

The Union

International Union Against  
Tuberculosis and Lung Disease  
Health solutions for the poor

THEUNION.ORG

# SILENT EPIDEMIC

A CALL TO ACTION AGAINST CHILD TUBERCULOSIS



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## ACRONYMS

<b>AfCHPR</b>	African Court on Human and Peoples' Rights	<b>ESCR</b>	Revised European Social Charter
<b>AIDS</b>	Acquired Immune Deficiency Syndrome	<b>HIV</b>	Human Immunodeficiency Virus
<b>ACHPR</b>	African Charter on Human and Peoples' Rights	<b>ICCPR</b>	International Covenant on Civil and Political Rights
<b>ACHR</b>	American Convention on Human Rights	<b>ICESCR</b>	International Covenant on Economic, Social, and Cultural Rights
<b>ADRDM</b>	American Declaration of the Rights and Duties of Man	<b>MSF</b>	Médecins Sans Frontières
<b>BCG</b>	Bacillus Calmette-Guérin	<b>R&amp;D</b>	Research and Development
<b>CRC</b>	Convention on the Rights of the Child	<b>RH</b>	Rifampicin and Isoniazid (in combination)
<b>DETECT</b>	Decentralise Tuberculosis services and Engage	<b>TB</b>	Tuberculosis
<b>Child TB</b>	Communities to Transform lives of Children with Tuberculosis	<b>UN</b>	United Nations
<b>ECHR</b>	European Court of Human Rights	<b>WHO</b>	World Health Organization

**REVISED EDITION:** Please note this edition is revised from that first issued to correct information on page 06. Correction made to state 90 percent of children who die from TB went untreated, and not that 90 percent of children with TB die.

## ACKNOWLEDGMENTS

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## PREFACE

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On 26 September 2018, the United Nations General Assembly will convene presidents and prime ministers at the first ever High-Level Meeting (HLM) on TB. The HLM will conclude with UN member states' approval of a concise and action-oriented political declaration on TB. The HLM is more than just a meeting, and the political declaration is more than just a document.

Together, the commitments they formalise hold the power to catalyse the action we need to end this epidemic preying on society's most vulnerable members: children. The HLM on TB presents a historic opportunity. Our hope and our intention is that this report will persuade leaders of UN member states to use their political power and resources to end the silent epidemic of TB among children.



## EXECUTIVE SUMMARY

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The right to equal access to healthcare is enshrined in international human rights agreements, including the Convention on the Rights of the Child, the European Convention on Human Rights, the American Convention on Human Rights, and the African Charter on Human and Peoples' Rights. Yet children are being made to suffer from an epidemic of TB — an airborne, communicable disease that is often fatal without treatment.

Child TB is a silent epidemic — one that impacts children mostly too young to advocate for themselves. The best available data show an estimated one million children under the age of 15 become sick with TB each year. Of those, 239,000 — nearly one in four — die. Children with TB rarely die when they receive standard treatment for the disease, but 90 percent of children who die from TB worldwide went untreated. This widespread neglect means the loss of a million children every four years, creating trauma for the families they leave behind.

This massive toll of deaths among children results from systematic disregard for children's rights to health. Within global public health, it is an open secret that health systems neglect children with TB because children are less contagious than adults (stopping the spread of TB is a priority), and because the standard tools used to diagnose TB work less well in children.

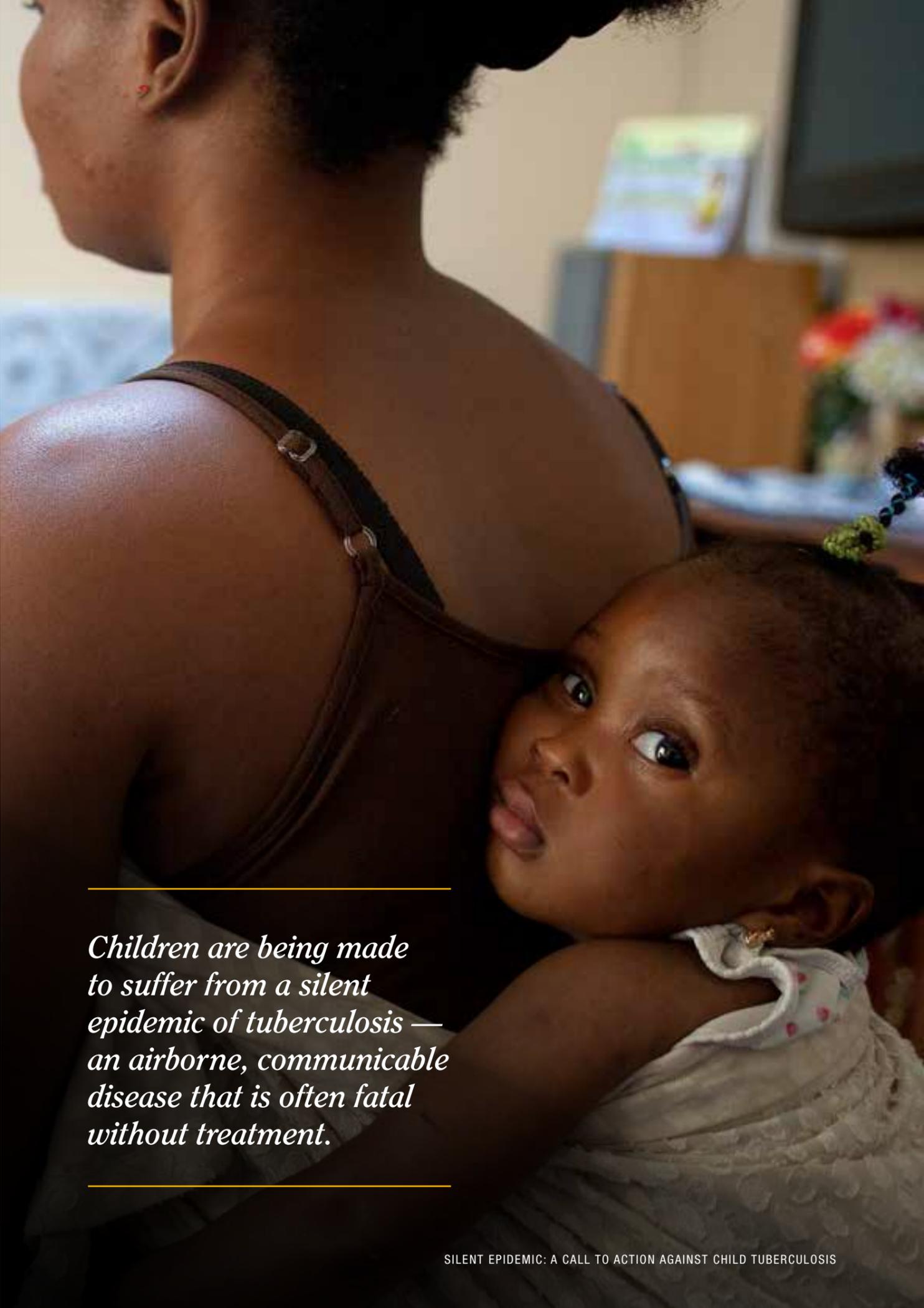
This neglect can no longer be excused on grounds of economy or expediency. TB is preventable, treatable and curable. Multiple international agreements state that equal access to medical care is a basic human right, along with the right to enjoy the highest level of personal health possible. These treaties are considered legally binding on all signatory nations. The continuing medical neglect of child TB, resulting in millions of avoidable deaths, constitutes a human rights violation by any reasonable measure.

