in the case of personal emergencies. Within the Kids to Care model, this is primarily for health costs.

- At the end of every annual cycle, all of the loans are paid back and the total money is shared out among members in proportion to their savings. This share-out includes all the group's profit from interest income and fines. Members can choose to rollover their savings into the next cycle or take the pay out and start their savings again.
- Groups need continuous support during the start-up phase of the group (at least the first 1-2 years) which should be provided by the implementing organisation, community health workers or community resource persons, depending on what is most appropriate for the context. After two years of operation, most groups can continue to operate independently but may need sporadic visits from mentors and facilitators to continue to strengthen the groups and ensure they are operating effectively.



**VSLA intervention summary**<sup>63</sup>: This two-pager provides insight into VSLAs and how they have been used within the Kids to Care model. It was produced by Aidsfonds.

**VSLA step-by-step formation summary**<sup>64</sup>: This provides step-by-step guidance for how to form and support Village Savings and Loan Associations. It was produced by Health Need Uganda, a Kids to Care implementing organisation.

**VSLA training manual**<sup>65</sup>: This can be used to train community health workers, community resource persons and Village Savings and Loan Association group members on group formation, processes and group strengthening. It was produced by Health Need Uganda.

**VSLA group services monitoring tool**<sup>66</sup>: This template can be used to keep track of services and support provided by implementing organisations to Village Savings and Loan Association groups. It was produced by ARISE Uganda, a Kids to Care implementing organisation.







### Village Savings and Loans Associations in Uganda

An impact study was conducted on Village Savings and Loans Associations within the TAFU project which is implemented by six partners in Uganda.

Groups are provided with three days of training and then supported to elect their own leadership and develop their own constitution/group agreements. Group members start buying shares and contributing to the social fund and once savings have grown, members begin to take loans. A start-up grant was provided to each group of 500,000 UGX (approx. USD \$130).

The lessons learned from the integration of Village Savings and Loans Associations into the Kids to Care model in Uganda include the following:

- Whole group training enabled members to understand their roles and the processes for saving and acquiring loans which was a critical building block for transparency in running group activities. This in turn increased trust among members.
- Integrating community resource persons such as community health workers and expert clients in Village Savings and Loans Associations groups was also successful. The resource persons helped conduct health education (in Village Savings and Loans Associations groups and communities), as well as identify and refer children and women suspected to be living with HIV to testing and care centres.
- Having people living with HIV in the savings groups facilitated experience sharing regarding living positively and care for children living with HIV. In this way the groups also function as peer support groups and were critical in enabling caregivers to overcome HIV stigma and increasing adherence to clinic appointments and treatment.

- Provision of top-up funding to groups increased the money available for group members to borrow and meet their health care and education needs of children in a timely manner. Indeed, most study participants had borrowed money to meet basic needs and praised their groups for providing such loans at low interest rates.
- Village Savings and Loans Associations kits were provided to groups including savings boxes, record books and stamps (for documenting group and individual member participation as well as savings and credit transactions). Doing this at the start was important to ensure effective group management and greater chances for success.

### Strengthening of peer-to-peer support groups

In [Module 3: Treat](#) peer-to-peer support groups can be established in the form of children's clubs, groups for adolescents and adults living with HIV and for caregivers. These groups require ongoing support to strengthen their functioning and to make sure members are benefiting from them.



- Community health workers, community resource persons or staff from implementing partners should visit support groups at least once a month to provide mentoring and coaching for group leaders and encouragement for group members.
- Group leaders should develop a schedule for regular health talks from community health workers, community resource persons or health care professionals.
- Groups should be linked into wider networks for shared learning and collective advocacy. Most contexts have national forums of people living with HIV or similar structures that can support groups.

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**Peer group mentorship protocol<sup>67</sup>:** This guidance outlines support mechanisms for peer-to-peer support groups and activities that can be integrated by implementing partners to strengthen these groups. It was produced by Health Need Uganda, a Kids to Care implementing organisation.

## Continued household visits

One of the main challenges to retention in care is that although HIV is treatable, treatment lasts for an individual's entire life. This can be challenging especially for children who acquired HIV as infants and need to take drugs for the rest of their lives, unless a cure for HIV becomes available. Managing side effects of treatment, coping with stigma and discrimination, maintaining good nutrition and coping with treatment fatigue are all addressed in the Kids to Care model through a personal approach with community health workers, community resource persons and mentor mothers.

In addition to the household visits provided in other stages of the Kids to Care model, a key component of Stage 4: Retain is the disclosure of HIV status. This is a gradual process for children living with HIV and requires psychosocial support as well as returning to questions and concerns as they arise. Supporting parents or caregivers to disclose HIV status to children and providing them with the support they need to understand the diagnosis is critical to long-term retention in care.



- Every recipient of care on antiretroviral treatment (adult, adolescent or child) should be linked with a community health worker
- In this role, community health workers become "case managers" and are the central link between clients and the health facility, following up on refills, reminding clients about appointments and supporting clients to manage complications or difficulties as they arise.
- Community health workers should provide monthly household visits on an ongoing basis
- During visits, they should provide psychosocial support, guidance on nutrition and treatment literacy, problem solving around difficult issues and support gradual disclosure for children or help with disclosure from adults to their partners.
- Community resource persons can also provide support through household visits as families are more settled into their treatment routine

Disclosure of HIV status for children is sensitive and should be handled with great care. After you have given the parent/guardian time to accept the results and have provided them with emotional support, discuss with them what information about HIV they want to share with the child. The parent/guardian must consent to share the results of the test with the child and is not required to do so until they are ready. It is important to reassure parents/guardians that this step does not have to be taken immediately.

Most often, partial disclosure is used with children under the age of 14. This means not giving all of the information regarding diagnosis and treatment to the child all at once, so that it is not overwhelming.

