

Prioritising Children, Adolescents & Caregivers Affected by HIV in the COVID-19 Response

Policy Briefing

"COVID-19 has increased the challenges that we as young mothers affected by HIV were already facing before this pandemic began. It is undermining our efforts to be empowered and to ensure that we and our children survive and thrive."

MIRIAM HASASHA

Coalition Ambassador



COVID-19 is having catastrophic and lasting consequences for millions of children, adolescents and caregivers affected by HIV and AIDS. We must act now. If not, the precious gains made in the fight against HIV and AIDS will be reversed. And those already made vulnerable by HIV and AIDS will be further impacted by both COVID-19 and its consequences.

This policy brief is for global donors and policy makers. It sets out what global policy changes are required, based on the latest evidence related to children and adolescents affected by HIV, and those working alongside them. It is championed by the Coalition for Children affected by AIDS (the Coalition) – an independent group of thought leaders from across UN, donor, NGO and academic communities.

SNAPSHOT OF CHILDREN, ADOLESCENTS AND HIV

**2.8
million**

2.8 million children and adolescents live with HIV¹

1/2

Around half (47%) of all children living with HIV are not treated²



15 million children are especially vulnerable to disease on account of being exposed to HIV during pregnancy³



Adolescent girls and young women are twice as likely to become infected with HIV than their male peers⁴

**13.8
million**

13.8 million children and adolescents have lost one or both parents to HIV/AIDS⁵



The majority of children and adolescents living with HIV are all in Sub-Saharan Africa⁶

"As Members of the Coalition we stand in solidarity with children, adolescents and caregivers affected by HIV and AIDS and we speak with one strong voice to call for them to be prioritised during the COVID-19 pandemic."

LISA BOHMER

Conrad N. Hilton Foundation and the Coalition

*"Children are not the face of this pandemic.
But they risk being among its biggest victims."*

UNITED NATIONS⁷

INTRODUCTION

Whilst COVID-19 has impacted all children and adolescents everywhere, its effects on those already affected by HIV and AIDS are especially severe. The stigma, co-morbidities and socio-economic vulnerabilities associated with HIV and AIDS, leave them especially vulnerable to this new pandemic and its impacts. And lock downs have curtailed livelihoods and support that they rely upon to survive and thrive. This policy brief looks at why this is happening and what can be done about it.

DISRUPTED HEALTH SERVICES

Settings with a high burden of HIV often also have poor health infrastructure. Here, local clinics and community-based health workers - many of whom are unpaid or poorly stipended volunteers – are the backbone of health services. They now face the double burden of fighting HIV and AIDS and other health challenges, whilst also tackling COVID-19. Health workers across Africa have already spoken out about chronic gaps in guidance and resources to address COVID-19. In a survey in April 2020 they highlighted how only 13% of clinics have a triage system in place to address cases of COVID-19; less than 4% have sufficient PPE; and 71% have no respirator support equipment.⁸

These shortfalls severely limit their capacity not only to tackle COVID-19 but also to provide wider health support and essential services to children, adolescents and families affected by HIV. At the start of the pandemic far fewer children, adolescents and caregivers accessed HIV testing, treatment and care. Many were too fearful of COVID-19 infection to attend health clinics, even when they were exempt from lockdown. Others, were no longer able to afford to get there due to the impacts of COVID-19 on livelihoods.

Many HIV service providers were redeployed to the COVID-19 response. And many community services all but halted. Health providers experienced stock-outs of antiretroviral medicines (ARVs), HIV testing kits, and other sexual and reproductive health supplies. Children, adolescents and caregivers living with HIV ran out of medication and resorted to rationing and sharing with others – both of which are harmful. Meanwhile, increased income poverty due to COVID-19 left many without enough food with which to take their medication.

