

# Aidsfonds Paediatric HIV **Theory** **Of Change**



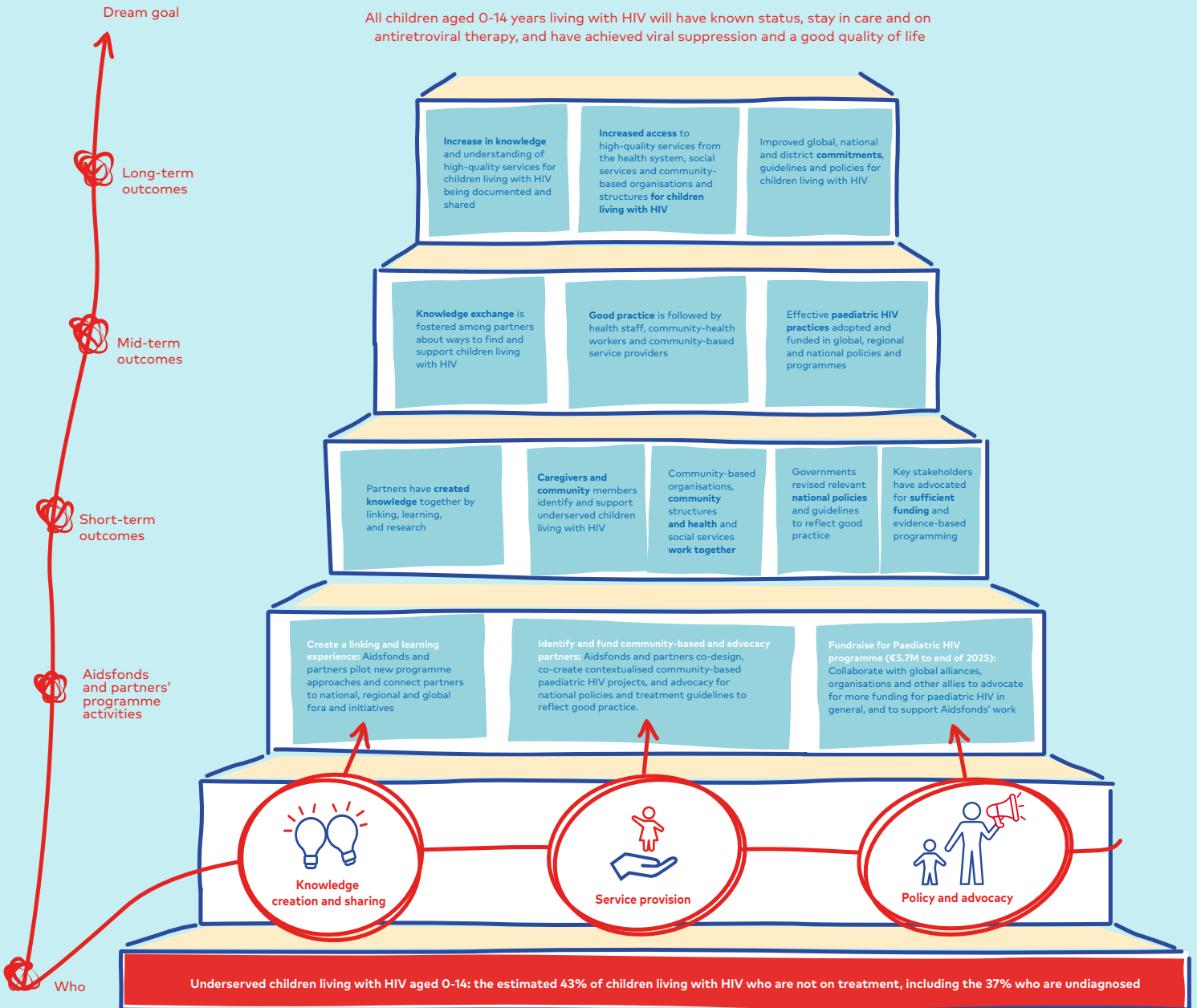
# Contents

Theory of Change	3
Rationale, narrative, assumptions, and definitions	4
Aidsfonds' role	7
How the Theory of Change was developed	8

# Theory of Change

## No children die of AIDS

All children aged 0-14 years living with HIV will have known status, stay in care and on antiretroviral therapy, and have achieved viral suppression and a good quality of life



# Rationale, narrative, assumptions, and definitions

## Rationale

This Theory of Change focuses on the children aged 0-14 living with HIV who are underserved.

