

UNCOUNTED AND UNREACHED

**The unseen children
who could be saved by
better data**



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This report was written with significant contributions and research from Geraldine Ryerson Weld, and based on previous work done by Rachel Coghlan, Hilary Pereira, Isis Sunwoo, and the Child Health Now team at World Vision International.

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World Vision has produced several reports and resources that provide greater detail and analysis on where and why children under the age of five are still dying and outline what can be done. These include the following:

The Killer Gap (<http://www.wvi.org/child-health-now/publication/killer-gap>)

More Than Numbers (<http://www.wvi.org/publication/more-numbers>)

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Executive Summary

“Some children live in remote areas so there are no health posts or hospitals nearby and road access is poor. There are more ill patients than there are doctors for treatment. Government and leaders should visit children to check up on the health of children and then send doctors to treat those who are ill.” Sujata, aged 15, Nepal (pictured).

We hear stories like this from children around the world every day at World Vision – children who cannot access the health care they need, children who suffer from the kinds of illnesses that have been all but eradicated in many other countries, children whose brothers and sisters didn’t live past the first day, or the first month, of their lives.

We know that many of these child deaths and illnesses go unreported. This is why investing in the reach of current information systems is critical. It’s why measuring, tracking and reaching the most vulnerable – often the invisible, unseen and uncounted – children needs to be a priority for international, national and local governments and leaders. It is not simple, but now is the right time. We have new technology to harness, years of learnings and successes to capitalise on; we just need the focus, the resources and the political champions to help finish the job and ensure all children survive to the age of five.

Every mother and child counts, and so every mother and child should be counted and able to access the systems that affect their lives. But this is impossible for many when a government uses inaccurate population statistics to plan its child health-care coverage, or when a local authority does not set up a clinic for assisted delivery because its statistics inaccurately show low levels of maternal mortality in the district because mothers are dying unreported at home, not in hospitals.

Governments and donors can invest in policies and programmes that target and reach the most vulnerable communities. We know these save lives. Being counted in Uganda makes the difference between a sick child seeing a doctor and not. Being registered in Indonesia means government funding for all children in a community to be immunised. Being visible to health services in Afghanistan means a mother knowing what help to get when she goes into early labour and how to access it.

Amid the amazing progress in improving child health we have seen in our lifetimes, tragic gaps still exist – as the child mortality figures every year remind us. We are gearing up for the final push to the deadline of the Millennium Development Goals (MDGs) in 2015, and working to develop a sustainable development framework for what happens post-2015. While doing so, our focus needs to be on accelerating the progress we have made, and dramatically reducing further the number of children we lose every year. We have until the end of next year to achieve the goals of reducing child mortality by two-thirds since 1990, and maternal mortality by three-quarters. This is achievable only if we find ways to reach those babies, children and mothers who remain outside health systems, unaffected by funding and unreached by strong policies that have been proven to save lives. We must find out who is still being left out – and why.

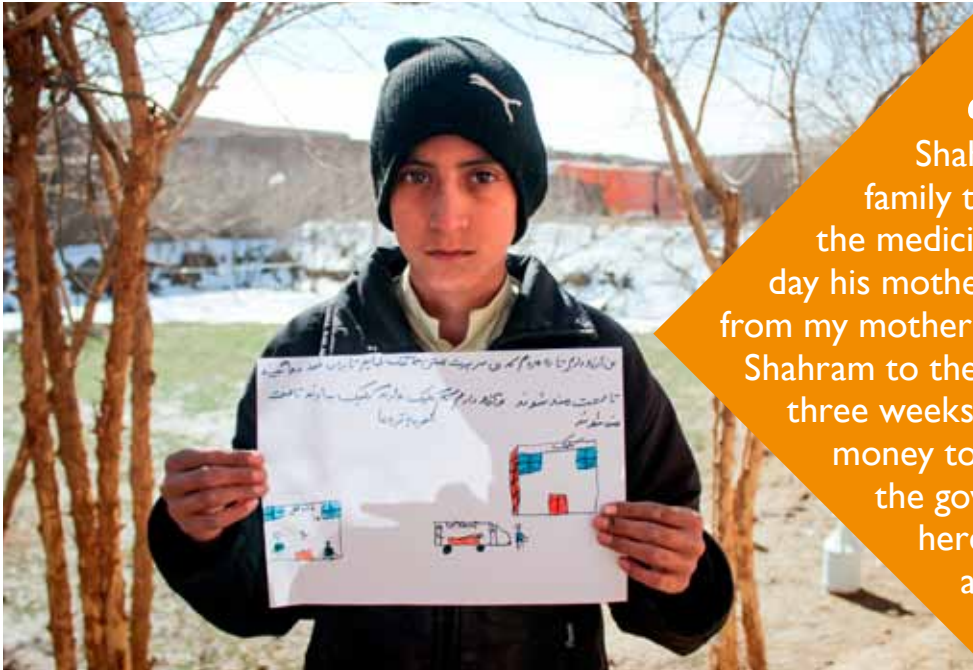
World Vision's campaign to end the preventable deaths of children under the age of five, Child Health Now, is in its fourth year, and this May, we are joining millions of people, churches, organisations and leaders around the world, to show our support for a final push to reach the unseen, uncounted children who deserve to survive, to thrive. Join us – make the difference we know is possible. As a global community, and as individual countries and organisations, we have made great progress that should be celebrated as we refocus energy on reaching the world's most vulnerable children.