Over the last two decades, legal activists have effectively used human rights law to make healthcare provision more equitable, regardless of social, economic, ethnic, cultural, or other special status. Precedents from national courts and international tribunals, including the Committee on the Rights of the Child, the European Court of Human Rights (ECHR), and the African Court on Human and Peoples' Rights (AFCHPR) have compelled governments to ensure the delivery of TB treatment. These cases show that in some circumstances, systems of justice can compel governments to provide TB care to children.

Ending the child TB epidemic requires local interventions, sensitive to social and cultural context, to reach at-risk children using simple tools for active screening and diagnosis. Even in resource-limited areas, projects like DETECT Child TB are demonstrating that medical professionals can be equipped with the knowledge and tools to diagnose and treat TB in children, with access to care provided at the community level. Screening households where an adult is diagnosed with TB to see if children have been exposed in the home must become the standard implemented everywhere. Where The Union has piloted this approach in Uganda, 72 percent of at-risk children were able to receive preventive TB treatment, up from less than five percent previously.

In the long run, greater investment in research and development needs to deliver better diagnostics, treatments and an effective vaccine that prevents TB. To be a success, the UN HLM on TB in September 2018 needs to generate concrete action, where governments are held accountable for achieving time-bound targets, for investing in new research and delivering the care to which all children with TB have a fundamental right.

To download this report in full go to [ChildTB.theunion.org](https://ChildTB.theunion.org)



*Children are being made to suffer from a silent epidemic of tuberculosis — an airborne, communicable disease that is often fatal without treatment.*

# INTRODUCTION

## The widespread neglect of children with TB constitutes a human rights violation that demands urgent attention from the international community.

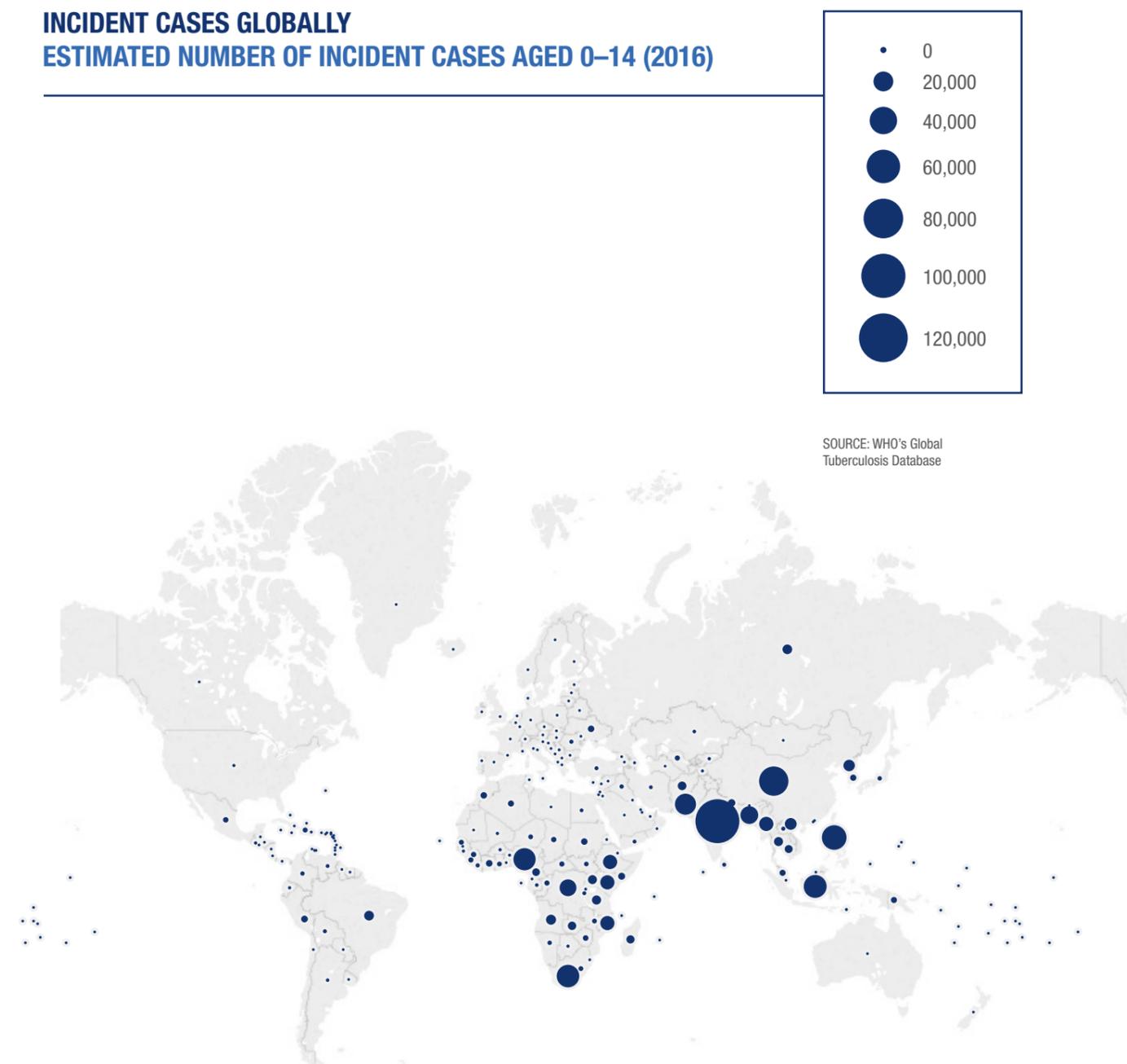
The right to equal access to healthcare is enshrined in international human rights agreements, including the Convention on the Rights of the Child, the European Convention on Human Rights, the American Convention on Human Rights, and the African Charter on Human and Peoples' Rights. Legal remedies should be a last resort, however, as timely action from both developing and donor countries can save millions of lives. At the same time recent precedents, including cases decided in national courts, have made it easier for legal activists to use human rights law to redress unequal access to healthcare.<sup>1,2</sup>

Children are particularly vulnerable to TB. Children with TB are at high risk of developing severe forms of the disease and at high risk of dying — especially infants and children under five years of age. Furthermore, strong evidence of the effectiveness of TB prevention and treatment in children has been available for decades. However, in most countries affected by TB a substantial gap remains between policy guidelines, based on international and national recommendations, and actual practice.