Several months on, the longer-term impact of COVID-19 on HIV services is becoming clearer. At the time of writing (December 2020), UNAIDS reports significant decreases in HIV testing⁹ and new treatment initiation.¹⁰

Whilst COVID-19 has also impeded HIV treatment and care, disruptions have not been as severe as originally feared. Over time, health providers and communities have found innovative ways to reach children, adolescents and caregivers with ARVs and other support. Multi-month prescriptions, telehealth and mobile community-based service provision are just some of the innovations that have enabled many to resume with their HIV treatment and care.

Despite this, the precious gains made in tackling HIV are at risk of reversal. Even a short disruption in HIV support has lasting consequences. More children, adolescents and caregivers will have become infected with HIV; more will become ill or die from AIDS related causes; and more will experience the severe and lasting social, economic and physical consequences of HIV. In May 2020, UNAIDS reported that service disruptions could cause pediatric HIV infection rates to rise across Sub Saharan Africa - by as much as 162% in Malawi.¹¹

Whilst we do not yet know whether children and adolescents living with HIV are at heightened risk of COVID-19, we must remain vigilant to this possibility. Other disease epidemiology suggests that the low immunity caused by HIV and AIDS, if left untreated, makes it harder to fight off COVID-19. With only just over half of all children living with HIV on ARVS, the potential risk of COVID-19 to them could be significant. Moreover, the chronic stigma associated with HIV and AIDS makes it harder for children, adolescents and caregivers affected by the disease to access broader services, including support for COVID-19.

“Thirty years ago, children were not considered a priority in the AIDS crisis, despite the fact that children were contracting HIV and dying from AIDS. Children were excluded from key research and clinical trials and were seen as an afterthought. It is imperative that we learn from these mistakes as we deal with the impact of COVID-19 on children right now.”

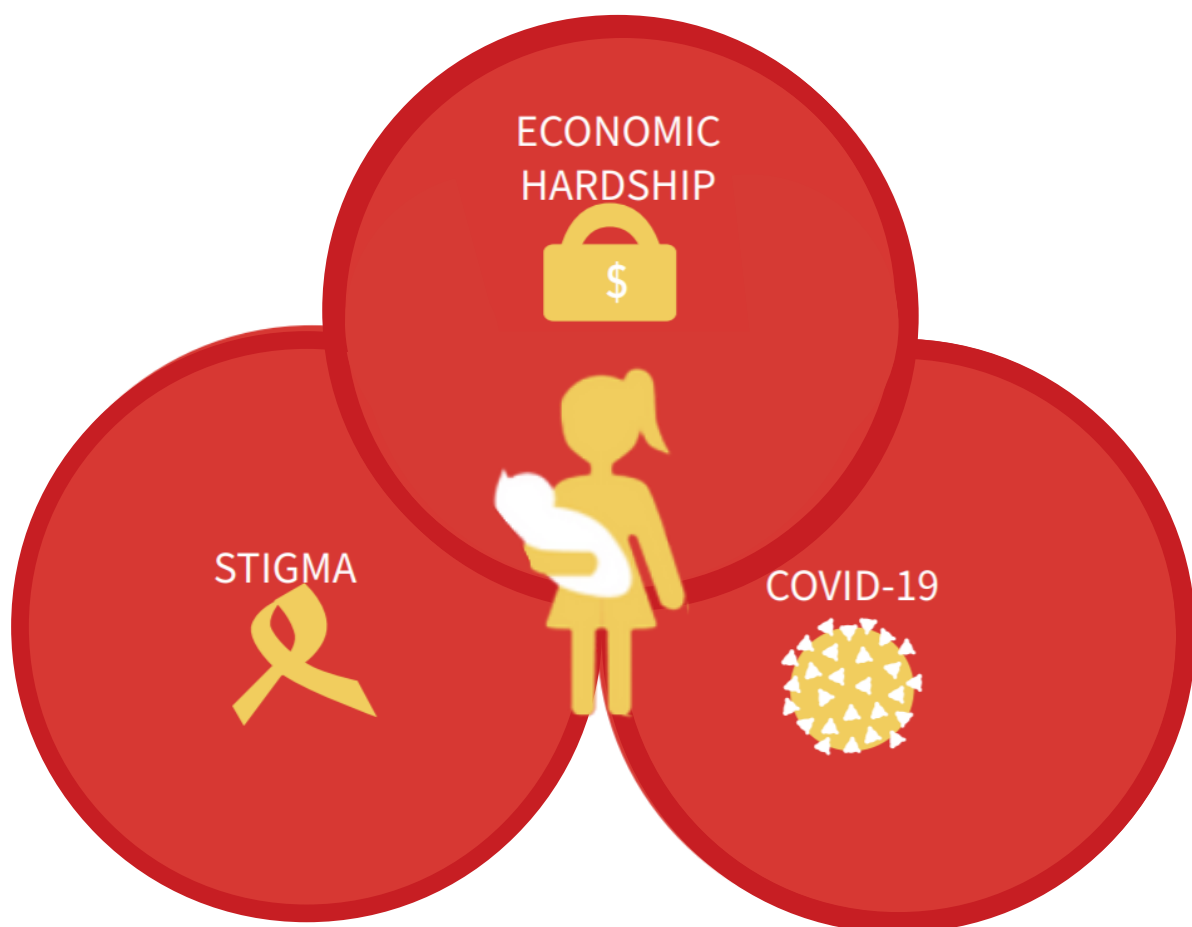
CHIP LYONS
Elizabeth Glaser Pediatric AIDS Foundation