Every child, every mother, everywhere has the right to be counted; the invisible deserve to be given visibility, and vulnerable children deserve to have the opportunity to survive and fulfil their potential.

We need to see the following simple and inexpensive solutions implemented at all levels, everywhere, so that every child can survive and thrive:

- Community-driven statistics and monitoring initiatives supported, integrated into national information systems and scaled up by governments
- Global-level endorsement of approaches that put real people – families and communities – at the front and centre of efforts to count and reach the most vulnerable children in the most need
- Political champions willing to stand up for those children furthest from health centres and people's minds and put them at the forefront of the next development agenda
- Increased investment in effective systems for civil registration and vital statistics
- Greater attention at the highest political level to strengthen routine data collection systems locally, nationally and internationally to measure inequalities
- Commitment to ensure children and the most vulnerable groups are involved in generating surveys and mapping
- Bridging the gap with families and communities by engaging and empowering their participation in data collection and in the planning, delivery and review of health services

Charles Badenoch
Partnership Leader – Advocacy and Justice for Children
World Vision International



AFGHANISTAN

“ I had a close friend, Shahram. He was sick. His family took him to a doctor, but the medicine was expensive. One day his mother even borrowed money from my mother to take a car to transfer Shahram to the city. Shahram died after three weeks because they didn't have money to buy medicine. I think the government should come here and see how we live and then help us.”

SAMI, 13

DEMOCRATIC REPUBLIC OF CONGO

“ I know the case of Bobette, a child in our community who died after a fever. Her mother had not wanted to sell her goods to bring her to the hospital. She stayed at home and after a few days she died at home. If we had a free health centre, her mother would have taken her. ”

ESSENTIEL, 12



BANGLADESH

“ My parents take me to the nearest health clinic when I am sick as my father is a Rickshaw puller and can provide the family with food and medicine. I am making a happy picture, but I feel sad thinking about Rohima, a friend of mine who is not able to use the hospital facilities because of her poverty. ”

ZAKIA, 10



Unknown and unseen – A global crisis

All over the world, children live, get sick and die, invisible to the systems and people that could most help them. It is a problem at times beyond imagining, and one that will be solved only with commitment and dedication from those who are in power.

More than 230 million children¹ are unknown and unseen by their governments and health services. Children live and die, invisible to those who make decisions affecting their health, well-being and futures. They slip through the cracks because there are not enough doctors, not enough trained midwives, not enough medicine, and because governments underestimate or misunderstand their needs. In an age of remarkable strides in global health, these invisible, uncounted children are paying a price.

The relatively simple yet crucial process of counting every birth and death is common practice in the world's wealthy countries and communities, but in many poor, remote and troubled areas, it is rare. Only two in three births of children worldwide are registered, according to best estimates.² Even if these children are registered, many other risks, such as homelessness, trafficking or inadequate or poorly staffed health systems, can push them out of sight again. And when they or their parents die, this too may never be counted.

Count

/kount/, v.

1. determine the total number of (a collection of items)
2. take into account; include

Oxford Dictionary

“I know that children of families who mostly live in streets and have migrated here for labour work cannot afford to buy medicines.”