Disclosure is a gradual process. Readiness for disclosure should be based on the following criteria:

- Child's age and cognitive development
- The need for the child or adolescent to protect themselves and stay healthy
- Child or adolescent adherence to their treatment regimen and ability to take responsibility for their care
- Upcoming onset of sexual activity and the need for sexual and reproductive health education

Disclosure should come from the parent or caregiver with support from the community health worker and health care worker at the facility. A plan can be developed for how and when to start disclosure and what information to be provided by whom. The community health worker can support the parent or caregiver on how to respond to questions from their child or adolescent. Ongoing counselling may be needed for both the parent/guardian and the child to accept the diagnosis and to embrace the steps needed to live positively. This should be planned for before test results are shared.

To initiate partial disclosure, a child or adolescent living with HIV needs to understand why he or she attends the clinic and takes medications. Community health workers and parents or caregivers can start by explaining that:

- The child has an illness and the antiretroviral medications help to put "germs" to sleep that make them ill
- The medicine keeps the child healthy and strong
- Medicines (including antiretrovirals and cotrimoxazole) help to stop or prevent any new sicknesses
- Antiretrovirals are not all the same and can change as you grow up
- To use medicines well, blood tests are needed every few months to check on the number of the body's "good cells."



### **Disclosure of HIV status for paediatric and adolescent populations**<sup>68</sup>:

This toolkit explores the challenges and barriers to disclosure, the stages of disclosure and how to effectively plan and prepare for it. It includes tools to assess readiness to disclose, role-plays and job aids that can be used by community health workers to support the disclosure process. It was produced by New Horizons and the Elizabeth Glaser Pediatric AIDS Foundation.

**Caregiver guide**<sup>25</sup>: this provides additional support for community health workers working with caregivers. It goes beyond the TAFU training manual with more detail on disclosure: understanding antiretroviral treatment and adherence; stigma and discrimination; child abuse and protection; sexual and reproductive health and family planning; loss, grief and bereavement; transition in care (adolescent to adult); child/adolescent mental health; tuberculosis; nutrition for children living with HIV. The guide was produced by the Elizabeth Glaser Pediatric AIDS Foundation.

**Children Treatment Literacy Booklet**<sup>37</sup>: This provides detailed guidance for caregivers on treatment literacy for children. It can be used to develop key messages for organised diffusion (sharing of messaging through community structures). The booklet was developed by the Elizabeth Glaser Pediatric AIDS Foundation.





### Helping carers disclose HIV status in child-friendly ways

The KidzAlive Foundations of HIV Testing Services Disclosure and Adherence with Children project implemented by ZoeLife in South Africa focuses on building the capacity of health care workers within local health facilities and community-based settings, to provide child-friendly HIV testing services and to support caregivers throughout the continuum of care.

First they train health care workers on the basics of working with children, disclosure, HIV testing services and adherence. They provide them with job aids such as the KidzAlive Talk Tool which uses cartoon characters to tell a story that can be used to explain HIV diagnosis to children. They also encourage them to create a child-friendly space within the health facility, displaying posters and opportunities for child-centred psychosocial support and nutrition education.

Within the disclosure module, trainers focus on how to provide psychosocial support and use 'feeling faces' within conversations with children about their status. The training also focuses on negotiating disclosure with the child and caregiver and can flag potential issues related to abuse in the family. Finally, the training supports identification of opportunistic infections/tuberculosis in a way that is led by the child.





## Transitions in care

For children who acquire HIV as an infant, they will move through many transitions during their HIV care journey. Major transitions include: child to adolescent and adolescent to adult. However, there are minor transitions within these categories: young child to older child, young adolescent to older adolescent, adult to parent.

Community health workers and community resource persons play a critical role in transitions in care. They help clients prepare for major and minor transitions, ensuring that they are ready for new treatment regimens or moving from one type of support group to another, and they provide psychosocial support to help clients cope with transitions.

Community resource persons can be particularly helpful during transitions in care. Linking with schools and teachers can provide an opportunity to support children and adolescents living with HIV within the school system. This is particularly important when adolescents attend boarding school. Engaging with community leaders and community forums to continue to work on reducing stigma and discrimination helps to create a more supportive environment for transitions in care and for long-term retention.

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Transitions in care represent changes in responsibility for care and adherence, available support structures and antiretroviral treatment regimens. The diagram below is from the Elizabeth Glaser Pediatric AIDS Foundation in a toolkit called "Adolescent and Youth Transition of Care Toolkit"<sup>69</sup>

The diagram outlines the variations in care between paediatric (0-14 years), adolescent (15-24 years) and adult (15+ years). Definitions of paediatric, adolescent and adult vary from one context to another and in some contexts children transition from paediatric to adult care at 15 years of age. In other contexts, children move to an adolescent transition stage first before moving to adult care.