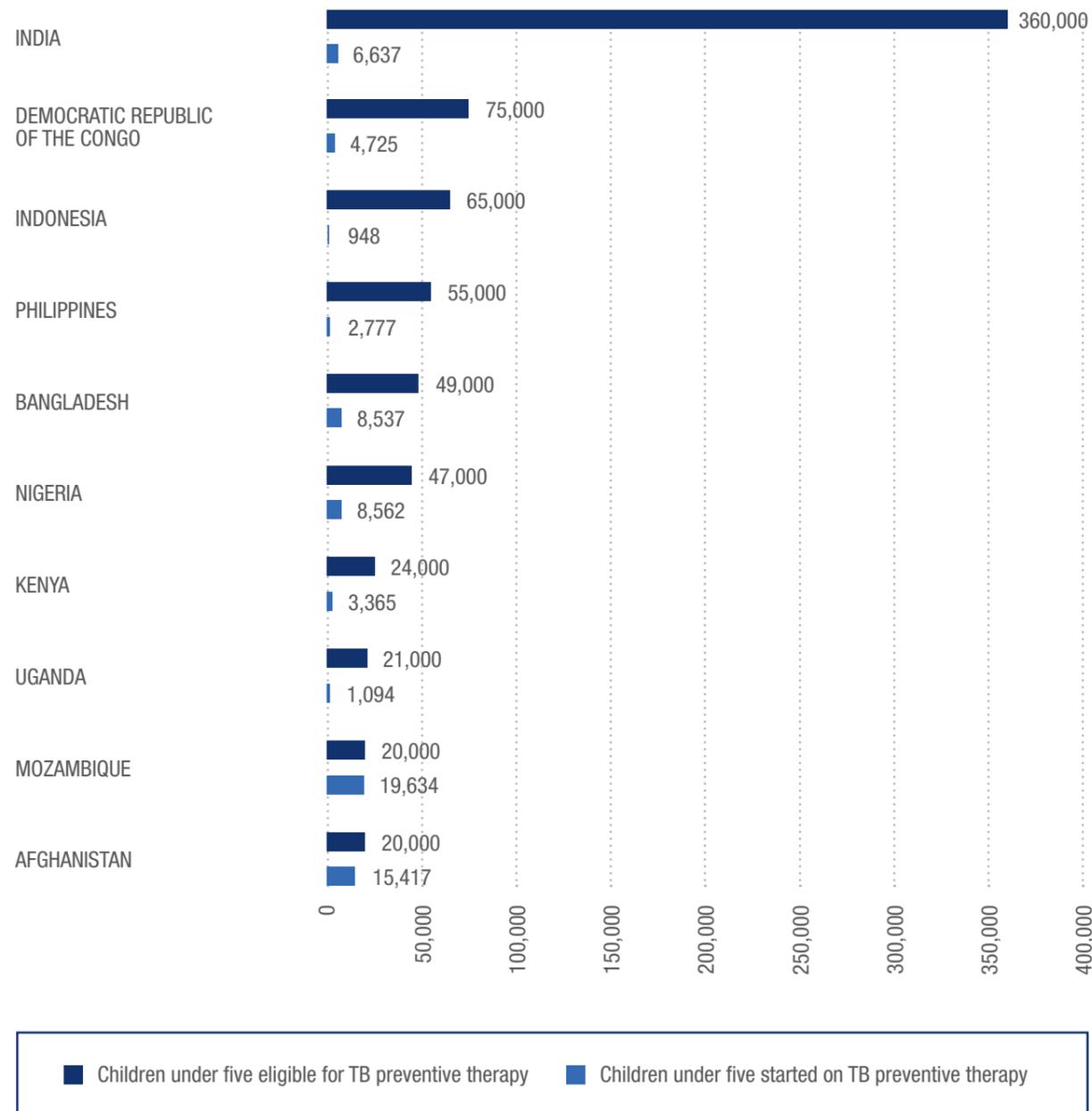
One major reason for this long-standing neglect is that children with TB, especially young children, are much less likely to be contagious than adolescents or adults with the disease.<sup>3,4,5</sup> But if not detected and treated, they are more likely to develop severe disease and die. According to new research, around a million children worldwide develop active TB and 239,000 die every year, representing one in seven of all TB-related deaths.<sup>6</sup> Children with TB die from the disease at disproportionate rates compared with adults, representing 10 percent of TB incidence\* but 16 percent of TB deaths globally.<sup>7,8</sup> The burden of child TB is highest in low- and middle-income countries, where children may represent over a fifth of all cases.<sup>9,10</sup> Immature immune systems make children more likely to develop severe forms of the disease, such as TB meningitis, disseminated TB, and TB of the bones and joints.

\* Incidence is the number of new cases in a given year.

## INCIDENT CASES GLOBALLY ESTIMATED NUMBER OF INCIDENT CASES AGED 0–14 (2016)



## CHILDREN ELIGIBLE FOR AND STARTED ON TB PREVENTIVE THERAPY TOP 10 COUNTRIES BY NUMBER ELIGIBLE



SOURCE: WHO's Global Tuberculosis Database

Most TB-related deaths in children occur in young children who have not been diagnosed or treated, representing a missed opportunity for prevention.<sup>11</sup> The burden of multidrug-resistant TB (MDR-TB) in children is still largely unknown but it is estimated that less than 10 percent of all children with MDR-TB are detected and treated.<sup>12</sup> As child mortality overall has fallen in many countries over the last 20 years, the continued neglect of TB in children has resulted in TB now being one of the major infectious diseases causing death in children globally, despite it being treatable and preventable. TB also has profound indirect consequences on child health as children are commonly orphaned or suffer the consequences of increasing poverty due to catastrophic costs to the family or household that are often associated with having TB.

Ending neglect of TB in children calls for more integrated, family-centred approaches to TB care and prevention, as well as engagement with the wider health sector including the maternal and child health sectors. Furthermore, there is major potential to make much more progress with the low-cost tools that we possess, including child contact screening and management — the standard of care in high-income, low TB burden countries, but which is rare in TB endemic countries. Contact screening requires a health worker to determine if any TB patient has contacts in the home, workplace, or even social environments, which are at risk of becoming infected with TB due to their proximity to the patient. A programme in the resource-limited, high TB-burden setting of Uganda has proven successful in increasing the detection of children with TB while, at the same time, dramatically increasing the numbers of children — who have been exposed to TB — receiving TB preventive therapy, with services delivered to whole families within their own communities.

The fight against TB has reached a critical turning point. A concerted effort by the global public health community helped save more than 50 million lives from TB between 2000 and 2016, as global incidence\* fell by a third and the annual death toll fell by almost half over the same period.<sup>13, 14</sup> However, far

greater efforts are required to end the global TB epidemic. The global End TB Strategy adopted in 2015 provided an unprecedented opportunity for the global health community to finally end the long-standing neglect of TB in children — but children with TB continue to be neglected in large numbers.

Above all, ending the epidemic of child TB requires political will and, in this respect too, the fight against TB is at a turning point. On 26 September 2018, the United Nations will convene the first HLM on TB where heads of state and government will, for the first time ever, issue a political declaration on global TB. The political commitments that will be enshrined in this declaration have the potential to dramatically change the trajectory of the epidemic. The political commitments secured at previous UN HLMs on HIV/AIDS, non-communicable diseases and antimicrobial resistance have accelerated the response to those other global health challenges. The HLM on TB provides a historic opportunity to galvanise support for ending the child TB epidemic.

*We must seize the opportunity. Millions of young lives hang in the balance.*

\* TB incidence is the number of people who develop TB each year.