POONAM, 15, NEPAL

LIFE AS AN INVISIBLE, UNCOUNTED CHILD – THE EFFECTS

The infographic consists of six horizontal rows, each with an icon on the left and a list of effects with checkboxes on the right. The background is orange.

- Row 1:** Document icon. Birth certificate Name registration
- Row 2:** Mother and child icon. Antenatal care Skilled birth attendant
- Row 3:** Family icon. Orphaned Adopted Trafficked
- Row 4:** Medical cross icon. Health care Immunisation
- Row 5:** House icon. Homeless Refugee
- Row 6:** Grave icon. Death certificate Cause of death known

Most people in Africa and Asia are born and die without leaving a trace in any legal record or official statistic.

THE LANCET, 'A SCANDAL OF INVISIBILITY'

How many are there really? We shouldn't have to guess. Yet, the reality is we do not know the true extent. No child or family should be deprived of a legal name, an identity or a nationality in a world where these make the difference between having access to education, better health and protection of rights, and not.

Not being counted affects children's lives every day, contributing to whether they can reach a nurse or doctor when ill, or get medicine that makes the difference between life and death. As health information and services overlook or bypass them, millions of children and mothers suffer, when they could be spared by the simple and cost-effective health interventions that we know work.

The consequences are far reaching. Information about where children are born, where they live, what they are getting sick from, disabilities, levels of malnutrition and other vital areas of a child's life is essential to enable governments and organisations to identify where problems are occurring and how to remedy them. Most countries gather some of this information, but it varies in degrees of quality and regularity. And it happens too rarely in poor and less-developed places, rural areas and fragile states, making life even harder for the children and families who live there.



© Achel Baysenge/World Vision

Audrey in Burundi writes about her community's need for local health facilities.

Counting children

Overcoming this problem and its deadly consequences means first knowing who and where vulnerable children and families are. It means measuring in smarter ways to understand what affects them, and what health services they can (or can't) access.

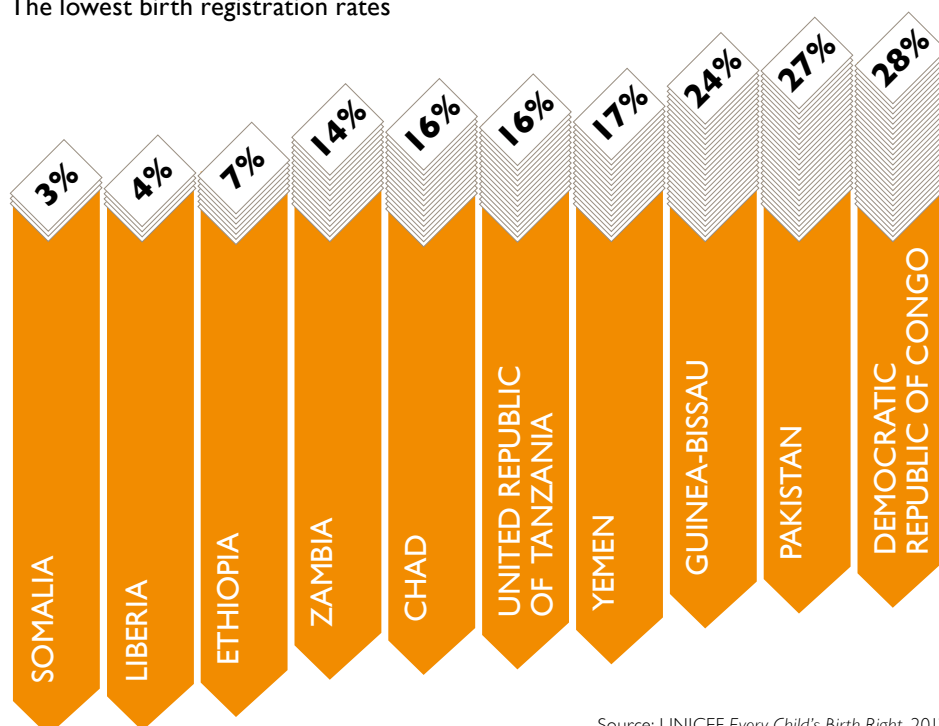
The Millennium Development Goals (MDGs) that culminate in 2015 have helped focus extraordinary political efforts on saving lives and reducing poverty. But success has been uneven, with the limitations of current measurements masking inequalities even within the same nation. A lack of investment to improve civil registration and vital statistics was characterised in medical journal *The Lancet* as 'the single most critical development failure over the past 30 years'.³