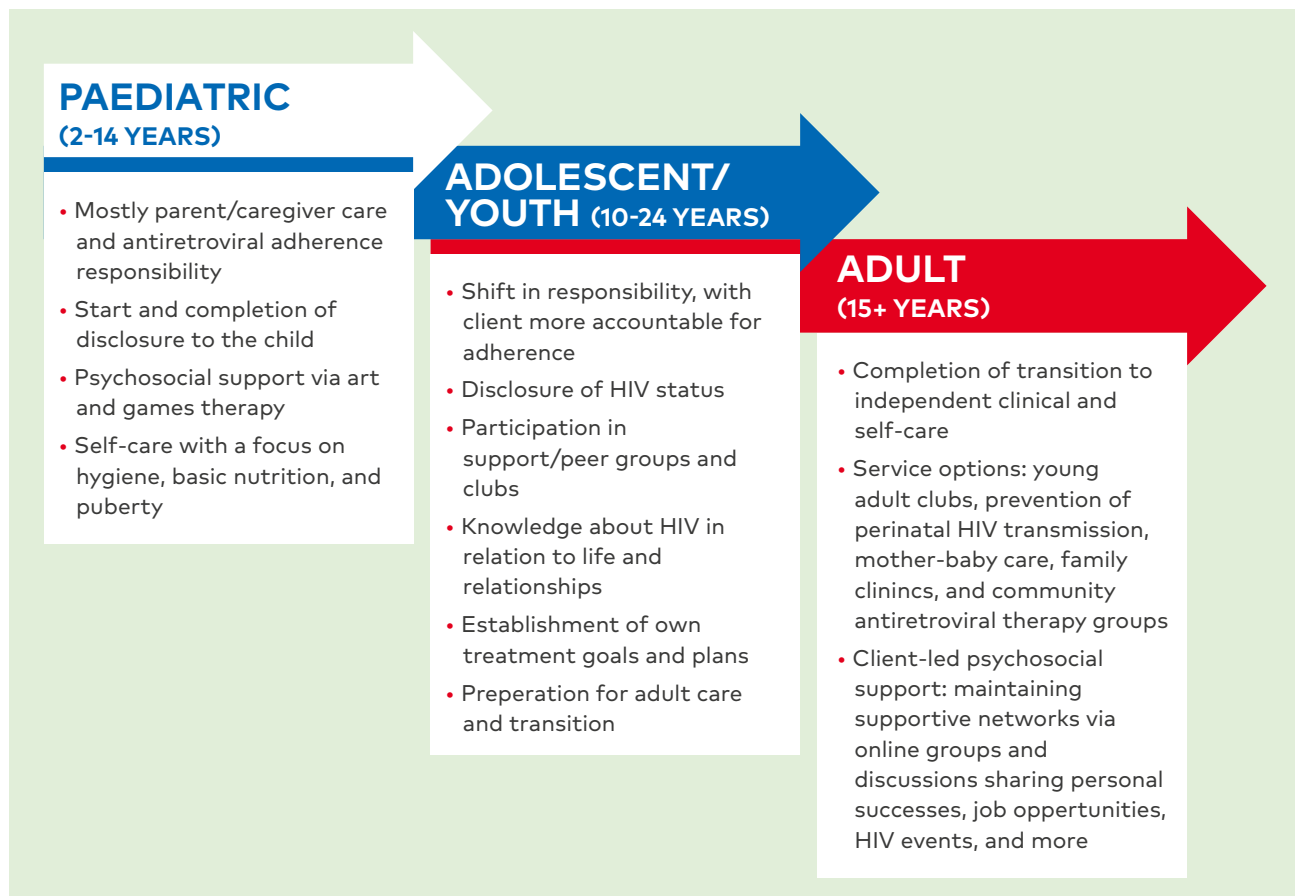


### Adolescent and Youth Transition of Care

Toolkit<sup>69</sup>: This is for community health workers and healthcare workers to support the transition from paediatric to adolescent care and from adolescent to adult care, as well as the transitions of care that occur during and after pregnancy. It was produced by New Horizons and the Elizabeth Glaser Pediatric AIDS Foundation.

### Transition of Care and Other Services for

Adolescents Living with HIV<sup>70</sup>: This toolkit is designed to support community healthcare providers to work with families, caregivers and adolescents through the transition of care from paediatric to adult care. It was produced by AIDSSTAR-ONE and USAID/PEPFAR.



## To consider: Differentiated Service Delivery

Each community and each household is unique and faces different barriers to retention in care. It is important for community health workers to adapt their support to respond to the barriers that households face. It is also vital that Kids to Care projects adapt to the specific barriers faced by communities.

Examples of this include:

- **Multi-month dispensing:** Kids to Care implementing organisations have advocated for multi-month dispensing of antiretroviral treatment from clinics to avoid the need to return to the clinic as often to refill prescriptions. This can reduce the costs of transport and time lost in productive activities for families and support retention
- **Community-based distribution points:** Some Kids to Care implementing organisations have utilised community-based distribution points where people can come to a central location to refill their prescriptions instead of travelling to the clinic. As with multi-month dispensing, this can support retention by reducing transport costs and time spent visiting clinics
- **Antiretroviral treatment delivery:** In some contexts, it has been possible to arrange antiretroviral treatment delivery by community health workers to households. This can be a helpful support when the clinic is far away and a community-based distribution point is not possible

It is also important to remember that the Kids to Care process is not always linear. At times, people living with HIV drop out of care and need to be identified to return to care. The barriers that people face to retention in care differ and their reasons for dropping out of care vary. It is essential for community health workers, community resource persons and where relevant, mentor mothers, to provide tailored support for people living with HIV who drop out of care and return at a later time.

## Sustainability considerations

This stage of the Kids to Care model is about building sustainability of care and thus about the sustainability of interventions for the long-term. The following considerations are critical to long-term retention in care:

- Linking Village Savings and Loans Associations with local government structures, especially community development departments and other implementing organisations to provide opportunities for groups to access additional support
- Strengthening Village Savings and Loans Associations through continued mentorship and training of group members to increase the chances of long-term group success
- Involving community health workers in Village Savings and Loans Associations is an opportunity to sustain their role while advocacy work continues for stipend and/or salary support from the government health system
- Providing ongoing support through community health workers, community resource persons and mentor mothers to support viral suppression and transition in care.

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## Advocacy considerations

If children, adolescents and adults are to be retained in care, consistent stock of optimal antiretroviral treatment - both adult and paediatric - must be consistently available. This builds on the advocacy done in [Module 3: Treat](#) to ensure consistent access to medications.

Long-term retention in care requires the reduction of stigma and discrimination so that people living with HIV - adults, adolescents and children - can live freely and without fear of discrimination in their daily life or in their relationships. Community resource persons are key to reducing stigma and discrimination through organised diffusion and advocacy as outlined in [Module 1: Find](#).

Finally, poverty reduction and food security lay the foundation for retention in care. Without these, people living with HIV cannot reach viral suppression and live healthy and full lives. Working to advocate for access to markets, training opportunities for Village Savings and Loans Associations group members and food distribution to target those who are most vulnerable, are key advocacy considerations in this stage.