EXACERBATING INEQUALITY

Children, adolescents and caregivers affected by HIV and AIDS are especially vulnerable to the broader health, social and economic shocks caused by the COVID-19 response. They are already disproportionately affected by poverty, violence, sexual abuse, gender inequalities, poor access to education, as well as wider health issues including poor mental health and early childhood development delays. And many live in areas where there is a high population density, and on-going emergencies such as drought, conflict or economic distress.

Children and adolescents already facing social and structural exclusion are of particular concern. This includes adolescent mothers affected by HIV and their children¹² and the children of key populations¹³ - sex workers, people who use drugs, transgender people, gay men and other men who have sex with men. They are at far greater risk of HIV infection as well as inter-relating physical, social and economic challenges. They face a double burden of stigma – associated with both HIV and their broader status in society. And they are often left out of health, social and economic development interventions.

The cumulative impacts of mass job losses and disrupted support services created by COVID-19 lockdowns has pushed already vulnerable children, adolescents and families into extreme hardship.





LIFE-LONG SOCIAL & ECONOMIC CONSEQUENCES

Disruptions to child and adolescent-centred services will have life-long consequences for millions of vulnerable children and adolescents affected by HIV and AIDS. This includes school, pre-school and early childhood development centres, nutrition programmes, maternal and newborn care services, sexual and reproductive health services, alternative care facilities, community-based child protection programmes, and case management systems.

Early Childhood Development

The risks to early childhood development amongst children affected by HIV and AIDS are especially concerning. What happens to children during the first 1000 days of life determines their path through life.¹⁴ Children born into HIV-affected households are at heightened risk of early childhood development delays that limit their potential to learn, earn and thrive across a lifetime. Therefore, the disruptions or reduced access to immunisations, nurturing care services, social protection, pre-school, nutritional support and other support for early childhood development will have a particularly devastating impact on children affected by HIV.

Education

It is questionable whether many vulnerable children and adolescents affected by HIV and AIDS will ever recover education lost due to the COVID-19 pandemic. In many settings with a high HIV burden, access to on-line schooling is extremely limited and the temporary closure of schools during COVID-19 lockdowns has resulted in a complete cessation of formal education.

Anecdotal evidence suggests that many children and adolescents affected by HIV may never return to education. In particular, adolescent mothers - many of whom were already marginalised from school - may be less likely to return due to increased economic hardship and fewer resources to pay for childcare; girls and boys from families in economic hardship have taken on odd jobs; and increases in early and unintended pregnancies during lockdown are causing girls and young women to drop out of school.