This lack of information on who and where the most vulnerable children are has significant implications for planning, resourcing and delivering health services. Health information systems in many countries have remained focused on meeting the data needs of central governments, donors or global databases, largely disconnected from the individual children and families whose lives are most affected. A change in this approach must happen, to drive improvements and ensure that all children – no matter where they are or how they live – are included and reached.

The demand for more and better data is not new, but there is growing momentum behind strengthening the systems used to share information. A data revolution is needed: more and better data must be gathered, but perhaps more importantly, people at the centre must be involved in the collection, analysis and use of it. This is key to saving millions of lives.

INVISIBILITY LEVELS

The lowest birth registration rates



Source: UNICEF *Every Child's Birth Right*, 2013

THE VITAL SIGNS

What we need to know about people to help plan good health services

- Fertility rates
- Access to antenatal care
- HIV treatment for pregnant mothers
- Skilled attendant at birth
- Exclusive breastfeeding for six months
- Live-birth registration
- Deaths during childbirth
- Maternal mortality
- Access to post-natal care
- Under-five child mortality
- Number of stunted children
- Immunisation coverage
- Population numbers
- Unmet need for contraception
- Treatment for pneumonia
- Disease and disability reports
- Death registration
- Cause-of-death reports

“Quite a few children live in the remote areas of this village. Access to clinics and health posts is not easy. I would inform health workers of their conditions so that they get treated timely.”

ROHIT, 13, NEPAL

The seven groups of unseen and unreached

Governments, policymakers and health planners often fail to recognise the needs and realities of life for unseen and uncounted children. Until the facts are reliably gathered and used, this will continue to be the case. It is not always simple, and innovative approaches may be needed to fill the gaps, but it is not impossible.

Without systems to count and reach those most in need, vulnerable children are at risk of falling through the gaps. A number of factors contribute to this, but there are clear groups of people who suffer more than most. Many of the hundreds of millions of children who are uncounted and unreached fit into one, or more, of these groups.

Vul • ner • a • ble

'vʌln(ə)rəb(ə)l/ adj.

2. (of a person) in need of special care, support, or protection because of age, disability, or risk of abuse or neglect

Oxford Dictionary

1. THE UNREGISTERED

Children not registered at birth or death

Without birth registration, children remain invisible to governments and health services, and their rights to health, education, legal identity and protection are unrealised. Only two-thirds of all children born in 2011 had their births registered. More than 100 countries do not have a system that registers births and deaths, and only 34 countries produce quality cause-of-death data.⁴

2. THE MISSED

Mothers and newborns who die in childbirth

Pregnancy and childbirth are the biggest killers of mothers in developing countries today. About three-quarters of neonatal and maternal deaths occur in the first week of the child's life, but most aren't adequately reported. Censuses identify only pregnancy-related deaths, not maternal deaths. In the routine data collection systems of countries with the highest burden of these deaths, there are very few, if any, indicators gathered for newborns.⁵

3. THE ISOLATED

Indigenous children and ethnic minorities

The information that does exist indicates indigenous groups tend to live in the more remote and hard-to-reach parts of their countries, and their children are more likely to suffer undernutrition and die than those from non-indigenous groups.



4. THE UNTRACED

Child labourers and trafficked children

Being trafficked or forced into labour drops children outside the counting process, and children who are invisible are more vulnerable to falling prey in the first place. Victims' fear of coming forward to report, difficulties in law enforcement correctly identifying victims, and inconsistent definitions of trafficking make it virtually impossible to provide reliable statistics for these children. Best estimates put the number of child labourers worldwide at 215 million, most of whom will not be covered by household surveys.