Another key consideration in the long-term retention of children living with HIV on treatment is domestic resource mobilisation. It is critical that community-based organisations advocate for resources from the government, relevant ministries, through the health service and through various extension projects to sustain the gains made through the Kids to Care model and the long-term availability of support for children living with HIV.



**The next module is the Monitoring, Linking and Learning Guide.** This module provides insight into how to set up monitoring and evaluation systems for the Kids to Care model and how to share learning with key stakeholders.



# Monitoring, Linking and Learning Guide

The Kids to Care model is a response to the urgent need to improve health outcomes for children living with HIV in low resource settings. This community-based intervention model seeks to fill the gaps in existing HIV services and to provide the critical support for children and pregnant women to first be identified, then tested, enrolled in treatment and retained in care over the long-term. The model has been developed based on the experience of implementing community based and community led paediatric HIV interventions by civil society organisations in five African countries with support from Aidsfonds.

As a community-based model, Kids to Care is context-specific. It is essential that it is adapted to local realities so that it can be as effective as possible. Sharing learning between contexts is critical to supporting growth of the model and to refining how it is implemented to maximise effectiveness.

## In this module, you will learn:

- What data is important to collect within the Kids to Care model
- How to collect that data
- When and how to use the data
- Opportunities to share learning with other practitioners and stakeholders.



### Top tip!

Tools have been provided in this module for each intervention/step. It is important to adapt these tools to your own context so that they can be utilised effectively and be relevant for your work.



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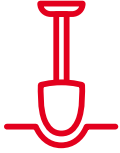
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## What data is important to collect?

Within the Kids to Care model there are three key stages of data collection, each with different types of data that can be collected.



Before starting any implementation, it is important to lay the groundwork through a needs assessment. The Kids to Care model is driven by data and implemented where the need is greatest, for example by targeting specific geographical locations or certain age groups or other specific target groups. Conducting a needs assessment ensures that your project is implemented where there are the most pressing needs and in a way that can be most effective.

Laying the groundwork includes:

- Situational assessment
- Community mapping
- Performance and barriers analysis.

Guidance on how to conduct each stage of laying the groundwork can be found in the preliminary modules of this toolkit.

### Baseline and endline assessments

Once you have identified the needs and gained a good understanding of the community structures, health system performance and key barriers, you can conduct a baseline assessment. This will help you set targets and measure the impact of your work and is helpful for you to demonstrate that you accomplished what you set out to do. It also helps you monitor results to learn what is working well or what is not working so that you can adjust and increase your effectiveness.

A baseline assessment should be conducted at the start of your project and an endline assessment at the end. It is recommended that you use mixed methods to explore the key indicators of the Kids to Care model, which

means that your baseline and endline should include, at a minimum: quantitative survey, key informant interviews and focus group discussions. Other tools and methods can be added depending on the objectives of your assessment.



### **Key outcome and output indicators for**

**the Kids to Care model**<sup>77</sup>: This document summarises the key outcome and output indicators used within the Kids to Care model and can be used as a starting point for creating a monitoring and evaluation framework for implementation. It was created by Aidsfonds and Kids to Care implementing organisations.

**Sample M&E frameworks:** The following monitoring and evaluation frameworks were built on the outcome and output indicators for the Kids to Care model and utilised within the TAFU and Breakthrough Partnership projects in Uganda. These samples can be used to develop your own monitoring and evaluation framework building on the outcome and output indicators provided above: [Uganda framework - August 2022](#)<sup>72</sup> and [TAFU + BTP framework](#)<sup>73</sup>.

### **Research and learning**

This stage is where you document the impact your work is having and build an evidence base for community-based interventions. There are two critical components of research and learning:

- Embedding community monitoring data in the national health information system. This helps increase the visibility of the contributions your work makes to health outcomes for children and pregnant women. It builds a track record for community organisations and improves their recognition by the government and other implementing partners as key stakeholders

- Documenting impact. This enables you to share the impact that your work is having with key stakeholders - other implementing organisations, government representatives or funding partners for example - increasing opportunities for community-based organisations to access financial support

## Who will collect data?

Community health workers are best positioned to collect data for the project. However, it is recommended that your organisations conducts joint monitoring with government stakeholders to increase visibility of the project and collaboration in implementation.

Health care workers at health facilities must also collect data and submit it into the national health information system, alongside data from community health workers. You and your community health workers should collaborate with health facility staff to either receive information for data collection (e.g. test results, treatment initiation etc) or to compare different data sources at community and facility level (did people who were referred actually visit the clinic? etc).

## How will you collect it?



**Community health workers and community resource persons monitoring form<sup>74</sup>:** This form can be used for you to track activities conducted by community health workers and community resource persons. It was produced by Health Need Uganda, a Kids to Care implementing organisation.

**Health facility monitoring form<sup>75</sup>:** This can be used by healthcare workers at a health facility within the project implementation area to track services provided that are relevant to the project. It was produced

by Health Need Uganda, a Kids to Care implementing organisation.

**Event/meeting report<sup>76</sup>:** This form can be used to keep track of event/meeting participants, key topics discussed, as well as action points and persons responsible. It was produced by the Community Health Alliance Uganda, a Kids to Care implementing organisation.

## Sharing learning

Sharing learning is an important part of improving services available for children and pregnant women. Building on what works and learning from what doesn't will support increased effectiveness and sustainability in the long-term.

### Who will you share learning with?

Key stakeholders you can share learning with include: government representatives, implementing organisations, funding partners and other community-based organisations.

### How will you share learning?

If you can share learning in a visual and engaging way it will help create interest in your work and the impact it is having. There are good tools available to make your data visual, and create reports and other information products that communicate your messages in compelling ways.



