



# Informing the agenda: A dialogue with mothers and caregivers on the priorities for children and adolescents with perinatal HIV exposure

Event alongside IAS 2025, the 13th IAS  
Conference on HIV Science

**13 July 2025 | Kigali, Rwanda**

Over the past several decades, significant progress in HIV prevention and treatment has led to a marked reduction in HIV vertical transmission. As of 2024, an estimated 16 million children under the age of 15 globally have been perinatally exposed to HIV but remain HIV-free. An increasing and consistent body of evidence shows that despite starting life without HIV, these children face elevated risks of adverse birth outcomes, infectious morbidity, mortality, impaired growth and suboptimal neurodevelopment.



On 13 July 2025, a dialogue, titled "Informing the agenda: A dialogue with mothers and caregivers on the priorities for children with perinatal HIV exposure", was convened in Kigali alongside IAS 2025, [the 13th IAS Conference on HIV Science](#). The roundtable, organised by IAS – the International AIDS Society – in collaboration with the Rwanda Network of People Living with HIV (RRP+), Rwanda Biomedical Center, UNICEF, International Community of Women Living with HIV Eastern Africa (ICWEA) and members of the Organizing Committee for the 11th Symposium on Children and Adolescents with Perinatal HIV Exposure, brought together mothers and caregivers of children and adolescents with perinatal HIV exposure, creating an important platform to share lived realities and highlight the support needs of this population.

This roundtable recognized the vital role of mothers and caregivers in shaping effective, family-centred policies and programmes. Their perspectives underscore the need to prioritize the health and long-term outcomes of children and adolescents exposed to HIV. The insights gathered will inform future advocacy, reinforcing a call for collaborative, family-centred approaches that ensure that children and adolescents not only survive, but thrive.

## Factors contributing to poor health and development outcomes among children and adolescents with perinatal HIV exposure

Mothers and caregivers of children and adolescents with perinatal HIV exposure provided important insights into the everyday realities shaping their children's health and development, as well as the interlinked factors that contribute to poor outcomes. Their perspectives highlight gaps that go beyond clinical care, touching on family support, community dynamics and broader systemic challenges. To address these issues, caregivers identified the following key factors that contribute to poor health and developmental outcomes among children and adolescents with perinatal HIV exposure:

### Family-level factors

- Poverty and food insecurity undermine families' ability to access healthcare, maintain nutrition and provide stable support environments.
- The fear of stigma, emotional distress or uncertainty about how to disclose often delay open conversations about HIV within families. Lack of disclosure can cause mistrust, anxiety and psychological trauma in children and adolescents, especially if they learn about their parents' status from external sources.
- Limited family-based, accurate and practical HIV information among caregivers weakens their ability to support children with prevention practices and stigma reduction.
- Weak follow-up of children exposed to HIV after vertical transmission prevention programmes are completed means many fall through the cracks once initial prevention services end, missing critical ongoing medical and psychosocial support as they grow older.

### Community-level factors

- Limited HIV awareness among community leaders and the wider public sustains stigma, weakens advocacy and reduces community engagement in the HIV response.
- Fragmented and under-resourced community systems, including weak coordination between health facilities and community-based organizations, and limited incentives for volunteers, results in gaps in outreach and care.
- Inadequate youth and marginalized group engagement results in missed opportunities to empower adolescents with knowledge, protective behaviours, and access to culturally sensitive services.
- Underutilization of innovative communication platforms such as digital tools, social media and local radio limits the reach and effectiveness of HIV education and community mobilization.

## Education system-level factors

- Harmful misconceptions about HIV in school curricula reinforce fear and misinformation, portraying HIV as a moral failing or fatal disease, rather than a manageable condition.
- Stigma and discrimination in schools from peers, teachers and staff undermine children's emotional well-being, confidence and academic performance.
- Limited access to counselling and psychosocial support services in schools leaves children and adolescents from households affected by HIV vulnerable to mental health challenges and social isolation.
- Absenteeism and dropout risks arise from illness, stigma and financial hardship, limiting long-term development and opportunities.

## Health system-level factors

- Stigma and discrimination in healthcare settings discourage families from seeking or remaining in care.
- Limited training and support for caregivers and mothers on nutrition and psychosocial care reduces their ability to provide consistent support.
- Weak sustained monitoring of children exposed to HIV beyond infancy leaves gaps in long-term follow-up despite ongoing vulnerability to acquisition and health challenges.
- Insufficient financial and nutritional support for vulnerable households exacerbates poor health outcomes.