Violence

Violence is another critical area of concern. Whilst the cumulative impacts of, economic hardship, a lack of support, and home confinement are causing increased risk of violence for all children, those with the added burden of HIV are especially vulnerable. UNFPA predicts up to 7 million unintended pregnancies due to COVID-19, many as a result of gender based violence towards girls and young women.¹⁵

This is corroborated by widespread anecdotal evidence from front-line health providers in Sub Saharan Africa, where girls and young women are also at increased risk of contracting HIV, if they are not living with it already. Meanwhile, UNAIDS reports widespread increased in violence against key populations, including LGBTI youth.¹⁶

Mental Health

Children, adolescents and caregivers affected by HIV are also especially vulnerable to the mental health impacts of COVID-19. Those living with HIV are at increased risk of developing mental health conditions, often suffering from depression and anxiety. COVID-19 and its impacts place an added layer of stress.

Meanwhile, caregivers also face the additional worry of going without HIV treatment, or of trying to access it when health services are severely compromised.

COMMUNITY RESILIENCE

The COVID-19 pandemic has highlighted yet again how local community-based organisations are highly effective service providers for children, adolescents and families left behind. They have stepped in to replace many of the large-scale institutional service providers that have been disrupted by COVID-19. They have devised new ways to continue to serve those most in need, most often combining biomedical, social and economic support and making innovative use of technologies.

There are numerous examples to draw from including: sex worker mothers in South Africa providing each other with food and essential items for themselves and their children via the Mothers for the Future programme;¹⁷ mothers affected by HIV across Sub Saharan Africa providing each other with information on health, HIV, and COVID-19 via a *Virtual Mentor Mother Platform* available in 30 languages;¹⁸ and adolescent and young mothers affected by HIV in Uganda, Tanzania, Malawi, Zambia supporting each other with case management on HIV, mental health, social and economic challenges via a new mobile App - Ask, Boost, Connect, Deliver.¹⁹

“Communities are tackling this pandemic in inspirational ways that show their experience, skill, adaptability and responsiveness. The wider world would do well to learn from them and to follow their lead.”

20
FRONTLINE AIDS

Yet, despite their critical importance, community-based organisations themselves have come under threat during the COVID-19 pandemic. The diversion of HIV resources towards the COVID-19 pandemic has significantly reduced their capacity, forcing many to downsize or close altogether. Restrictions on movement have also reduced the capacity of civil society organisations to question or scrutinise state policies and services and in some settings governments are using this as an opportunity to oppress LGBTQ, drug users, sex workers and other marginalised groups.²¹

“Our emergency is food, electricity, transport to collect HIV medication; there are new babies who need nappies. We cannot work. And because we are sex workers we get no help from the government. We rely upon each other. My priority right now is to collect as many donations as I can to support my fellow sex worker mothers.”