**Microsoft Excel:** the simplest way of visualising data is to create charts and graphs that convey your findings and this can be done using Microsoft Excel. You can create up to 20 different types of charts and graphs using just Excel. If you don't have access to Microsoft products, you can use Google sheets online as a free alternative.

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**PowerBI:** This is a more advanced option for visualisation of data, which imports data (usually from Excel) and visualises it in a variety of formats.

**Tableau:** One of the easiest options for data visualisation software is Tableau which creates a wide range of visualisations and is available as a free version, Tableau Public. Data shared in Tableau Public is available to anyone so should not be used for sensitive or identifying information.

## Where will you share learning?

It is important to consider who you want and need to share the data with.

**Local and regional networks of people living with HIV and community groups:** It is important to initially share learning within communities and with networks of people living with HIV that are close to where the project has been implemented. This can lead to improvements in project activities, support of people living with HIV and inform advocacy. It can also create opportunities for the celebration of successes.

**National networks of people living with HIV:** Sharing learning can be filtered up from regional networks of people living with HIV to national networks. This can help to inform other groups working in this field and support cross-learning.

**Technical working groups:** These are a great opportunity for your organisation to share learning with others who are working with children or who are working specifically on paediatric HIV. These groups often include representatives from different government ministries, implementing organisations, and other key stakeholders and are formed around a specific thematic area.

**Partner meetings:** these gatherings are for implementing organisations working in partnership on interventions to support children or paediatric HIV. They are often more formal partnerships or consortiums

and bring together organisations who are key contributors to those initiatives. In some contexts, these meetings are convened by the Ministry of Health for all partners working to support paediatric HIV initiatives. They are an important space to share learning and adaptations to interventions that are improving impact.

**Conferences:** There many conferences where practitioners, researchers and policy-makers gather to discuss issues related to HIV and specifically paediatric HIV. Participating and presenting in these forums is a good opportunity to increase visibility, share experience and raise advocacy issues.

Key conferences include:

[International Paediatric HIV Symposium in Africa](#)<sup>78</sup> (IPHASA) - a bi-annual conference supported by the International AIDS Society.

[International Conference on AIDS and STIs in Africa](#)<sup>79</sup> (ICASA) - this is held bi-annually and hosted by the Society for AIDS in Africa.

[International AIDS Conference](#)<sup>80</sup> (IAC) - the bi-annual conference hosted by the International AIDS Society.



# Tool Annex

This annex provides a summary of all of the tools that have been referenced within the Kids to Care toolkit. You will also find links to these in each module within the stage and intervention where they can be applied.



## Top tip!

The tools provided in this toolkit have been produced by Kids to Care implementing organisations or other organisations also working on paediatric HIV and elimination of vertical transmission. It is important to adapt these tools to your own context so that they can be utilised effectively and be relevant for your work.

## Start module: Laying the groundwork



- **Secondary data checklist<sup>81</sup>**: Reviewing secondary data helps give you insight into where needs are greatest and how you can focus your intervention. This checklist provides key areas that can be reviewed prior to starting any Kids to Care intervention.

- **Community Services Register<sup>17</sup>**: This tool helps you track what services are available in a community, where they are accessed and how referrals for these services are made. It provides questions you can use to map services for families, those provided by implementing organisations and services available through the government health system. The tool was developed by Health Need Uganda, a Kids to Care implementing organisation.
- **BASICS Pediatric HIV Toolkit<sup>18</sup>**: This provides more detailed questions for assessing processes and services for paediatric HIV case identification, referral and care at the community level. This tool was produced by BASICS and can be part of key informant interviews within a situational assessment.
- **Community mapping<sup>19</sup>**: Mapping the community helps you identify the essential community structures that you can build on in your project. Two of the primary Kids to Care model key principles are that the response is community-based and community-led, and builds on existing community structures. Community mapping helps you understand what structures exist and what resources are available in the community - this can include human resources (community health workers and other cadres), community groups, forums, meetings and faith groups.

- **PLHIV Stigma Index<sup>20</sup>:** This tool provides data compiled by UNAIDS, the Global Network of People Living with HIV (GNP+) and International Community of Women Living with HIV. It provides insight into how stigma and discrimination impact on the lives of people living with HIV which can be used to advocate for improved rights and access to services. This can support you to map social norms within your situational assessment.

- **UNICEF Service Delivery Framework<sup>21</sup>:**

This framework was developed by a group of experts to provide guidance on how to improve service delivery for paediatric HIV care and treatment. There are three parts of the Service Delivery Framework that are helpful in analysing performance and barriers within your situation assessment:

- Performance along the locate-link-treat-retain continuum (key indicators by age group (0-4; 5-9; 10-14; 15-19) - page 20
- Key Programme Assessment Questions - page 21
- Barriers analysis (demand and supply side barriers by age group) - to inform interventions and advocacy - page 22-23

- **Selecting Community Health Workers<sup>22</sup>:**

Selecting community health workers is a critical step in the Kids to Care model. It is important to identify the right cadre to work with and to select the right participants for training, capacity building and mentoring throughout your project. In this step, you are setting the foundation for every other stage of the model and each of the interventions you will implement. This document outlines the roles and responsibilities of community health workers and the criteria for selecting who to work with.

## Module 1: Find



- **Selecting Community Resource Persons<sup>23</sup>:**

Community resource persons are people in the community who have an influence over social norms, particularly those that relate to children and pregnant women. Social norms are the unwritten rules of how a society operates. They vary from one culture to another and influence how people behave and what is seen as normal and acceptable. In all cultures there are social norms that are positive and norms that are negative. Community resource persons can be mobilised to generate support for paediatric HIV by working to shift negative social norms that act as barriers to care and treatment. This document outlines the roles and responsibilities for community resource persons and the criteria for selecting who to work with.

