



# **Building a Future of Health**

Leading the Fight to End AIDS and TB in Children

A CALL TO ACTION FOR PARLIAMENTARIANS | UNITE GLOBAL SUMMIT 2024

# An Unspoken Crisis: Children Are Being Left Behind

In 2022, one child died every six seconds. The causes of most of those deaths were preventable.¹ This is unacceptable. Whereas countries have the tools and knowledge to end preventable deaths and suffering in children, children face inequalities in access to health care. Parliamentarians play a critical role in taking deliberate decisions and actions to prioritize children's health through policies, budgets, and program decisions. Countries need a strong movement of parliamentarians to champion health equity in children. This brief was prepared by the Elizabeth Glaser Pediatric AIDS Foundation to ask parliamentarians and UNITE to champion that movement from local realities to global debates.

# A Call for Urgency: Prioritizing Child Health Now

Countries should move from the recognition that inequalities exist to decisive action, with concrete national targets, investments, and programs.

In 2023, 76,000 children died of HIV-related causes, a preventable and treatable disease. The fact that children account for 3.5% of people living with HIV but 12% of AIDS-related deaths should be the wake-up call everyone needs. The reality is that nearly half of children living with HIV (43%) are still not receiving antiretroviral treatment, versus 23% of all people living with HIV who are not accessing treatment.<sup>2</sup>

Tuberculosis (TB) remains among the top ten global causes of death in children under five years.<sup>3</sup> More than 80% of children who die from TB are under five years, and 96% of children die without ever receiving appropriate care.<sup>4</sup> In 2022, half of children with TB (51%) were not diagnosed or not reported to national TB programs.

The evidence is clear. We are witnessing a global failure in meeting children's needs. This is an injustice and a violation of the right of the child.<sup>5</sup> It is a stark reminder that there's more work to be done.

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An urgent need for action. Progress on child health has stalled in recent years and the trend is further exacerbated by inequalities. Progress to date is fragile, uneven, inequitable, and inadequate. There is a need for a change in mindset on how systems for health are built. Health systems will not deliver what children need if policies and practices remain to primarily focus on adult populations. Legislators and national leaders must take deliberate decisions and actions to prioritize children's health through policies and successful programs. Renewed leadership and sustainable investments are needed to achieve better health for children.



A national and global priority. Investing in children is key for a society to build a better future. The evidence is clear: Early investments in children's health, education, and development have benefits that compound throughout the child's lifetime, for their future children, and for society as a whole. Governments have committed to taking actions to improve child health. The rights and entitlements of children are enshrined within the UN Convention on the Rights of the Child (CRC), the world's most ratified human rights treaty. Its realization is the only pathway for countries to achieve the Sustainable Development Goals (SDGs) for children's health and well-being. Guided by the SDGs and the CRC, leaders should envision a world where no child dies from a preventable disease and all children reach their full potential in health and well-being. A great number of commitments through national and global resolutions, declarations, strategies, plans, and frameworks have been made by national leaders to translate that vision into action. Being accountable for those commitments is urgently needed to ensure all children live a healthy life.



We have the tools and knowledge to end preventable deaths and illness in children. Progress made over the last 15 years in addressing child health proves that it is possible to win the fight against almost every disease. We have the knowledge, technical, and programmatic experience to do more with existing tools. However, these tools and successful interventions are not being sustained or scaled up. Greater leadership at all levels is needed to implement international policies and guidelines.

# **Equity in Action: Building Health Systems for Every Child**

Stopping preventable child deaths and improving child health will happen if countries systematically invest in health systems that are adapted to the specific needs of children, adolescents, and their families and move towards universal health coverage. Since threats to child health and well-being originate in all sectors, a deliberately multisectoral approach is needed to ensure children and adolescents survive and thrive.

### 1. Ensure equal access to health services for children and families

Persistent inequalities in the availability and quality of health care for children are a main barrier to an effective health response. Even countries that achieved their global HIV targets for all populations are failing to meet the needs of children.<sup>6</sup> HIV treatment coverage among children living with HIV remained at 57%, compared with 77% among adults in 2023, and the percentage of children with viral load suppression was only 48% versus 79% in all populations.

Analyzing and documenting inequalities at local and national levels and building programs to tackle them with proper legislation and funding decisions is urgently needed. Legislators and the health community must work together to tackle inequities, ensure that all health services provide an accessible entry point for children, and guarantee newly designed models of care work for children and their families wherever they live. Above all, political commitment at the executive level is needed to coordinate across sectors to ensure: universal health coverage; good nutrition and food security; thoughtful urban planning; safe and affordable housing and transport; clean energy; and equitable social welfare policies.

Addressing children's inequities in health should be a priority for legislators. Documenting and identifying the magnitude and extent of underlying health inequalities, and their consequences, will be critical for achieving efficiencies and maximizing programs to meet people's real health needs through evidence-based policies.