# THE NEGLECT OF CHILD TB

Medical neglect of child TB has long been a generally acknowledged fact.<sup>15</sup> Paediatric TB screening and treatment have improved greatly in the developed world, but neglect of child TB remains common in low- and middle-income countries, reflecting the special pathology of TB in children.<sup>16, 17, 18, 19</sup> In contrast to adults with active TB, children tend to have 'pauci-bacillary TB', meaning there are relatively few bacteria in the patient's body, making them both less contagious and harder to diagnose. The bacteria are less likely to show up in sputum samples, further complicated by young children's difficulty producing sputum, yielding false negatives using the common acid-fast bacteria smear method. Children are less likely to develop lung lesions that show up on X-rays, and tests using fluid aspirated from the stomach can be inaccurate and difficult to perform.<sup>20, 21</sup>

Because their bacterial burden is lower, children with TB are also less infectious than sick adults, prompting healthcare providers in many countries to classify them as lower priority.<sup>22, 23, 24</sup> But a policy of triage or rationing in this way only puts distance between vulnerable children and the care they need. Furthermore, a survey of 29 high-burden countries by Médecins sans Frontières (MSF) found just five countries were widely implementing child-friendly fixed dose combination therapy for TB as the standard of care<sup>25</sup> while, according to the World Health Organization (WHO), just 13 percent of children eligible for preventive treatment with isoniazid receive it globally.<sup>26</sup> However, children respond well to commonly used treatments, with less than one percent mortality among children treated for TB (rising to 13 percent for children with MDR-TB) suggesting nearly all TB deaths among children are preventable with appropriate action.<sup>27, 28</sup>

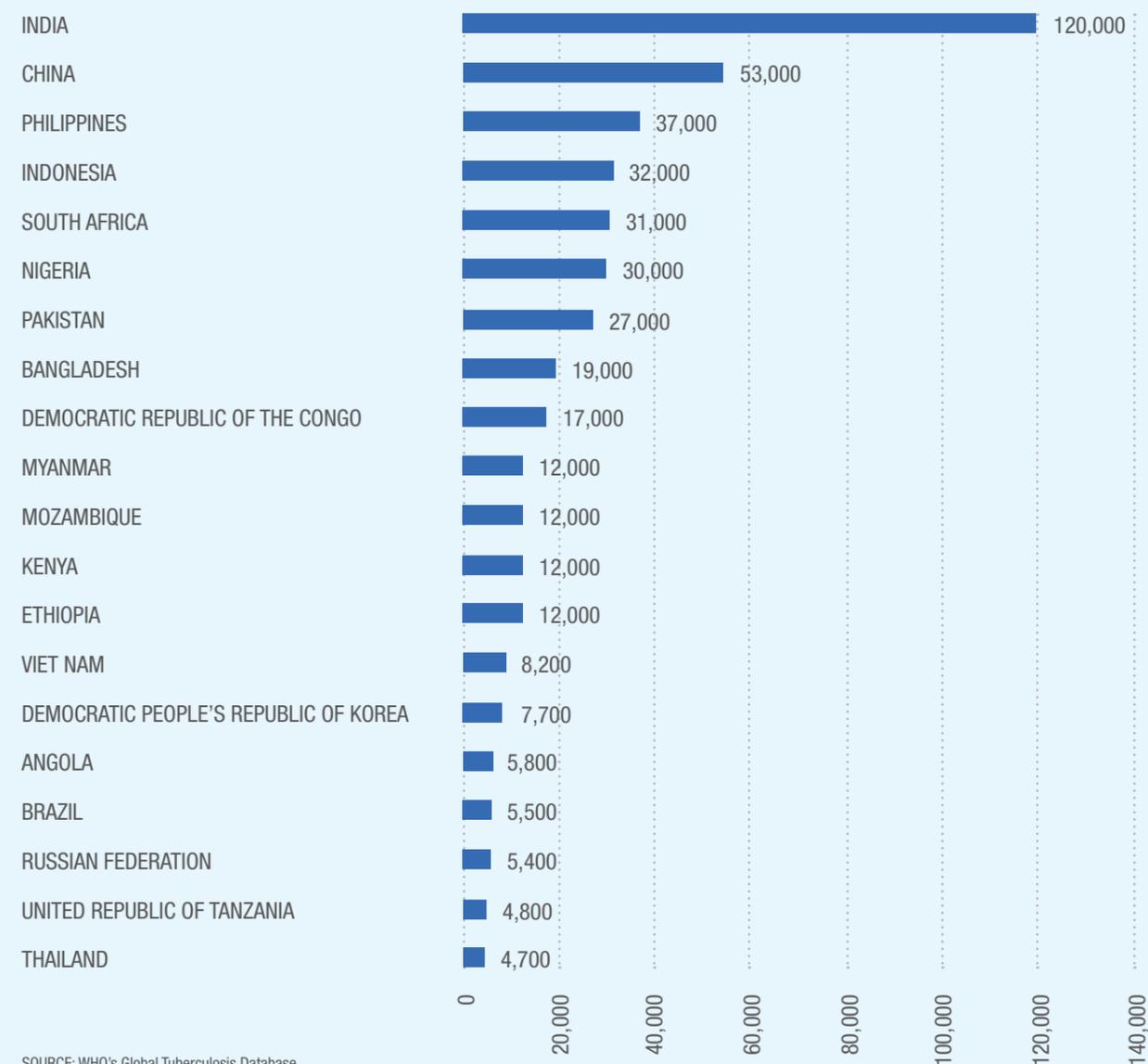
Beyond the tragic loss of life, the continued neglect of paediatric TB is dangerously shortsighted as individuals who have been infected with TB bacilli in childhood may still grow into sick, infectious adults, worsening the long-term burden of the disease and undermining efforts to eliminate it.<sup>29</sup>

*Children with TB are also less infectious than sick adults, prompting healthcare providers in many countries to classify them as lower priority.*



Children respond well to commonly used treatments, with less than one percent mortality among children treated for TB (rising to 13 percent for children with MDR-TB) suggesting most deaths are preventable with appropriate action.

## NUMBERS OF CHILDREN WHO BECAME SICK WITH TB (2016): TOP 20 COUNTRIES (ESTIMATED NUMBER OF INCIDENT CASES AGED 0-14)



SOURCE: WHO's Global Tuberculosis Database



## WHAT IS TB?

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*Adapted from World Health Organization: What is TB?  
How is it Treated?*

TB is an infectious disease caused by the bacterium *Mycobacterium tuberculosis*. While it typically affects the lungs, it can affect virtually any part of the body. TB spreads from person to person through the air when someone sick with the disease coughs, sneezes or spits. Another person needs only to inhale a few of these germs in order to become infected. Key symptoms include cough, fever, night sweats and weight loss, which can sometimes occur over many months.

While TB is treatable and curable in most cases, without proper treatment up to two-thirds of people with TB will die.

TB is treated with a cocktail of multiple antibiotics taken over the course of at least six months, though multidrug-resistant cases require treatment for up to two years. About a third of the world's population carries a latent TB infection.

Typically, each person infected with TB has a 10 percent chance of progressing to TB disease within his or her lifetime.

People with compromised immune systems — often caused by HIV, malnutrition, age, diabetes, or who use tobacco — regularly have a much higher risk of developing TB disease.



## THREATS NEW AND OLD

A number of factors are contributing to the spread of active TB among children and adults alike. Despite broad progress in the last few decades, the emergence of MDR-TB and continued prevalence of HIV, have combined with social and lifestyle factors such as smoking, diabetes and accelerating urbanisation, to threaten a renewed epidemic. Due to their special status as dependents, these trends affect children both directly and indirectly, via adult caregivers.