- **Training community health workers and community resource persons:**

- **TAFU training manual<sup>24</sup>:** this provides training materials for community health workers and community resource persons within 14 sessions in the areas of: understanding of HIV among children, pregnant and lactating women; identifying children who needs support; referral systems and coordination with health facilities; addressing stigma and discrimination; disclosure support; treatment adherence; prevention of vertical transmission; planning for activities; data and monitoring.
- **Caregiver guide<sup>25</sup>:** this provides additional support for community health workers working with caregivers. It provides support beyond the TAFU training manual by going into more depth on disclosure; understanding antiretroviral treatment and adherence; stigma and discrimination; child abuse and protection; sexual and reproductive health and family planning; loss, grief and bereavement; transition in care (adolescent to adult); child/adolescent mental health; tuberculosis; nutrition for children living with HIV. The caregiver guide

was produced by the Elizabeth Glaser Pediatric AIDS Foundation.

- **Training/mentoring report template<sup>26</sup>:**  
This template can be used to keep track of training conducted, topics covered and participants.
- **Clinic-community coordination:**
  - **Guidance for conducting coordination meetings with stakeholders<sup>27</sup>:** This outlines the key steps for conducting coordination meetings with stakeholders as part of implementation and planning for long-term sustainability. It has been developed by Kids to Care implementing partners.
  - **Clinic-Community Collaboration Toolkit<sup>28</sup>:** this toolkit goes into more depth about how to form an effective partnership between clinic and community within paediatric HIV programming and to strengthen the collaboration between stakeholders in implementation. The toolkit was produced by PATA.
  - **Memorandum of Understanding template<sup>29</sup>:** This provides a template for a memorandum of understanding between clinical and community partners working on paediatric HIV. It was produced by PEPFAR.
- **Household visits:**
  - **Home visit tool<sup>30</sup>:** This provides a template for tracking information during home visits and guidance on topics to discuss with household members. It can be used by community health workers and has been adapted from a tool produced by ARISE Uganda, a Kids to Care implementing organisation.
- **Risk and vulnerability assessment:**
  - **Risk/vulnerability assessment<sup>31</sup>:** This document provides guiding questions for a risk/vulnerability assessment and support for a community health worker to conduct the assessment within household visits.
  - **Community-based paediatric/adolescent HIV testing screening checklist<sup>32</sup>:** This checklist was produced by the Ministry of Health in Nigeria and provides additional questions that can be used in assessing risk/vulnerability to screen for HIV testing.
- **Community outreach and sensitisation:**
  - **Community mobilisation module<sup>24</sup>:** Module 4 of the TAFU training manual used to train community health workers and community resource persons provides content on community mobilisation with participant handouts to increase understanding of how to do community outreach and how to sensitise communities on HIV.
- **Community dialogues:**
  - **Guidance for conducting community dialogues<sup>34</sup>:** This provides core principles, top tips from implementing organisations and practical questions for how to organise a community dialogue and how to follow up on outcomes from the discussions.
  - **Example summary of community dialogues<sup>35</sup>:** This can be used to support the development of a community dialogues intervention. It was produced by N'weti, a Kids to Care implementing organisation in Mozambique.
- **Organised diffusion:**
  - **Pediatric HIV Advocacy 'talking points'<sup>36</sup>:** These talking points (on page 16 of the pediatric HIV Advocacy toolkit) provide a starting place to develop key messages on HIV for use in organised diffusion (sharing of messaging through community structures). The toolkit was produced by UNICEF and WHO.
  - **Children Treatment Literacy Booklet<sup>37</sup>:** this booklet for caregivers provides detailed guidance on treatment literacy for children and can be used to develop key messages for organised diffusion (sharing of messaging through community structures). It was developed by the Elizabeth Glaser Pediatric AIDS Foundation.



- **Index testing:**
  - **Index testing tool**<sup>38</sup>: This provides a template for tracking key contacts for index testing. It was produced by ARISE Uganda, a Kids to Care implementing organisation.
  - **Index client information form**<sup>39</sup>: This provides more in-depth questions for index testing, tracking of key contacts, partner information, intimate partner violence assessment, and space to document the outcomes of testing for the individual, partner and family members. It was produced by PEPFAR.
  - **Index testing for children job aid**: These two job aids for community health workers outline the key steps for index testing with children. They were produced by PEPFAR: Job Aid 1<sup>40</sup>: 6 Steps for Providing Index Testing to Children; Job Aid 2<sup>41</sup>: Pediatric Index Testing Job Aid for Orphans and Vulnerable Children and Community-Based Staff.
  - **TB screening tool**<sup>42</sup>: this tool can be used with index testing to integrate TB screening into HIV testing services. It was produced by ARISE Uganda, a Kids to Care implementing organisation.
- **Pre and post test counselling:**
  - **Pre and Post Testing HIV Counseling for Children**<sup>43</sup>: This booklet can be used to support caregivers and children themselves with pre and post HIV testing counselling support. It was produced by UNICEF.
  - **Pre and Post Testing HIV Counselling QA/QI checklist**<sup>44</sup>: this can be used by community health workers and implementing organisations to provide quality assurance and quality improvement support for pre and post HIV test counselling. It was produced by FHI 360.
- **Referral for confirmatory testing:**
  - **Sample referral form for confirmatory testing**<sup>45</sup>: This provides an example that can be used by community health workers to refer individuals for confirmatory HIV testing at a health facility. It was produced by CHAU, a Kids to Care implementing partner.
- **Antenatal care:**
  - **Breastfeeding and HIV**<sup>46</sup>: This advocacy brief provides guidance on breastfeeding and HIV that can be used during household visits by community health workers or mentor mothers with pregnant and lactating women. It was produced by the Global Breastfeeding Collective.
- **Early infant diagnosis:**
  - **HIV-exposed infants service delivery tool**<sup>47</sup>: This tool provides a template for tracking services provided to new mothers with HIV-exposed infants. It was produced by ARISE Uganda, a Kids to Care implementing organisation.
  - **Strategic framework for supporting point-of-care early infant diagnosis**<sup>48</sup>: This resource provides support for implementing organisations to understand early infant diagnosis, to increase demand for this service within the community and to advocate for improved quality of service delivery for infants in a variety of contexts. The framework was produced by the Global Network of People Living with HIV (GNP+).