## Recommendations

While scientific breakthroughs and policy frameworks have advanced, the benefits have not reached lived realities in families, schools and communities. Children exposed to HIV face unique vulnerabilities. A holistic approach is needed, integrating health, education, nutrition and psychosocial support and centred in families, schools and communities to ensure that children and adolescents with perinatal HIV exposure not only survive, but thrive. Families are not only caregivers, but also gatekeepers of trust and emotional safety. Mothers and caregivers are key partners as their lived experiences are essential for shaping responsive, family-centred research, policies and programmes. RRP+ and ICWEA emphasize that sustainable HIV impact must be rooted in the lived experiences of communities.

### Family level

- Support families with structured programmes on disclosure, communication and HIV awareness. Train and guide parents on age-appropriate disclosure to build trust and resilience in children.
- Strengthen family-based HIV education through peer support groups, faith-based networks and community outreach.
- Develop follow-up systems to monitor children exposed to HIV beyond vertical transmission prevention programmes, including psychosocial support.
- Provide targeted socioeconomic support (cash transfers, nutrition packages) to reduce poverty-related barriers.

### Community level

- Train and equip community leaders with accurate HIV information to lead stigma reduction and advocacy. Create structured opportunities for community health workers to speak at local gatherings and share information
- Structure awareness campaigns to reach families in culturally appropriate ways, using trusted community structures, including local leaders, community health workers and faith-based groups, to promote knowledge sharing, empathy and informed decision making.
- Strengthen collaboration between community-based organizations, health facilities and local authorities to ensure coordinated care and efficient resource use.
- Introduce incentives and capacity building for community volunteers to improve performance and motivation.
- Expand youth-friendly HIV education and engagement initiatives to empower adolescents.
- Tailor services to key populations and address structural and legal barriers to access.
- Leverage radio, digital platforms and social media to expand HIV communication and reach younger audiences.

## Education system level

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- Stigma and discrimination in schools from peers, teachers and staff undermine children's emotional well-being, confidence and academic performance.
- Limited access to counselling and psychosocial support services in schools leaves children and adolescents from households affected by HIV vulnerable to mental health challenges and social isolation.
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## Health system level

- Enforce anti-discrimination policies in health facilities and train providers in respectful, stigma-free care. This creates a safe environment that encourages individuals to seek and continue treatment.
- Provide caregivers with structured training on nutrition and psychosocial support, reinforced by regular home visits.
- Integrate financial and nutritional support into HIV care for vulnerable families.
- Institutionalize long-term monitoring and support for children exposed to HIV into their adolescent years.

# Call to action



## 1. Recognize children and adolescents exposed to HIV who are HIV-free as a priority population

Include children and adolescents exposed to HIV in national HIV, child health and development strategies and invest in research on their long-term health, developmental and psychosocial outcomes.



## 2. Strengthen family support and disclosure practices

Equip caregivers with counselling, peer support and age-appropriate guidance to disclose HIV status and build resilience in children.



## 3. Strengthen health services for children and adolescents exposed to HIV and their families

Train healthcare providers on their unique needs, integrate psychosocial, nutrition and parenting support into child health services, and promote respectful, stigma-free health services.



## 4. Ensure long-term monitoring of children exposed to HIV

Institutionalize follow up into adolescence for children exposed to HIV who are HIV-free, including testing, psychosocial care and health monitoring.



## 5. Combat stigma and misinformation across community and education systems

Improve HIV literacy in schools, including revising the HIV curricula, and enforce anti-discrimination policies. Support schools to provide safe, stigma-free and inclusive environments.



## 6. Expand psychosocial and mental health support

Integrate counselling, peer mentorship and family-centred psychosocial services into health, community and school systems. Ensure that children and caregivers have access to mental health services across health, school and community settings.



## 7. Transform schools into safe, inclusive spaces

Establish school-based counselling, integrate HIV awareness into curricula, and enforce equal treatment policies so HIV-affected children can thrive academically and socially.



## 8. Enhance community engagement and coordination

Engage mothers and caregivers in programme design and fund family-centred initiatives that address lived realities. Incentivize and train community volunteers and improve collaboration across community-based organizations and health facilities



## 9. Integrate socioeconomic and nutritional support

Provide targeted financial, food and livelihood support for vulnerable families to reduce poverty-related health and development risks.



## 10. Leverage digital and innovative communication tools

Support the use of digital platforms, mobile health tools, local media and social media to share accurate HIV information, reach young audiences and counter stigma.

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## Sponsors