Co-infection with HIV and TB remains the biggest driver of mortality among people with HIV of all ages, with TB accounting for 39 percent of AIDS-related deaths in 2015.<sup>30</sup> Currently there are approximately 3.4 million children living with HIV and 14 million individuals, of all ages, co-infected with HIV and TB, most in the developing world.<sup>31,32</sup> Foetuses and newborns are susceptible to maternal transmission of both diseases, while children orphaned by AIDS or TB are challenged in seeking medical attention and adhering to drug regimens.<sup>33,34</sup> WHO estimates there are 16.5 million children orphaned by the loss of one or both parents to HIV and 9.7 million orphaned by TB.<sup>35,36</sup>

Tobacco consumption is strongly correlated with development of active TB, accounting for over a fifth of global TB incidence, as well as recurrence.<sup>37,38,39</sup> Currently, 1.1 billion people around the world smoke tobacco, up from 721 million in

1980, with most of this increase in the developing world. Around 40 percent of children are exposed to second-hand smoke at home and 6.6 percent of African children are smokers themselves, as are some 625,000 Indian children aged 10-14 years.<sup>40,41,42</sup> Globally, WHO estimates that between 80,000 and 100,000 children become smokers every day, most of them living in Asia.<sup>43</sup>

Type 2 diabetes increases the risk of developing active TB threefold, as well as raising the risk of relapse.<sup>44,45</sup> Global prevalence of type 2 diabetes almost doubled from 4.7 percent in 1980 to 8.5 percent in 2014, due in large part to changing diets and increasingly sedentary lifestyles in the developing world.<sup>46</sup> The number of children diagnosed with type 2 diabetes has also increased, representing almost half of all new diabetes diagnoses among children.<sup>47</sup>

Finally, rapid urbanisation is also contributing to the spread of TB. The proportion of the world's population living in urban areas increased from 40 percent in 1980 to 54 percent in 2015, and a further increase of two-thirds is expected by 2050.<sup>48</sup> The trend is led by the developing world<sup>49</sup> where unlicensed building remains common due to weakness in state authority.<sup>50,51</sup> In many cases, unregulated habitations lack adequate ventilation and sanitation, providing breeding grounds for TB, which spreads from person to person through the air.<sup>52,53</sup> The numbers of people living in slums will more than double to three billion by 2050<sup>54</sup> — a special concern as most children with TB contract the disease from family members in a household setting.<sup>55</sup>

9.7M

9.7 million children are orphaned by TB.

625k

625,000 Indian children aged 10-14 years are smokers.

3B

The number of people living in slums will more than double to three billion by 2050.

## THE HUMAN RIGHTS IMPERATIVE

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The continuing medical neglect of child TB, resulting in millions of avoidable deaths, constitutes a human rights violation by any reasonable measure. Multiple international agreements state that equal access to medical care is a basic human right, along with the right to enjoy the highest level of personal health possible. These treaties are considered legally binding on all signatory nations. Furthermore, many signatories have passed laws to bring their national constitutions into alignment with these international obligations. Set out below is a digest of key treaties with specific articles and addenda that formalise children's rights and health as a human right.



**CONVENTION ON THE RIGHTS OF THE CHILD (CRC)<sup>56</sup>**  
**Committee on the Rights of the Child**

**ARTICLE 6**

States Parties shall ensure, to the maximum extent possible, the survival and development of the child.

**ARTICLE 24**

States Parties should recognise the right of the child to the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such healthcare services... States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures to: (a) diminish infant and child mortality... (c) combat disease and malnutrition, including within the framework of primary healthcare and, among other things, the application of readily available technology.

**COMMENT 4.4 (B)**

Accessibility. Health facilities, goods and services should be known and easily accessible (economically, physically and socially) to all adolescents, without discrimination.

**COMMENT 5.8**

Whatever their economic circumstances, states are required to undertake all possible measures towards the realisation of the rights of the child, paying special attention to the most disadvantaged groups. In case of any conflict in legislation, predominance should always be given to the Convention, in the light of article 27 of the Vienna Convention on the Law of Treaties, while only states are party to the Covenant and thus, ultimately, accountable for compliance with it. All members of society and individuals, including health professionals, families, local communities, inter-governmental and non-governmental organisations and civil society organisations, as well as the private business sector, have responsibilities regarding the realisation of the right to health...

**COMMENT 15 (IIB)**

In order to fully realise the right to health for all children, State Parties have an obligation to ensure that children's health is not undermined as a result of discrimination, which is a significant factor contributing to vulnerability. Children in disadvantaged situations and under-served areas should be a focus of efforts to fulfil children's right to health. (IIIA): Children are entitled to quality health services, including prevention, promotion, treatment, rehabilitation and palliative care services. At the primary level, these services must be available in sufficient quantity and quality, be functional, be within the physical and financial reach of all sections of the child population, and be acceptable to all.

**INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL, AND CULTURAL RIGHTS (ICESCR)<sup>57</sup>**  
**Committee on Economic, Social and Cultural Rights**

**ARTICLE 12.1**

States Parties to the present Covenant recognise the right of everyone to the highest attainable standard of physical and mental health.

**ARTICLE 12.2**

(a) the provision for the reduction of the still born rate and infant mortality, and for the healthy development of the child... (c) the prevention, treatment and control of epidemic, endemic, occupational and other diseases; (d) the creation of conditions which would ensure access to all medical services and medical attention in the event of illness.

**ARTICLE 15.1: (B)**

to enjoy the benefits of scientific progress and its applications...

**COMMENT 14**

...access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalised groups; the provision of essential drugs, as defined according to the World Health Organization's Action Programme on Essential Drugs; equitable distribution of all health facilities, goods and services; adoption and implementation of a national public health strategy and plan of action that is based on epidemiological evidence, and which addresses the health concerns of the whole population...

**COMMENT 14.12: (B)**

non-discrimination: health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalised sections of the population, in law and in fact, without discrimination on any of the prohibited grounds...

**COMMENT 14.17**

...provision of equal and timely access to basic preventive, curative, and rehabilitative health services and health education; regular screening programmes; appropriate treatment of prevalent diseases, illnesses, injuries and disabilities, preferably at community level; the provision of essential drugs; and appropriate mental health treatment and care.

**COMMENT 14.22: ARTICLE 12.2 (A)**

...outlines the need to take measures to reduce infant mortality and promote the healthy development of infants and children. Subsequent international human rights goals recognise that children and adolescents have a right to the highest standard of health, as well as access to facilities, in the treatment of illness.

**1996 REVISED EUROPEAN SOCIAL CHARTER (ESCR)<sup>58</sup>**  
European Committee of Social Rights

**ARTICLE 1.11**

Everyone has the right to benefit from any measures that enable him to enjoy the highest possible standard of health attainable.

**ARTICLE 7**

Children and young people have the right to a special protection against the physical and moral hazards to which they are exposed.

**ARTICLE 11.3**

...to prevent as far as possible epidemic, endemic and other diseases...

**ARTICLE 13.1**

...to ensure that any person who is without adequate resources and who is unable to secure such resources — either by his own efforts or from other sources, in particular through benefits under a social security scheme — be granted adequate assistance and, in case of sickness, the care necessitated by his condition...

**ARTICLE 17**

Mothers and children, irrespective of marital status and family relations, have the right to appropriate social and economic protection.

**AMERICAN DECLARATION OF THE RIGHTS AND DUTIES OF MAN (ADDDM)<sup>59</sup>**  
Inter-American Court of Human Rights

**ARTICLE VII.**

All women, during pregnancy and the nursing period, and all children have the right to special protection, care and aid.

**ARTICLE XI.**

Every person has the right to the preservation of his or her health through sanitary and social measures relating to food, clothing, housing and medical care, to the extent permitted by public and community resources.

**INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS (ICCPR)<sup>60</sup>**  
Human Rights Committee

**ARTICLE 24.1**

Every child shall have, without any discrimination as to race, colour, sex, language, religion, national or social origin, property or birth, the right to such measures of protection as are required by his or her status as a minor, on the part of his family, society and the state.

**AMERICAN CONVENTION ON HUMAN RIGHTS (ACHR)<sup>61</sup>**  
Inter-American Court of Human Rights

**ARTICLE 19**

Every child has the right to the measures of protection, required by his condition as a minor, on the part of his family, society and the state.