According to UNAIDS, in 2022 children accounted for 13% of all AIDS-related deaths, even though only 4% of the total number of people living with HIV are children. In 2022 an estimated 1.5 million children were living with HIV worldwide<sup>2</sup>. In the same year, 130,000 children newly acquired HIV<sup>3</sup>.

Progress on paediatric HIV remains limited for several reasons. These include limited funding for paediatric HIV community-based interventions, limited commitment of countries, the failure to find and test children and pregnant and lactating women, and to put them on treatment. Approximately 660,000 children living with HIV were not receiving antiretroviral therapy in 2022. Only 63% of children know their status, and only 57% of those are on treatment, compared to 87% and 77% for adults. The reasons for this equity gap are many and complex: the health system may fail to inform families of an infants' positive diagnosis, and even if their status is known, younger children depend on their caregivers and the wider community to act on their behalf<sup>4</sup>. Some children with HIV are hard to reach. For example, they may be children of young mothers, who need specialised services<sup>5</sup>; children of key populations, who face stigmatisation and further exclusion<sup>6</sup>; or be living apart from their biological families.

This has resulted in a significant number of children with HIV who are underserved: children who may have never been diagnosed, or who have been lost to follow-up and no longer receive HIV treatment. These children are the focus of the Theory of Change.

## Narrative

Aidsfonds' paediatric HIV programme focuses on the missing children with HIV: the estimated 43% of children aged 0-14 years with HIV who are not on treatment, including the 37% who are undiagnosed. We believe that to reach these underserved children living with HIV, we must invest in and work closely with community-based organisations. Strengthened partnerships between global alliances, national and district governments, health systems and community structures are essential to reach all children with HIV<sup>7</sup>.

To reach our dream goal that no children die of AIDS, all children with HIV should know their status, stay in care and on ART, have viral suppression and experience well-being. The programme's Theory of Change follows three pathways. These appear separate on the diagram, but they are interlinked:

- **Knowledge creation and sharing:** linking and learning activities create and share knowledge about the best ways to find and support children with HIV. We note our unique linking and learning role in the paediatric programme
- **Service provision:** community-based and advocacy partners co-design programmes to deliver high quality services to children living with HIV
- **Policy and advocacy:** advocating for more funding for paediatric HIV, and fundraising for Aidsfonds and partners' work, to support the adoption of effective paediatric practices, policies, and guidelines.

<sup>1</sup> Estimates provided by 2023 Global AIDS Update: [The path that ends AIDS: UNAIDS Global AIDS Update 2023](#). Geneva: Joint United Nations Programme on HIV/AIDS; 2023

<sup>2</sup> UNAIDS, 2022. [Global HIV & AIDS statistics - Factsheet](#)

<sup>3</sup> World Health Organization. 2023. African leaders unite in pledge to end AIDS in children. [African leaders unite in pledge to end AIDS in children \(who.int\)](#)

<sup>4</sup> Viewpoint Published in *Journal of International AIDS Society* Volume 27, International Children's Day, Issue 20 November 2023

<sup>5</sup> [Safeguarding the future: giving priority to the needs of adolescent and young mothers living with HIV](#), WHO and UNICEF, 2021;

<sup>6</sup> [Making the children of Key Populations a priority for equitable development](#), Advocacy Briefing, The Coalition for Children affected by AIDS, 2017

<sup>7</sup> [The Dar es Salaam Declaration for Action to End AIDS in Children](#). Geneva: Joint United Nations Programme on HIV/AIDS; 2023

## Assumptions

These assumptions are loosely organised according to the pathways in the Theory of Change. They are intended to check the logic of the Theory of Change, inform learning, and note risks. They will be used to guide evaluations. They allow different contexts, and do not presume that everything is known about a given context:

### Knowledge creation and sharing:

- Aidsfonds is recognised as an expert in paediatric HIV, trusted by donors and able to act as an intermediary with community-based programmes
- The definition of underserved children provided below is accurate
- Ways of reaching underserved children can be improved

### Service provision:

- There are children living with HIV who are not yet being reached<sup>8</sup>
- Community-based organisations are best placed to deliver community-based services and to provide a link to health services for children with HIV<sup>9</sup>
- Community structures are necessary to identify and support children with HIV
- By focusing on underserved children, programmes can reach more children living with HIV
- Reaching underserved children is expensive but not finding them is even more costly
- There are in-country civil society organisations who understand the context and can deliver community-based programmes that will improve the quality of HIV services for children
- Testing and treatment services are available in locations where Aidsfonds funds community partners
- Collaboration and exchange of best practices improves programmatic outcomes

### Policy and advocacy:

- Aidsfonds and partners have sufficient convening power to support global collaboration and advocacy for the rights of children living with HIV
- Governments are willing to adopt effective paediatric HIV practices in national guidelines and policies
- Incorporating an intervention into government programmes is a measure of sustainability of the community-based paediatric HIV interventions
- Long-term partnerships with global partners are more likely to create sustainable positive change to advocate for the rights of children living with HIV
- Prevention of vertical transmission is no longer a focus of Aidsfonds' limited paediatric HIV programme funding; other, larger funders are focused on vertical transmission prevention.

<sup>8</sup> Latest figures from UNICEF 2023 suggest there are children with HIV who are not being reached. If Aidsfonds' programmes fail to find missing children, this provides important lessons about estimates, and about ways of finding children with HIV.

<sup>9</sup> Published evidence to support this assumption includes: [Evidence on the effectiveness of community-based primary health care in improving HIV/AIDS outcomes for mothers and children in low- and middle-income countries: Findings from a systematic review 2021](#)

## Definitions

The term **'children'** is used throughout, for simplicity, recognising that the focus age group is 0-14 years, which includes young adolescents. Aidsfonds youth programme is aimed at young people aged 10-24. We acknowledge that children are not a separate entity, they are part of communities, families, and households.

The term **'services'** includes both clinic and non-clinic-based services, whether provided by the government or civil society. Aidsfonds provides funding to improve access to services, and collaboration between clinics and communities.

The term **'Community Health Workers'** covers the complete range of community-based cadres, including but not limited to Traditional Birth Attendants and traditional healers.

The term **'have known status'** is proposed based on the UNAIDS 'first 95', that 95% of all people living with HIV will know their HIV status. However, for young children, they may not personally know their status, until they are old enough.

**'Community structures'** are any groups or organisations outside the control of the state. The term covers a wide range of actors, starting with families and households, and including schools, churches, mosques, registered and unregistered community groups and clubs.

**'Include children's voices appropriately'**<sup>11</sup> by respecting their rights, creating safe environments, and using child-friendly communication. This involves diverse participation methods, feedback mechanisms, and ensuring that their perspectives contribute to project design elements that affect them.

A **'community-based organisation'** closely engages with and involves children, caregivers and people living with HIV in design, implementation, and evaluation of paediatric HIV projects. Community-based organisations are founded and registered in the country where they work, are non-governmental, non-political, and non-profit. Community-based organisations may be founded by and/or represent the voice of children and adolescents living with HIV and/or their caregivers.

**'Community-based interventions'** recognize the importance of children living with HIV and their caregivers' lived experiences when providing paediatric HIV services. They address their unique needs in a specific social cultural context.

**'Children living with HIV 0-14, who are underserved'** are inadequately served by standard services and refers to nearly 50% of children with HIV<sup>10</sup>. The term is contextual and will be agreed with partners. It will be explained as any children who were not tested or enrolled in community or health systems before the start of the project, this especially includes;

- ✓ children of members of key populations
- ✓ children of young mothers
- ✓ children living in a particular setting or circumstance, to be explained by the applicant, which could include children who do not live with their biological parents, children on the move, children with disabilities
- ✓ children who live far from the health facilities or have limited access to healthcare facilities, such as children in rural areas and living in households with limited resources
- ✓ adolescents up to age 14

What is meant by **'participatory partnership'**: Aidsfonds builds on community knowledge by putting communities at the centre of our work, whereby communities help to design and drive the paediatric programme. We jointly engage to set goals, make decisions about funding allocations, and evaluate impact to ensure children most impacted by HIV are reached. Aidsfonds promotes community participation and leadership, and mutual linking and learning, to shift power/work towards a more equal partnership and sustainability (e.g. broader resource base/government action). Good partnership as a funder means flexibility, multiple years of funding, information sharing, transparency, and capacity exchange.