DUDU DLAMINI
Coalition Ambassador

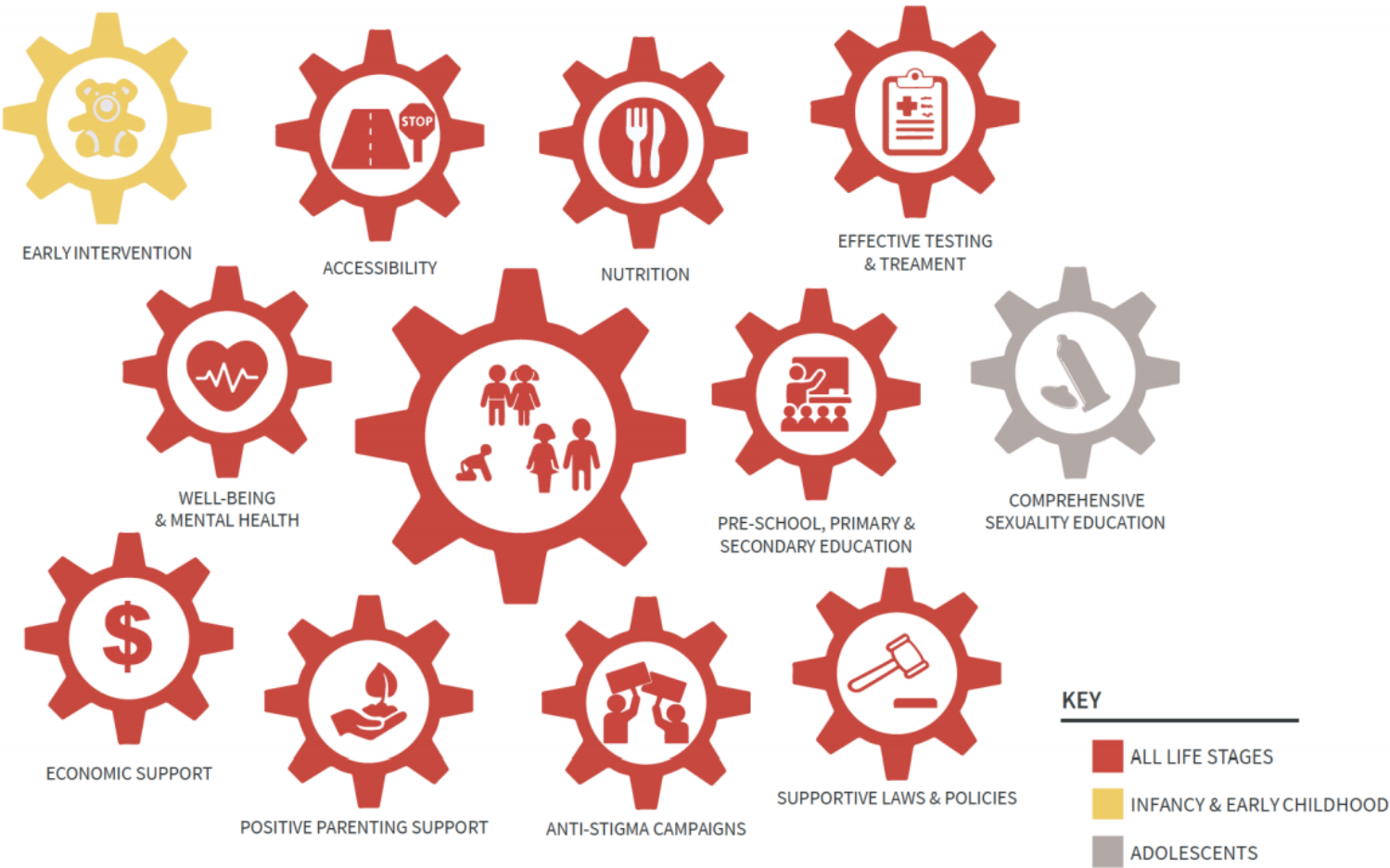


HOLISTIC SUPPORT

The COVID-19 pandemic has highlighted, once again, the inextricable link between a person's health, social and economic capacity. The UNAIDS joint program has learned over many years of responding to the HIV pandemic the importance of combining biomedical, social and economic support, and in 2019 Unicef and other key stakeholders defined a new framework of service delivery for children and adolescents affected by HIV that brings together different sectors.²²

Experience has shown that social protection, nurturing care for early childhood development, and support for mental health are critical interventions that enable vulnerable children and adolescents affected by HIV to survive and thrive; that each child and adolescent needs a holistic package of interventions tailored to their evolving needs across the life-cycle; that communities, families and children and adolescents themselves are best placed to reach those most marginalised from society; and that vulnerable children, adolescents and their caregivers must be supported to spearhead and deliver decisions and services affecting them.

CHILDREN AND ADOLESCENTS AFFECTED BY HIV AND AIDS NEED HOLISTIC SUPPORT ACROSS THE LIFE-CYCLE



CONCLUSION

COVID-19 and HIV are both infectious diseases that exacerbate inequalities and plague the most vulnerable. The last 30 years have shown us that unless we prioritise those facing social and structural exclusion, we will not achieve global HIV-related targets nor the Sustainable Development Goals.