**ADDITIONAL PROTOCOL 10.1**

Everyone shall have the right to health, understood to mean the enjoyment of the highest level of physical, mental and social well-being.

**ADDITIONAL PROTOCOL 10.2**

a) primary healthcare, which is also essential healthcare, is made available to all individuals and families in the community; (b) extension of the benefits of health services to all individuals subject to the state's jurisdiction; (c) universal immunisation against the principal infectious diseases; (d) prevention and treatment of endemic, occupational and other diseases; (e) education of the population on the prevention and treatment of health problems, and (f) fulfilment of the health needs of the highest risk groups and of those whose poverty makes them the most vulnerable.

**ADDITIONAL PROTOCOL 14.1: (B)**

to enjoy the benefits of scientific and technological progress...

**AFRICAN CHARTER ON HUMAN AND PEOPLES' RIGHTS (ACHPR)<sup>62</sup>**  
African Court on Human and Peoples' Rights

**ARTICLE 13.2**

Every citizen shall have the right of equal access to the public services of his country.

**ARTICLE 16.1**

Every individual shall have the right to enjoy the best attainable state of physical and mental health.

**ARTICLE 16.2**

States Parties to the present charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are ill.

**ARTICLE 18.3**

The state shall ensure the elimination of every discrimination against women and ensure the protection of the rights of women and children as stipulated in international declarations and conventions.

Beyond the basic right to healthcare, these international agreements also emphasise additional overlapping obligations on the state and private sector alike, including mandates to measure and report diseases, reach underserved populations — notwithstanding cultural, ethnic, or regional differences — protect the rights of women within the family, and ensure the rights of prisoners and others in state custody to judicial intervention. The treaties state the obligation of signatory countries to pass domestic laws to give weight to these promises and emphasises that the treaties prevail over existing laws in case of conflict.

## A PRECEDENT FOR LEGAL ACTION

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Over the last two decades, legal activists have effectively used human rights law to make healthcare provision more equitable, regardless of social, economic, ethnic, cultural, or other special status. Legal precedents have further reinforced the right to medical treatment in areas including children's health, women's reproductive health, chronic (non-infectious) disease and palliative care.<sup>63</sup>

Unsurprisingly, many of the precedents concern HIV treatment, reflecting the pioneering role of activists in HIV-AIDS treatment. In 2002, the constitutional court of South Africa ordered the government to implement a national programme to reduce maternal transmission of HIV through the provision of antiretroviral treatment.<sup>64</sup> In 2004, the constitutional courts of Peru and Argentina ruled that the state had to provide HIV treatment to poor individuals, regardless of the cost to the state.<sup>65,66</sup> In 2010, Bolivia's constitutional tribunal ruled that the government was obliged to provide HIV medication to children of poor families.<sup>67</sup>

The same imperatives also compel the treatment of TB — as affirmed by precedents from national courts and international tribunals, including the Committee on the Rights of the Child, the European Court of Human Rights (ECHR), and the African Court on Human and Peoples' Rights.<sup>68</sup>

Judgements by the ECHR have required signatory states to provide treatment for TB in cases involving minors in state custody, with disabilities and to those with co-infection with HIV. At the national level, Argentina's Supreme Court ruled in 2007 that the government had to treat members of the Toba, a marginalised aboriginal group, for TB. This was based, in part, on Argentina's obligations under human rights treaties as well as the national and provincial constitutions. In 2008, Colombia's Supreme Court of Justice held that the state was required to treat an indigent woman for active TB, warning that, 'disregarding this obligation would constitute a violation of fundamental rights'. In 2010, an Indian court condemned the death of a 16-year-old, who was in state custody, by deliberate medical neglect of TB as 'gross and of a magnitude to shock the conscience of the court'.<sup>69</sup>

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*Over the last two decades, legal activists have effectively used human rights law to make healthcare provision more equitable.*

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## DEVELOPMENT PERSPECTIVES

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In addition to the moral obligation of governments and societies to safeguard the health of children, broadly recognised in treaties and law, there are sound economic reasons for tackling child TB. Properly supervised development is critical to securing improved public health in the long-term, and even marginal decreases in child mortality can have substantial positive impacts on long-term economic growth.

Development is broadly correlated with lower child mortality and new research shows that decreasing child mortality actively contributes to economic growth.<sup>70</sup> Regional studies have addressed the correlation between reduced child mortality and economic growth in Africa and Asia.<sup>71,72</sup> Meanwhile, TB's economic toll is well established with WHO tallying US \$12 billion per year of lost economic productivity, as well as US \$9.2 billion in treatment and control costs, around the world. Another study calculates that TB costs African countries an average of three percent of their GDP growth annually<sup>73</sup> and economists estimate that, globally, a 10 percent increase in TB incidence is correlated with a 0.2–0.4 percent decrease in economic growth.<sup>74</sup>

The cost of TB treatment is affordable and, with widely available generic TB drugs, is roughly the same as other life-threatening diseases and far less than the growing burden of chronic disease among adult populations. In 2014 the average cost of treating ordinary (non-MDR) TB in low-income countries was US \$258 per patient.<sup>75,76</sup> Comparably, treatment for HIV costs an average of US \$136.8 per patient annually across low-income countries, increasing up to US \$208 in five high-burden African countries and at least US \$257 in Uganda.<sup>77,78,79</sup> Life-saving treatment for an episode of severe malaria costs an average of US \$150 in East Asia.<sup>80</sup> By contrast, in-patient hospitalisation for cardiovascular disease, soaring among adult populations, costs a minimum per hospitalisation of US \$455 and an average of US \$8,800 worldwide.<sup>81</sup> Given the impact that universal access to TB treatment would have on society, the World Bank and the Copenhagen Consensus have pointed to TB elimination as a best buy in global public health and international development, respectively.<sup>82,83</sup>

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*Even marginal decreases in child mortality can have substantial positive impacts on long-term economic growth.*

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## TECHNICAL ADVANCES AND NEW MODELS

Patients, lawyers, and public health activists have laid the groundwork for a robust defence of children’s human rights in the area of healthcare, but swift voluntary action is clearly preferable to drawn-out legal proceedings.<sup>84, 85</sup> Fortunately, a number of technical advances in the last few years hold out the promise of greatly reduced child TB mortality, by making it easier and less costly to screen, diagnose and treat children with TB.

Household contact screening, typically performed by frontline health workers, has been shown to increase the number of TB diagnoses by nearly two-thirds in developing countries.<sup>86</sup> In household contact screening, health workers determine if there are children who have been exposed to TB, then assess those children for TB signs and symptoms. Household contact screening of children has yielded increases up to tenfold in the number of eligible children who receive preventive treatment with the drug isoniazid, generally considered the most cost-effective intervention.<sup>87, 88</sup>

Recent research advances also point to a breakthrough in TB prevention. In March 2018, researchers with the AIDS Clinical Trials Group, funded by the United States National Institutes of Allergy and Infectious Diseases, demonstrated in a large, international Phase 3 clinical trial that a one-month long regimen of daily doses of the drugs rifapentine and isoniazid was at least as safe and effective at preventing TB in people living with HIV as the standard nine-month regimen using isoniazid. Patients in the trial, which included adults and adolescents, were also more likely to adhere to the full course of treatment than patients taking the standard nine-month regimen. If used widely and shown to be similarly effective in children, the regimen has the potential to transform global TB prevention efforts.

In the meantime, even in resource-limited settings medical professionals can make better use of diagnosing children with TB based on their pattern of symptoms — known as a clinical approach to diagnosis.