### Peer-to-peer support groups

- **Children's clubs:**

- **The Happy Made by Zed book<sup>49</sup>:** This can be used within children's support groups and clubs to share information on HIV and reduce stigma and fear. TAFU, a Kids to Care implementing organisation, utilised this book within their Kids to Care programme in Uganda. It was created by the Happy Made By Foundation.
- The **TalkTool<sup>50</sup>** was created by ZoeLife, a Kids to Care implementing partner organisation. The TalkTool is a job aid that can be used by healthcare workers, community health workers, and children's club facilitators to provide child-friendly HIV information.

- **Adolescent groups:**

- **Tiwale<sup>51</sup>:** This is a comic book created for young people living with HIV to help to reduce self-stigma and can be used within adolescent support groups.
- **CAYA Cartoons<sup>52</sup>:** is a resource designed for young people living with HIV to sparking conversations around treatment literacy. The cartoons were created by AVERT.
- **Positive Voices, Positive Choices<sup>53</sup>:** This toolkit provides activities and training resources for supporting adolescents living with HIV to become peer educators of support groups. The toolkit was created by ICAP.

- **Adults living with HIV:**

- **Guidelines<sup>54</sup> for establishing and operating successful support groups for people living with HIV:** This provides guidance on group formation, leadership and activities that can be conducted within groups for people living with HIV. The resource was produced by Catholic Relief Services.

- **Scaling Up Positive Prevention<sup>55</sup>:** This provides guidance on how groups can be formed and structured as well as suggestions for health information topics that can be discussed within the group. It was produced by FHI 360.

- **Pregnant and lactating women living with HIV:**

- **Positive Health, Dignity and Prevention for Women and their Babies<sup>56</sup>:** This guide was designed for pregnant women and mothers living with HIV and can be used by networks of women living with HIV, peer educators, women's groups or others who want to provide support to women through the decisions they need to take before, during and after their pregnancy. This guide was produced by GNP+, IATT and ICW.

- **Caregiver support groups:**

- **Children Treatment Literacy Booklet<sup>37</sup>:** This provides detailed guidance for caregivers on treatment literacy for children. The booklet can be used to develop key messages for organised diffusion (sharing of messaging through community structures). It was developed by the Elizabeth Glaser Pediatric AIDS Foundation.
- **Caregiver guide<sup>25</sup>:** This provides additional support for community health workers working with caregivers. It goes beyond the TAFU training manual by going into more depth on disclosure; understanding antiretrovirals and adherence; stigma and discrimination; child abuse and protection; sexual and reproductive health and family planning; loss, grief and bereavement; transition in care (adolescent to adult); child/adolescent mental health; tuberculosis; nutrition for children living with HIV. It was produced by the Elizabeth Glaser Pediatric AIDS Foundation.

## Household visits

- **Home visit tool**<sup>30</sup>: This provides a template for tracking information during home visits and guidance on topics to discuss with household members. It can be used by community health workers and has been adapted from a tool produced by ARISE Uganda, a Kids to Care implementing organisation.
- **Care and Treatment Plan**<sup>57</sup>: This provides guidance to community health workers on creating a care and treatment plan for children and families. It can be used within household visits to support access to and retention on treatment. It was produced by HealthNeed Uganda, a Kids to Care implementing organisation.
- **Viral load monitoring tool**<sup>58</sup>: This template can be used by community health workers to track viral load for HIV positive individuals as part of household visits. It was produced by ARISE Uganda, a Kids to Care implementing organisation.
- **Example child protection referral form**<sup>59</sup>: This can be used as a referral form for child protection and support services if these are needed by children who are being supported by community health workers. It can be used as it is or adapted to suit the context where the Kids to Care model is being implemented.

## Mentor mothers

- **Mentor Mothers Training Manual**<sup>60</sup>: This can be used by implementing organisation to train mentor mothers to provide support to pregnant women and lactating mothers living with HIV. The manual was produced by 4MM and the Salamander Trust.

## Nutrition education and support

- **Caregiver guide**<sup>325</sup>: This provides additional support for working with caregivers and includes content on nutrition for children living with HIV. The guide was produced by the Elizabeth Glaser Pediatric AIDS Foundation.
- **Nutrition care for People Living with HIV**<sup>61</sup>: This guidance provides insight into nutrition requirements for people living with HIV, how to support improved food quality, nutrition counselling and drug-food interactions to be aware of. This can be used within peer-to-peer support groups, household visits, community dialogues or other forums. It was produced by FHI360.

## Advocacy on treatment:

- **Advocacy training guide**<sup>62</sup>: This training manual can be used with people living with HIV networks to identify issues that need to be addressed through advocacy and to raise them effectively with decision-makers. It was produced by NAFOPHANU, the National Forum of PLHIV Networks in Uganda, a Kids to Care implementing organisation.
- **Pediatric HIV Advocacy Toolkit**<sup>36</sup>: This provides guidance on key advocacy messages related to paediatric HIV, how to mobilise support for paediatric HIV through Ministries of Health and practical resources for presenting facts and key messages to decision-makers (slidedecks, info sheets, videos, etc.). The toolkit was produced by UNICEF and WHO.

## Module 4: Stay



### Village Savings and Loans Associations (VSLAs) (intervention)

- **VSLA intervention summary**<sup>63</sup>: This two-page summary provides insight into the VSLA intervention and how it has been used within the Kids to Care model. It was produced by Aidsfonds.
- **VSLA step-by-step formation summary**<sup>64</sup>: This resource provides step-by-step guidance for how to form and support VSLAs. It was produced by Health Need Uganda, a Kids to Care implementing organisation.
- **VSLA training manual**<sup>65</sup>: This can be used by implementing organisations to train community health workers, community resource persons and Village Savings and Loan Association group members on group formation, processes and group strengthening. It was produced by Health Need Uganda.
- **VSLA group services monitoring tool**<sup>66</sup>: This template can be used to keep track of services and supports provided by implementing organisations to VSLA groups. The template was produced by ARISE Uganda, a Kids to Care implementing organisation.