5. THE NEGLECTED

Orphaned and homeless children

Surveys vary in their ability to count orphaned children residing in households, and they fail to count homeless and street children. Counting the numbers of children orphaned by HIV and AIDS is hugely problematic due to the sensitivities in dealing with stigma. Household surveys, by definition, neglect children living on the streets, those living in institutions or in urban slums, and mobile or landless people. The current estimate of 153 million orphans worldwide does not include children living in institutions, such as orphanages or group homes, or on the streets.⁷

6. THE UNCLAIMED

Refugee, stateless, internally displaced children

Rarely captured in surveys, national population censuses and sometimes even in refugee registration programmes, this group accounts for some of the poorest health outcomes and limited access to health services. Children make up almost half of the 36.5 million official refugees, internally displaced or stateless people, according to United Nations High Commissioner for Refugees estimates.⁶ These figures do not include the large number of illegal immigrants, most of whom are not counted.

7. THE UNACKNOWLEDGED

Children living with disabilities

Censuses provide limited or no data on children with disabilities. Data gaps can be filled by targeted household surveys,⁸ but even these may not reveal the true number of children with disabilities, because of discrimination and stigma. Special approaches may be needed. Global estimates put the number of children aged 14 or younger who are living with a disability at 93 million, but the real figure could be much higher.⁹

Mea • sure

'mɛʒə/ v.

1. ascertain the size, amount, or degree of (something) by using an instrument or device marked in standard units
2. assess the importance, effect, or value of (something)

Oxford Dictionary

How we count now

Achieving the majority of the MDGs — including those for child and maternal survival — relies on accurate collection of vital data.¹⁰ Health information systems generally use data gathered from population-based sources, such as censuses, vital registration, and from facility-based sources, such as hospital service records and household surveys. While these can collect and organise much data, each one has its limitations.

Only 39 of 192 World Health Organization member states have strong information systems to track where children are being born and what they're dying from. A strong information system means having functioning ways to gather vital registration, and conducting a major household survey. The majority of countries with strong systems are developed economies. A concerning number of countries — 90 — have systems with very weak capability, meaning they either have only one census or household survey, or no data at all.¹¹ Of the 20 countries with the highest child mortality rates, 16 have weak information systems to track where their children are being born and what they're dying from.¹²

CENSUSES

Dating from ancient times, this official count of population has traditionally been used to register citizens and property, usually for tax collection and other governance purposes. Most national statistical systems in developing countries are focused largely on meeting the information needs of central governments. This is

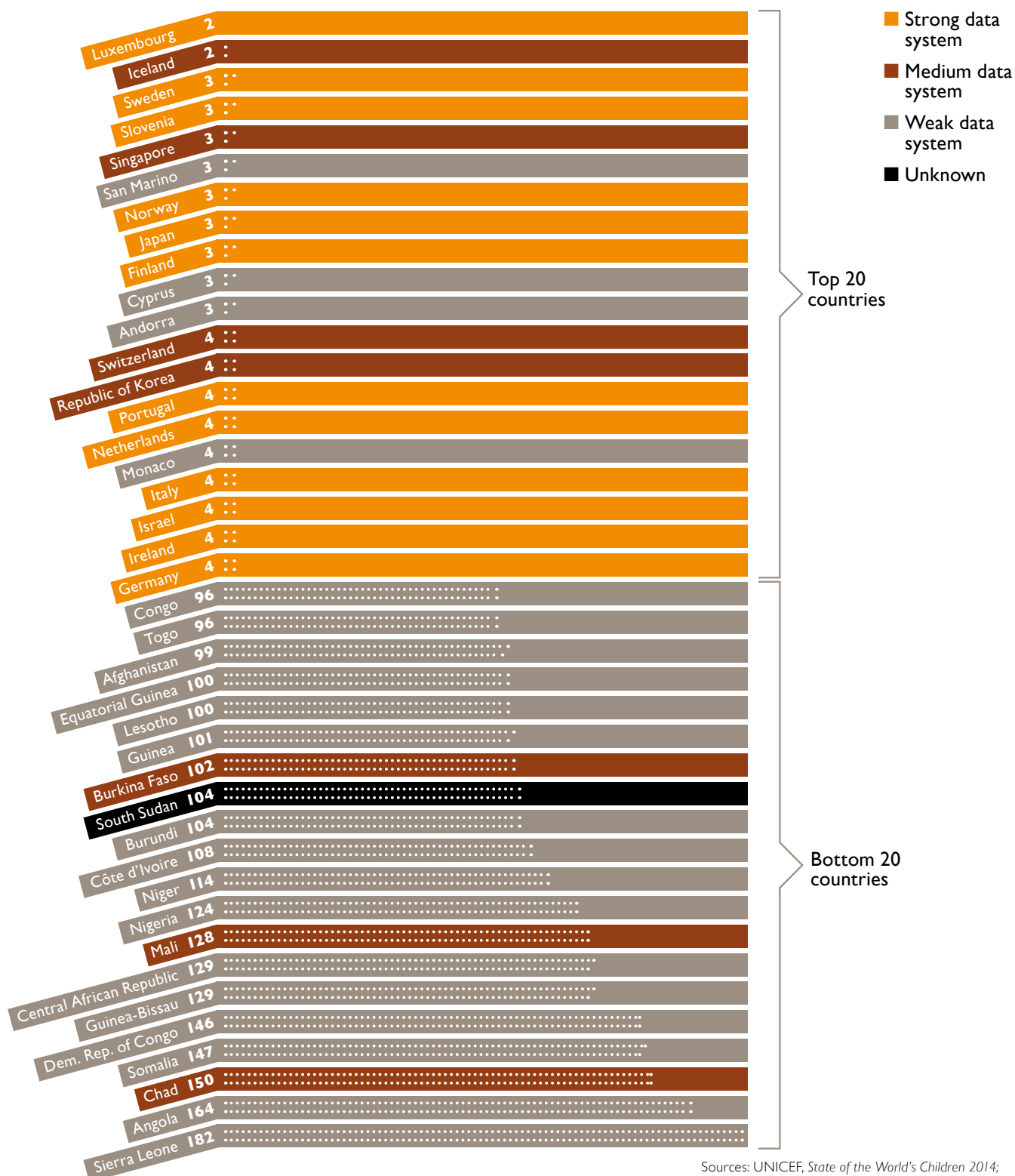
“Here, they did not give us [teen mothers] the same attention they gave to others and they get a long time to see us... I felt both sadness and anger.”