### CHILD-FRIENDLY TREATMENTS

Flavoured child-friendly treatments, dispersible in liquid, and in WHO-approved doses, were developed and made widely available by the TB Alliance and Unitaid in 2015.<sup>89, 90</sup> In the area of diagnosis, the Xpert MTB-RIF assay test, endorsed by WHO in 2010, uses nucleic acid amplification in a small machine, and GeneXpert detects TB, as well as resistance to rifampicin — one of the most commonly used TB drugs — in less than two hours. Cepheid, its manufacturer, is expected to introduce a battery-powered version of GeneXpert, called Omni, enabling wider testing in areas without reliable sources of electricity.<sup>91</sup> This is a welcome step forward in moving TB diagnosis to the place at which patients receive care, but since the technology tests samples of sputum, it remains inadequate for diagnosing TB in children.<sup>92</sup> The “holy grail” of TB diagnosis in children remains a non-sputum-based biomarker test, such as a blood- or urine-based test, that is delivered at the point of care.



## THE UNION'S DETECT TB PROJECT

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One effective public health approach implemented in Uganda by The Union identifies children who have been exposed to someone with TB — typically an adult — who has sought care at the local health centre. These children are typically living in households where an adult has been diagnosed with TB, and are diagnosed by health professionals using a clinical approach. Working with partners, including Uganda's Ministry of Health and local government officials, the Decentralise Tuberculosis services and Engage Communities to Transform lives of Children with Tuberculosis (DETECT Child TB) project created a decentralised model for diagnosing and treating children with TB. This model uses online training and a mobile smartphone app to educate and empower frontline health workers to provide TB screening at the community level, with volunteers identifying likely TB cases based on symptoms.

Strengthening diagnosis of child TB at primary and secondary care levels with simple symptom-based screening for child TB household contacts, yielded a major increase in detection and treatment of child TB. Where children made up nine percent of all TB notifications in Uganda before DETECT Child TB, they represented 16 percent of total cases diagnosed during the initiative, with both test districts more than doubling their total number of child TB diagnoses over this period. The initiative achieved 95 percent success in treating children diagnosed with TB, up from 65 percent, and on larger numbers, while 72 percent of at-risk children received preventive treatment with isoniazid, up from less than five percent previously. Following implementation, case detection was successfully decentralised with the majority of children with TB diagnosed in secondary and primary levels of care.

As a result of the initiative, the majority of children diagnosed with TB in these districts are now diagnosed at village health centres and other peripheral health facilities, rather than in large hospitals, catching the disease earlier and lessening the burden on large, and often more physically distant, health facilities. The initiative also resulted in lower rates of people 'lost to follow up', helping to ensure that patients completed their treatment regimens, and decreasing mortality as well as the risk of new drug resistance. Additionally, a spillover effect saw more adults with TB identified based on symptoms, reflecting the increased knowledge and confidence of healthcare workers.

The initiative's success prompted Uganda's Ministry of Health to incorporate the DETECT guidelines into the country's national TB action plan and the ministry is currently scaling up the programme to include eight more districts.<sup>93</sup> Looking beyond Uganda, this, or similar community-based approaches, could benefit other high-burden countries facing similar challenges including large underserved populations, rapid unplanned urbanisation and adverse social trends.



# NEXT STEPS

Decentralised screening strategies such as DETECT hold promise. But eliminating child TB will require an integrated model combining innovative public health interventions with new technology, research and development for improved, child-friendly diagnostic techniques and treatments and, above all, sustained effort from high-burden and donor countries alike. Achieving these goals, in turn, calls for political leadership and support at the highest levels. Key objectives for controlling child TB must include strengthening:

## POLITICAL LEADERSHIP

- **The United Nations is preparing to issue its first ever high-level political declaration on TB on 26 September 2018.** Past high-level political statements have been instrumental in spurring action on health threats including HIV, non-communicable diseases and antimicrobial resistance. The forthcoming declaration should adopt the recommendations of the Stop TB Partnership, calling for member states to establish inter-ministerial task forces to combat child TB by 2019; setting a goal of 90 percent of at-risk children receiving preventive therapy and 90 percent of children with active TB or MDR-TB receiving diagnosis and treatment by 2022; and calling for new commitments from member states to research child-friendly diagnostics, treatments and an improved vaccine.<sup>94</sup>

## SYSTEMS OF JUSTICE

- **Appeal to the legal system.** Children have a human right to TB prevention, treatment and care, guaranteed by a host of conventions, treaties and laws. While using legal measures should usually be a last recourse for forcing government action, precedent shows courts have upheld individuals' rights to life-saving medical treatment for HIV, TB and other health conditions.
- **Place the global TB response on a human-rights foundation.** The political declaration to be approved at the UN High Level Meeting on TB must declare human rights as the foundation of the global TB response. The Convention on the Rights of the Child must become the guiding framework for the global response to child TB.

## TB SCREENING AND DIAGNOSIS

- **Universally implement TB contact screening** in order to identify all children who have been in close contact with people with TB. Contact screening is a simple, common sense strategy for discovering child TB cases that otherwise go undiagnosed. Whenever an adult is diagnosed with TB, healthcare workers should immediately find out if there are any children in the household and arrange for additional screening.<sup>95</sup>
- **Use clinical diagnosis** i.e. diagnosis made on the systematic evaluation of symptoms of TB in children. Highly effective, low-cost tools are already available for screening and diagnosis of child TB, with trained volunteers identifying child TB cases based on symptoms such as cough, fever and weight loss. This simple technique is easily taught, empowering community-level workers to provide active screening of at-risk children in resource-challenged areas.
- **Combine clinical diagnosis with wider use of diagnosis with rapid molecular techniques** in cases where children have pulmonary TB and can produce sputum. New technology such as the Xpert Ultra MTB/RIF can provide faster, more accurate diagnosis of TB, often catching cases missed by the common smear technique or microscopy; results are typically available within two hours.<sup>96</sup> A battery-powered version of Xpert is in development.

## TB PREVENTION AND TREATMENT

- **Treat accumulative 3.5 million children with TB by 2022, using child-friendly drug regimens.** Cost-effective child-friendly treatment became available in 2015 and approximately 80 countries have since ordered these improved medicines. However, access has been delayed in some priority countries, in part due to bureaucratic and procedural hurdles at the national level — for example, unrealistic local procurement quotas or redundant in-country safety studies. Streamlining and simplifying national regulations should lead to wider adoption.<sup>97</sup>
- **Ensure access to preventive treatment.** Healthcare providers have long recognised preventive treatment with medications as the most cost-effective means of reducing TB prevalence. However, existing preventive therapies remains underutilised in the developing world, due, in part, to failure to implement rigorous TB screening systems and the lack of knowledge of preventive treatments among health workers, as well as concerns about shortages.<sup>98, 99, 100</sup> Better screening, educating health workers and ensuring adequate supplies should help bring about wider adoption of TB prevention.
- **Pursue prevention with short-course therapy.** Based on the results of recent research that demonstrated a one-month course of rifapentine and isoniazid was at least as effective and safe as the standard nine-month course of isoniazid for preventing TB in adults and adolescents living with HIV, the use of the shorter regimen should be tested in children. A shorter TB prevention regimen holds huge potential promise for preventing TB in children with far less burden on children, families and health systems.
- **Build capacity.** Combating TB and other infectious diseases requires strengthening healthcare provision nationally and locally, including training of staff at every level of the healthcare network and decentralising services, as far as possible, to the community. In the model employed by The Union in Uganda, village-level volunteers provide active contact screening of children in households of adults with active TB, using simple clinical criteria. It also calls for the establishment of clinical supervision, monitoring and evaluation to establish baselines and track progress against targets (it is worth noting that TB in children represents recent transmission, so accurate monitoring of the incidence of TB and MDR-TB in children can also be a valuable tool to measure progress towards ending TB overall).