#### 2. Bring urgency to end child mortality

In 2022, one child died every six seconds. <sup>9</sup> Across the world, infectious diseases, including tuberculosis, pneumonia, diarrhea, and malaria, along with preterm birth complications, remain the leading causes of death for children under five years. An average of 208 children died each day because of AIDS-related illness (76,000 in total) in 2023. One child died of TB every three minutes. Most of the causes of deaths in children are preventable. Each number represents a young life, dreams unfulfilled and potential unrealized.

While substantial global progress has been made in reducing childhood mortality, survival gains have stalled significantly since 2010. Fifty-four countries will fall short of meeting the SDG target for under-five mortality and 63 countries will not achieve the SDG target for neonatal mortality.

Reducing maternal and child mortality is a global health priority. In 2024, WHO member states endorsed a resolution at the World Health Assembly (WHA) to accelerate the reduction of maternal and child mortality. This is an important milestone and direct result of political leadership. This WHA resolution commits to tackling the leading causes of maternal and child deaths, especially in the worst affected countries.

Parliamentarians should build on this WHA resolution and translate it into national targets and commitments to reduce child and maternal mortality. Parliamentarians should advocate for implementing this resolution and championing this topic at the global level through active engagement in global gatherings, conferences, and platforms, including during the World Health Assembly.

#### 3. Address data gaps in children

Evidence-based decision making is the cornerstone of global health programming and investment; however, available data and evidence around children's health is often unavailable, incomplete, of low quality, or not relevant for daily practice. Improved pediatric program monitoring, data disaggregation, and data analysis can help stakeholders and decisionmakers better understand the current situation, improve programs, and plan for the future.

There have been improvements in data collection and accessibility in pediatric and adolescent HIV and TB over the last decade. These improvements have helped to quantify the extent of the TB epidemic in this age group and to plan interventions to address their specific needs. At this moment, we have the opportunity to capitalize on these advances to further improve data collection tools, improve the quality of data, collect additional data where possible, and use the data for country-level action to end TB among children and adolescents. We should also look at new models and methods of data gathering and use, such as community-led monitoring.

Parliamentarians should ask "where the children are" in any health discussion and ensure they get the data they need for their representation, legislation, and oversight work. If data is not available, Parliamentarians should advocate for better data gathering, including age-disaggregated data collection.

#### 4. End AIDS and TB in children by 2030

Ending AIDS and TB is a global priority. We have the programmatic knowledge and the tools to stop new HIV and TB infections and deaths in children. Achieving this will happen if countries systematically invest in health systems and interventions that focus on improving prevention and treatment outcomes for children and their families.

Ending AIDS-related deaths among children will save tens of thousands of lives each year and can contribute to a future where no child dies from preventable and treatable causes. Eliminating vertical transmission of HIV can advance the elimination of other diseases including syphilis, hepatitis, and chagas.

Parliamentarians should advocate for sustainable and adequate investments to end AIDS and TB in children, and pave the way to more equitable health systems adapted to children through policies and political leadership.

#### 5. Invest in innovative and integrated models of care adapted to children and families

Decentralization, integration, and community and family-centered care are three broad strategies that can reduce barriers to services. Programs should be built and financed in a way that promotes integrated, people-centered services and enhances partnerships to ensure effective and efficient service delivery.

Evidence shows that integrating and decentralizing TB services into child health care services can increase TB case detection and improve treatment outcomes. Integration of HIV testing and treatment into maternal and child health care has prevented almost 3.4 million HIV infections in children since 2000. Integrated family planning and HIV services contribute to reducing unintended pregnancy and pregnancy-related maternal mortality among women living with HIV. In the contribution of HIV testing and treatment into maternal mortality among women living with HIV. In the contribution of HIV testing and treatment into maternal mortality among women living with HIV.

Several innovations can be adopted to better integrate care: incentives for joint planning and integration of services across relevant government health departments including RMNCH, HIV, sexually transmitted infections (STI), hepatitis and laboratory; routine use of dual rapid diagnostic tests (RDTs) for HIV/syphilis in screening of pregnant women; introduction of hepatitis B birth dose vaccination and innovative methods of delivery outside birth facilities; adoption of hub-and-spoke models to deliver health care services to peripheral sites.

Delivering health interventions from primary care, rather than as stand-alone programs, improves coordination and continuity of care. Many governments have implemented structural and financial reforms to move away from fragmented provider-centered models of care. At the heart of this endeavor lies the indispensable role of a well-trained health care workforce, and implementation of family and community practices for health, growth, and development.

Parliamentarians should advocate for a stronger system-wide approach adapted to children and family needs, with strong political support for primary health care, integration of services, and community engagement, guided by the vision of health systems centered around people rather than diseases or health institutions.

Parliamentarians should also advocate for the continuum of care for HIV, TB, hepatitis, and other infectious diseases in children and adolescents to be integrated into all services.

#### 6. Accelerate and sustain access to better medicines for children

Ensuring access to essential medicines is an integral component of the broad right to health enshrined in international human rights conventions. Yet appropriate medicines to save and improve the lives of infants and children often do not exist, are unavailable, or are not quality assured, especially in low-resource settings.