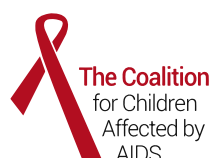
Adolescent mothers affected by HIV and their children, and the children of key populations are amongst those being left behind. Strengthening community-led services that combine biomedical support with support for social protection, mental health and early childhood development are game changers that will enable us to tackle COVID-19 and advance on the hard-won gains against HIV. This integrated approach challenges us to stop working in siloes, and to channel resources to those who need them most.

CALLS TO ACTION

- 1. Put equity at the heart of COVID-19 response and recovery efforts.** Prioritise children, adolescents and caregivers facing social and structural exclusion - in particular, adolescent mothers affected by HIV and their children, and the children of key populations. Ensure they have equitable access to services, support and information. This includes tackling stigma and exclusion within laws and policies, as well as involving them in the design and delivery of support.
- 2. Channel funds to communities - fast,** and without the usual red tape, to support whatever action community-based organisations deem best to cope in the absence of outside support. Build their capacity to support vulnerable children, adolescents and caregivers and to link them with health facilities.
- 3. Integrate biomedical, social and economic support.** Social protection, support for mental health, nurturing care for early childhood development, and child protection are especially needed alongside biomedical interventions. Invest in these areas as well as in the invisible architecture behind multi-sectoral collaboration such as information sharing, joint planning and monitoring, and broadened funding and programming parameters.
- 4. Grow and integrate HIV programmes for children, adolescents and caregivers.** Invest and protect funds; provide guidance and support for new ways to deliver and evaluate HIV programmes during physical distancing; and prevent stock-outs of ARVS, sexual and reproductive health supplies and HIV testing kits.
- 5. Strengthen the voices of children, adolescents and caregivers affected by HIV.** Ensure they are represented in decision-making and accountability platforms - from local to global - and support them to design and deliver support to their peers.
- 6. Provide frontline health workers with the support they need to deliver essential services.** This includes, personal protective equipment, and COVID-19 guidance and tools. Frontline health workers are best placed to identify what is needed – listen and respond to them.
- 7. Promote accurate, accessible information on COVID-19 and its impacts to children, adolescents and caregivers affected by HIV and AIDS.** This includes advice for those living with HIV, as well as advice more generally, on positive parenting, mental wellbeing, child protection and how to access support. For low income settings, radio communication is especially important. And messaging should target men and boys as well as women and girls.
- 8. Research and monitor the impact of COVID-19 in children, adolescents and caregivers in areas of high HIV burden.** This includes in clinical trials for treating COVID-19 and in standard reporting to monitor COVID-19 and HIV co-infection.
- 9. Support a People's Vaccine.** The COVID-19 vaccine must be patent-free, rapidly made, equally distributed, and free for all.

Notes

- 1 UNICEF (2020) <https://data.unicef.org/topic/hiv/aids/global-regional-trends>
- 2 UNAIDS (2020) Progress Towards the Start Free Stay Free AIDS Free Targets
- 3 Slogrove, A. Powis, K. et al (2019) Lancet Global Health 2020, Estimates of the global population of children who are HIV exposed and uninfected
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- 8 PATA (2020) <http://teampata.org/portfolio/pata-covid-19-survey-report/>
- 9 UNAIDS (13 October 2020) https://www.unaids.org/en/resources/presscentre/featurestories/2020/october/20201013_covid19-impacting-hiv-testing-in-most-countries
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- 14 The Lancet (2016) Advancing Early Childhood Development: From Science to Scale
- 15 UNFPA (2020) Impact of the COVID-19 Pandemic on Family Planning and Ending Gender-based Violence, Female Genital Mutilation and Child Marriage
- 16 UNAIDS (2020) Rights in a Pandemic
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- 18 <https://m2m.org/2020/08/06/tech-for-good>
- 19 <https://teampata.org/portfolio/phase-i-end-of-pilot-report-the-abcd-of-thinking-healthy/>
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- 21 Ibid
- 22 UNICEF (2019) Improving HIV Service Delivery for Infants Children and Adolescents: A framework for service delivery



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Fighting for an AIDS-free generation



Written by Corinna Csaky for the Coalition for Children Affected by AIDS, December 2020