JOYCE, 15, BRAZIL



DEADLY IMPACT OF POOR DATA SYSTEMS

Categorisation of countries with highest and lowest child mortality rates (deaths of children under the age of five, per 1,000 live births), based on the degree of equity analysis information they have available.



Sources: UNICEF, *State of the World's Children 2014*; WHO, *Integrating Equity into Health Information Systems*

“In the absence of reliable administrative data, household surveys have become a key source of data to monitor levels and trends in birth registration. In most low- and middle-income countries, such surveys represent the only source of this information.”

UNICEF, ‘EVERY CHILD’S BIRTH RIGHT’

“Abandoned children receive less attention and most of the time they are not loved. Their health is not prioritised.”

BRIDGET, 10, MALAWI

often accomplished through national censuses, which generate data that is rigorous at the national level but lacks the disaggregated detail that local governments need to plan targeted interventions.

VITAL REGISTRIES

Vital or civil registries comprise national birth, death and marriage records. When comprehensive and reliable, these generate estimates for mortality rate, life expectancy and sometimes cause-of-deaths statistics. However, in many less-developed places these registries are weak and the information unreliable or incomplete for more general use.

INSTITUTIONAL RECORDS

Institutional records, such as health service records and patients’ medical charts, can provide rich data with a great deal of local applicability and relevance. However, by their nature they capture information only for people who receive those services. People living in the poorest and most remote areas and on the margins, who do not access health facilities, remain unrecorded.

SURVEILLANCE

There are several types of surveillance systems, such as disease-outbreak monitoring that aims to identify risk factors and track cases of diseases that could become epidemics. Many low- and middle-income countries have also established demographic surveillance sites, where information is collected for a particular defined population over a long period of time.¹³ These surveillance systems produce and communicate high-quality data but usually with limited scope, purpose or geographic area.

HOUSEHOLD SURVEYS

Household surveys, including the UNICEF-supported Multiple-Indicator Cluster Surveys (MICS) and the Demographic and Health Surveys (DHS) supported by USAID, are the primary data source of health coverage indicators for children and women for most countries. They usually provide disaggregated information on urban and rural location, wealth, gender, age groups and nationally defined ethnic groups.¹⁴ However, household surveys reach only people living in the stability of their own homes and typically miss homeless and institutionalised people, nomadic or pastoralist groups, people in hard-to-define households; and those who live in areas deemed too dangerous.¹⁵

INVISIBLE IN DRC

“This community is often forgotten in immunisation programmes because children are not registered at birth,” says Pastor Jean Mona, in a village near the Democratic Republic of Congo capital, Kinshasa.