### Strengthening of peer-to-peer support groups

- **Peer group mentorship protocol**<sup>67</sup>: This outlines support mechanisms for peer-to-peer support groups and activities that can be integrated to mentor and strengthen these groups by implementing organisations. The protocol was produced by Health Need Uganda, a Kids to Care implementing organisation.

### Continued household visits

- **Disclosure of HIV status for pediatric and adolescent populations**<sup>68</sup>: This toolkit explores the challenges and barriers to disclosure, the stages of disclosure and how to effectively plan and prepare for disclosure. It includes tools to assess readiness to disclose, role-plays and job aids that can be used by community health workers to support the disclosure process. The toolkit was produced by New Horizons and the Elizabeth Glaser Pediatric AIDS Foundation.
- **Caregiver guide**<sup>25</sup>: This provides additional support for community health workers working with caregivers. It goes beyond the TAFU training manual by giving more details on disclosure; understanding antiretroviral treatment and adherence; stigma and discrimination; child abuse and protection; sexual and reproductive health and family planning; loss, grief and bereavement; transition in care (adolescent to adult); child/adolescent mental health; tuberculosis; nutrition for children living with HIV. The guide was produced by the Elizabeth Glaser Pediatric AIDS Foundation.
- **Children Treatment Literacy Booklet**<sup>37</sup>: This booklet for caregivers provides detailed guidance on treatment literacy for children. The booklet can be used to develop key messages for organised diffusion (sharing of messaging through community structures). It was developed by the Elizabeth Glaser Pediatric AIDS Foundation.

## Transitions in care

- **Adolescent and Youth Transition of Care**

**Toolkit<sup>69</sup>:** This provides guidance for community health workers and healthcare workers to support the transition from paediatric to adolescent care and from adolescent to adult care, as well as the transitions of care that occur during and after pregnancy. It was produced by New Horizons and the Elizabeth Glaser Pediatric AIDS Foundation.

- **Transition of Care and Other Services for**

**Adolescents Living with HIV<sup>70</sup>:** This toolkit is designed to support community healthcare providers such as community health workers to work with families, caregivers and adolescents through the transition of care from paediatric to adult care. The toolkit was produced by AIDSSTAR-ONE and USAID/PEPFAR.

## Monitoring, Linking and Learning



m&e

### Indicator frameworks

- **Key outcome and output indicators for the Kids to Care model<sup>71</sup>:** This document summarises the key outcome and output indicators used within the Kids to Care model and can be used as a starting point for creating a monitoring and evaluation framework for implementation. The indicator summary was created by Aidsfonds and Kids to Care implementing organisations.
- **Sample M+E frameworks:** These monitoring and evaluation frameworks were built on the outcome and output indicators for the Kids to Care model and utilised within the TAFU and Breakthrough Partnership projects in Uganda. These samples can be used to develop your own framework building on the outcome and output indicators provided above. They are available here: [Uganda framework - August 2022<sup>72</sup>](#) and [TAFU + BTP framework<sup>73</sup>](#).

### Data collection tools

- **Community health workers and community resource persons monitoring form<sup>74</sup>:** This form can be used by an implementing organisation to track activities conducted by community health workers and community resource persons. This form was produced by Health Need Uganda, a Kids to Care implementing organisation.
- **Health facility monitoring form<sup>75</sup>:** This can be used by healthcare workers at a health facility within the project implementation area to track services provided that are relevant to the project. The form was produced by HealthNeed Uganda, a Kids to Care implementing organisation.

- **Event/meeting report<sup>76</sup>:** This form can be used to keep track of event/meeting participants, key topics discussed, as well as action points and persons responsible. It was produced by the Community Health Alliance Uganda, a Kids to Care implementing organisation.

## Data visualisation

- **Microsoft Excel:** The simplest way of visualising data is to create charts and graphs that convey your findings and this can be done using Microsoft Excel. You can create up to 20 different types of charts and graphs using just Excel. If you don't have access to Microsoft products, you can use Google sheets online as a free alternative.
- **PowerBI:** This is a more advanced option for visualisation of data. It imports data (usually from Excel) and can convert it into a variety of visual formats.
- **Tableau:** This is one of the easiest options for data visualisation software, creating a wide range of visualisations and is available in a free version, Tableau Public. Data shared in Tableau Public is available to anyone so should not be used for sensitive or identifying information.

## Additional resources

- [A Practical Guide to Implementing Community-based HIV Prevention Services](#), produced by Desmond Tutu Foundation. Sharing experience in community-based HIV prevention services, HTS and quality assurance.
- [Community-Facility Linkages To Support The Scale Up Of Lifelong Treatment For Pregnant And Breastfeeding Women Living With HIV](#), produced by UNICEF. Promising practices in community-facility linkages include the following domains: empower recipients of care; provide longitudinal follow-up; improve the care-seeking environment; facilitate access.
- [Social Norms Exploration Tool](#), produced by the Institute for Reproductive Health at Georgetown University. A step-by-step guide for exploring social norms through a set of participatory tools.
- [Youth Care Clubs: an adolescent & youth-friendly HIV treatment and care model](#), produced by USAID/PEPFAR. Step by step guide on youth care clubs for adolescents living with HIV.
- [Village Savings and Loans Associations Methodology and Tools](#) for group formation and strengthening, produced by VSL Associates. Summary of the Village Savings and Loans Associations methodology and training guides for establishing groups in the community. Note: field guides adapted for country contexts are available for some countries.

# End notes

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