## RESEARCH: FROM INCLUSION IN TREATMENT TRIALS TO NEW TOOLS

- **Develop a new TB vaccine.** For decades the developing world has relied on the BCG vaccine, first introduced in 1921, to provide preventive coverage for children. But the vaccine is flawed, with effectiveness of 60–80 percent against severe forms of TB, and limited ability to protect adults against pulmonary TB.<sup>101</sup> BCG interferes with tuberculin skin tests, making this common screening measure less effective, and is not considered safe for use in children with HIV. By one estimate, a new infant vaccine with a 10-year duration could save US \$185 million a year in future treatment costs.<sup>102, 103</sup>
- **Procure child-friendly MDR-TB treatment.** There is still no widely used child-friendly formulation for MDR-TB, threatening to fuel this new, dangerous phase of the global epidemic for generations to come. Countries should make full use of the available child-friendly MDR-TB regimens they can procure from the Global Drug Facility. At the same time, research and development for short, safe child-friendly MDR-TB treatment is urgently needed to prevent millions of new infections and deaths.<sup>104, 105</sup>
- **Develop shorter treatments.** One of the main obstacles to patient adherence has been the length of TB treatment, so shorter regimens for both active and preventive treatment are needed. New research has shown that a three-month regimen, using the paediatric formulations combining rifampicin and isoniazid, is as effective as six months of isoniazid and is currently recommended by WHO. The Union is studying a three-month regimen using new (RH) formulations for children.
- **Include children in clinical trials.** One of the main obstacles to development of more child-friendly diagnostic tools and treatments has been the absence of children from clinical trials, leaving health professionals with no guidance in areas such as dosing, effectiveness, safety, and drug interactions. In future, children should be included in clinical trials from the beginning, rather than waiting to establish efficacy in adults first.<sup>106</sup> Children must be included as early as possible in research for new diagnostics, new drugs, short regimens for treatment, and prevention — including for MDR TB — with greater attention to addressing the particular diagnostic challenges for children.



## YOUNG LIVES, TIMELESS RIGHTS

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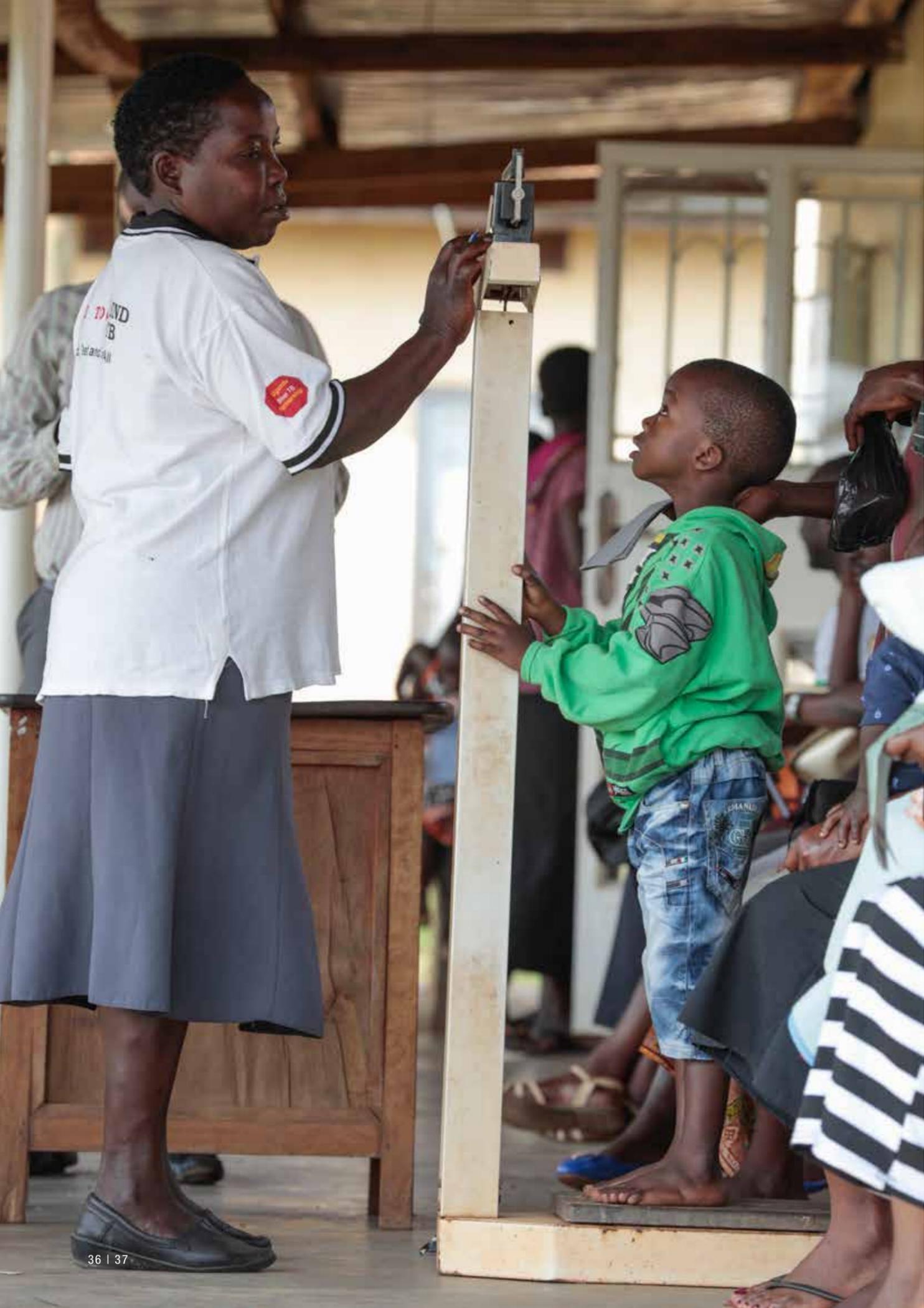
Despite its needless burden of death and distress, child TB has long been ignored in the developing world simply because sick children don't pose the same threat of contagion as adults with the disease. This neglect can no longer be excused on grounds of economy or expediency, as recent advances make it easier than ever to identify and cure child TB, while scientific and technical innovation holds out the possibility of even more effective diagnostics, treatment and preventive measures in the near future.

Technical capacity alone isn't enough, as some of the biggest obstacles to reducing child TB mortality are structural, including lack of basic knowledge about TB symptoms and treatments in communities with limited resources. Tackling child TB requires local interventions, sensitive to social and cultural context, to reach at-risk children using simple tools for active screening and diagnosis. Programmes already operating in places such as Uganda provide useful models that are easily scalable and adaptable to other high-burden regions around the world.

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*The burden of child TB is highest in low- and middle-income countries, but its significance is global, challenging the world to fulfil the promise implicit in the concept of universal human rights.*

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## ABOUT THE UNION

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The International Union Against Tuberculosis and Lung disease (The Union) is the world's first global health organisation, founded in 1920. We are a global leader in ending TB, we fight the tobacco industry, and we solve key problems in treating major diseases.

[theunion.org](https://theunion.org)