Getting to hospital is a distant dream for people who rely on traditional medicine to treat health problems.

“Many children are not listed in the official statistics of the

municipality because women do not give birth in hospital; they give birth at home with the help of midwife,” says Pastor Jean.

Sophie is raising three children alone and says getting to the nearest hospital is out of the question.

“I already struggle to feed my children. Where will I find the money to go to the hospital?” she asks. “All I do is pray God that the disease disappears.”

The power of better data

Extraordinary progress has been made in saving children's lives in the past two decades; the number of children who die before reaching the age of five has dropped from more than 12 million a year to 6.6 million. However, existing monitoring systems often fall short of reflecting the most vulnerable children and families who are yet to be reached with services.

Input driven by communities themselves can generate rich and useful information that complements conventional data collection methods and plugs knowledge gaps. Many sick children never reach a health facility, and speaking to community members is fundamental to understanding where and why this happens. Families, communities and individuals hold the key to shaping and monitoring future health systems if we are to truly change the world children live in.

For this to happen, political champions are needed to drive changes to existing models and methods – leaders who recognise every child's right to be counted, and to have good access to the health services that make the difference between life and death. These leaders need to come from government, civil society, universities, corporate organisations; they need to lead changes, rally donors and develop and implement strong policy. Better data adds up to saving children's lives.

A lack of financing for stronger health information systems, along with widespread lack of comprehensive national strategies, has hampered progress in this area. Making up a tiny 0.16 per cent of international aid, funding assistance for statistics peaked at US\$518 million in 2011, and fell to US\$394 million in 2013.¹⁶



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da • ta

'datə, 'dātə/ n. pl.

1. facts and statistics collected together for reference or analysis.
- 1.2. things known or assumed as facts, making the basis of reasoning or calculation.

Oxford Dictionary

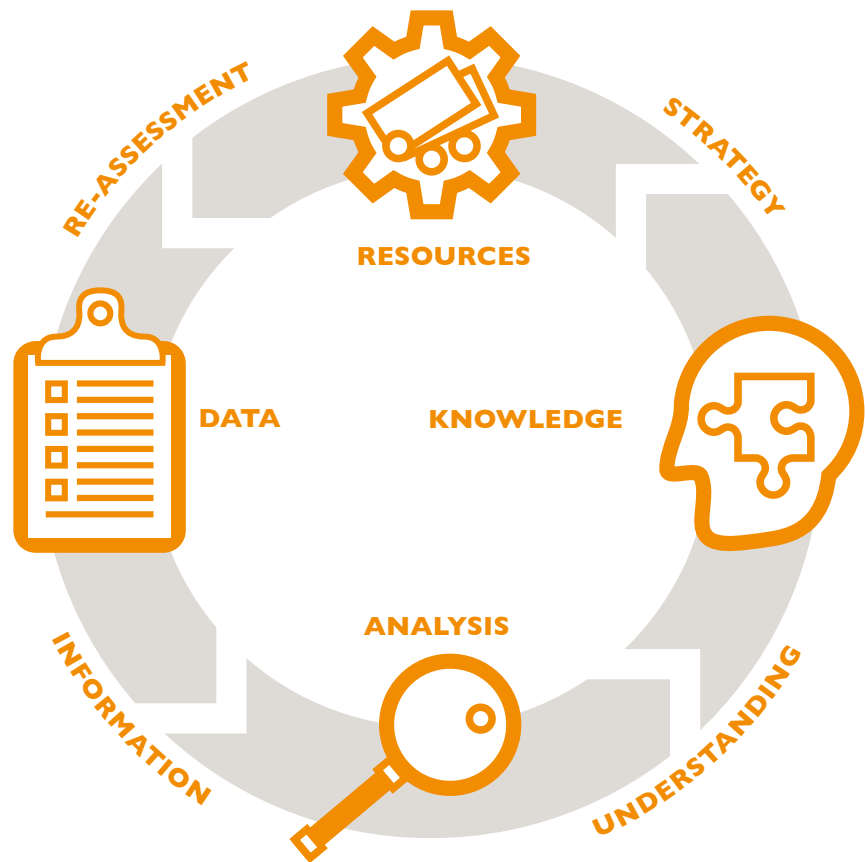
“Bombs were falling all around our house in Syria, and we were forced to leave without bringing any of our identity papers, including a school certificate to allow me to carry on with my studies in Lebanon.”