**'Effective'** means successful in producing a desired or intended outcome. Effective approaches should

<sup>10</sup> See rationale above.

<sup>11</sup> Article 12 of the Convention on the Rights of the Child states that every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. When representing the voices of children with HIV, this does not necessarily mean requiring children themselves to do this work, but that partners and programmes have the means and processes to ensure that children are consulted about decisions that affect them.

be based on evidence.

**'High quality'** is defined according to context, but must include being child-friendly, non-discriminatory, age-appropriate and based on the latest evidence.

**'Good practice'** is defined as following latest treatment guidelines, childfriendly, age appropriate, non-discriminatory.

**'Knowledge'** is defined as good practice, evidence, guidelines, and policies.

**'Fostered'** means co-documented good practice, shared evidence, guidelines, and policies, joint research.

**'Advocacy'** means identifying and calling for change. Advocacy calls for changes in laws, policies, practices, and structures to improve people's lives<sup>12</sup>.

## Aidsfonds' role

This Theory of Change is for Aidsfonds' paediatric programme. It sits within, and relates to, the full Aidsfonds Theory of Change<sup>13</sup>. Following Aidsfonds' 'Lifecycle Approach'<sup>14</sup>, it is aligned with Aidsfonds' Youth<sup>15</sup> programme.

In line with Aidsfonds' strategy, the paediatric programme works together with partners<sup>16</sup>; leads by example and promotes ownership. Aidsfonds' role within our Theory of Change is to be a:

- 1. Fundraiser:** we collaborate with global alliances, organisations, and other allies to advocate for more funding for paediatric HIV in general and among the Dutch public to support our work
- 2. Involved funder:** we fund community-based organisations for service delivery and advocacy. We work together as equal partners, co-designing and co-creating contextualised community-based paediatric HIV projects
- 3. Catalyst:** we invest in linking and learning: Aidsfonds and partners pilot new programme approaches and connect partners to national, regional, and global fora and initiatives.

<sup>12</sup> IPPF: <https://www.ippf.org/our-approach/advocacy>

<sup>13</sup> See Aidsfonds Soa-AIDS Nederland strategy 2022-2025

<sup>14</sup> More on the Lifecycle Approach here

<sup>15</sup> More on the Young People programme here

<sup>16</sup> Aidsfonds will partner with organisations that share similar values and strategies. This includes: being inclusive, participatory, community-centred, child-centred, having expertise on paediatric HIV programmes, collaborative with governments, community structures, community, clinics, and consortium partners, transparent, willing, and open to learning and sharing knowledge to improve the work and ensure that other sub-grantees and partners also learn as well; and able to understand the context and analysis of challenges and barriers, with skills in monitoring and evaluation.

# How the Theory of Change was developed

Aidsfonds used a participatory process to develop the Theory of Change. Working with consultants, Aidsfonds undertook a desk review and key informant interviews to inform thinking. Following this, Aidsfonds staff and selected partners, expert witnesses and stakeholders met to develop a draft Theory of Change. Aidsfonds staff refined this draft and discussed it with stakeholders. The process began in October 2023, with this draft produced in January 2024.

Design principles for the Theory of Change were developed during the consultation process, which are also in line with Aidsfonds' approach<sup>17</sup>. They stated that the Theory of Change should:

- Be evidence based and allow for differences in context
- Be flexible and transparent
- Value Linking and Learning
- Use participatory approaches for funding, learning and decision making, and include children's voices appropriately
- Commit to longer-term partnering

<sup>17</sup> Aidsfonds Soa-AIDS Nederland strategy 2022-2025