Recent analyses showed that less than half of WHO-recommended medicines for neglected tropical diseases are approved for children.<sup>13</sup> Furthermore, there is an average of four to over eight years difference in the time between approval of cancer medicines for children and those for adults, and approval of some medicines for children has taken more than 22 years after approval for adults.<sup>14</sup> This is also the case for HIV, where development of optimal pediatric formulations still lags 8 to 10 years behind that of adults.<sup>15</sup>

Pediatric medicines represent a low volume market, which makes these drugs less appealing for pharmaceutical companies to invest in. In addition, clinical research in pediatric populations (and particularly in neonatal babies) is particularly challenging without adequate capacity on the ground and without enabling norms and standards. Increased funding and political support both for research and development and to support the introduction and sustainability of better medicines for children is urgently needed.

At the national level, parliamentarians play a critical role in ensuring a strong national system to ensure quick and sustained access to better medicines for children. Parliamentarians should engage with civil society, advocates, practitioner and medical associations, and patient groups to ensure sustainable access to the optimal medicines for children at affordable prices and to ensure that public insurance coverage schemes cover medicines deemed essential for children.

Parliamentarians play an important role in ensuring access to better medicines for children remains on global, regional, and national agendas through advocacy and high-level political engagement. This can be done by promoting accountability in the context of international debates and platforms and through active engagement in regional-level debates and policy development.



## A Call to Action: Lead the Change to Prioritize Pediatric Health

Parliamentarians have a responsibility to build a healthier present and a brighter future for their countries. Parliamentarians play a crucial role in supporting the health of the people they represent by reviewing legislation, advocating for better policies, debating and approving budgets, holding governments to account, and operationalizing national and international commitments.

#### **Become Champions for Children's Health by:**

- 1. Meeting civil society and community representatives and amplifying their experience, evidence, and voices. This includes visiting hospitals, facilities, and service providers and getting firsthand information and reality on the ground to shape national policies and health debates.
- 2. Engaging with media, families, schools, churches, sport facilities, and work across sectors by leveraging high-level political leadership to champion, promote, and protect child health.
- 3. Promoting citizen participation and community action, including the voices of children themselves, as powerful forces for change during policy and social health debates. Social movements play a transformational role in securing the rights of communities to care for children and provide for families.
- 4. Acting globally by speaking out at conferences and on global platforms to advocate for child health, and ensure country accountability by reporting back to the agreed global commitments, including in the context of the World Health Assembly and the High-Level Political Forum on Sustainable Development, among others.

### In Parliament, We Urge You to:

- 5. Champion child health in country through your legislative role and capacity, and ensure this topic gets high-level attention in the national political debate. This could happen through specific parliamentary inquiry where parliamentarians analyze current policies, practices, and gaps impacting child health and propose specific recommendations for implementation nationally and globally.
- 6. Bridge the gap between science, data, and policy and ensure that health laws and policies, as well as their implementation, are informed by the latest scientific evidence. Parliamentarians should advocate for improved data gathering systems and ensure data is available, complete, of high quality, and relevant for daily practice and policy decisions. Provide political support to community-led monitoring as a relevant source of information to address local challenges in access to services.
- 7. Ensure parliament oversees the implementation of international commitments on health, including for HIV & AIDS, TB, universal health care, access to medicines, and maternal, newborn, and child health, among others, and that policies are in place to enable implementation. Ensure there is a nationwide vision for addressing the specific needs of children and that a system to collect quality data is in place to keep the country accountable. When possible, conducts field visits to assess national responses to international commitments and to scrutinize the process for law reform.
- 8. Document and share good practices within and across countries and make recommendations for increased international global health attention to gaps and challenges in child health.

#### **UNITE Network: Strengthen Parliamentarian Advocacy for Children's Health by:**

- 9. Leveraging its strong partnerships to produce evidence-based tools for parliamentarians; developing the required capacity and competencies within parliaments and promoting accountability for women's, children's, and adolescents' health, leveraging core parliamentary functions; supporting capacity building and strengthen parliamentary advocacy from community to global levels.
- 10. Locating child health high on its global health agenda and ensuring child health is specifically approached in its different global health development areas.
- 11. Contributing to the creation of parliamentarian champions and networks within UNITE to exchange information and experiences and champion this issue regionally and globally.

### **Endnotes**

- <sup>1</sup> Levels & trends in child mortality. Report 2023. United Nations Inter-Agency Group for Child Mortality Estimation
- <sup>2</sup> The urgency of now: AIDS at a crossroads. Geneva: Joint United Nations Programme on HIV/AIDS; 2024. Licence: CC BY-NC-SA 3.0 IGO.
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- <sup>7</sup> State of inequality: HIV, tuberculosis and malaria. Geneva: World Health Organization; 2021.
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## About EGPAF

The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) is a proven leader in the global fight to end HIV and AIDS, and an advocate for every child to live a full and healthy life into adulthood. For more than 30 years, EGPAF has been a leader in meeting urgent needs in pediatric HIV and AIDS in the world's most affected regions. EGPAF leverages our core expertise in service delivery, capacity building, research, and advocacy to comprehensively address an evolving HIV and AIDS epidemic, and through our presence on the global stage, we advocate for the health and well-being of children as they transition into adulthood. For more information, visit www.pedaids.org.