IBRAHIM, 16, REFUGEE

Many Syrian refugees in Lebanon left identity papers behind when they fled fighting in their homeland.

Data drives decisions and helps to defy death

Investing in strong information systems saves children's lives



BRIDGING THE GAP WITH TECHNOLOGY IN AFGHANISTAN

In rural Afghanistan, near Herat City, access to health facilities for mothers and children has been difficult for years. Getting health care “is difficult because we don’t have [a] clinic here... There is not any doctor here. They have to walk a far distance,” says 13-year-old Razita.

Sami, 13, knows what he can do to help his people access health care: “I will make a hospital for them.”

It is as much about facilities as it is awareness. For decades, women in Afghanistan have had to gamble against one of the world’s highest maternal mortality rates.

Poor access to maternal and newborn care services is caused by geography, insecurity and constraints against women leaving home without a man, or receiving care from male health workers.

To help tackle the problem, working with a number of partners, World Vision designed and implemented a way to use mobile phones to help health workers reach the mothers and children out of reach. Community health workers, working in male-female pairs, visit pregnant

women at specific times during their pregnancy to discuss their health and prenatal care. Using mobile phones, the health workers use a specially designed application to access information for mothers, such as antenatal care and birth planning.

They use the application to upload information to central databases, and to make referral calls to the nearest birthing facility when women go into labour.

In just under two years, the project saw remarkable increases in the use of official health services by women and children:

- A 22 per cent increase in the number of babies delivered in a health facility.
- A 20 per cent rise in antenatal care visits.
- A 14 per cent increase in the use of iron supplements.

The “mHealth” approach focuses on improving health service delivery at the household and community level but it also forms a link with the broader health information system. The information it gathers and provides helps to strengthen the evidence base at wider levels.¹⁷

BANGLADESH

“ I have never seen what a hospital looks like inside, though I suffer from sickness around half of the time. In my picture, a patient is being taken to hospital by van. But I don't know if she will survive until she gets there as I know the road is very poor from my village. It is my desire to have good treatment in my own community.”

SONIA, 10



© Lipy Mary Rodrigues/WorldVision



NEPAL

“ Some children live in remote areas, so there are no health posts or hospitals nearby and road access is poor. There are more ill patients than there are doctors for treatment. Government and leaders should visit children to check up on the health of children and then send doctors to treat those who are ill. ”

SUJATA, 15

DEMOCRATIC REPUBLIC OF CONGO

“ Lately, when I got sick, I had a fever and vertigo. I could not play with friends. My father [a traditional healer] gave me a treatment with avocado leaves. I felt good and the next day I started playing again, and then suddenly I fell seriously ill. If we had a free clinic in the community, it would have helped. ”

EWA, 12



© Aime Kamuha/WorldVision

Vi • tal

'vītɪl/ adj.

1. absolutely necessary or important; essential
 1.1 indispensable to the continuance of life

Oxford Dictionary

“Due to shortage of drugs, parents don’t take their children to the hospital at all. They see it as a waste of time. Government should stock all hospitals with more medicine to help sick children.”

CHIMEMWE, 10, MALAWI

Putting people at the centre

Traditional means of data collection and monitoring have generally been top-down, centrally controlled and extractive in nature. They tend to feed the needs of national governments, donors or global databases but leave a gulf when it comes to providing detailed, current and local information that drives planning and decisions in health districts, local authorities and communities.

Improving existing methods is essential, but “these could progressively be combined with tracking, performance and progress monitoring using ‘new data’ from, e.g., crowd-sourcing, social audits and citizen report cards, thereby enhancing participation and accountability,” as the UN suggests.¹⁸

Accountability in this case means children and families holding decision makers to account for their actions and ensuring investments in development that works. The ability to assess the efforts to improve health, as well as the needs, is essential. Engaging members of communities in gathering and sharing accurate data on their circumstances is a powerful step towards developing strong and accountable relationships with local authorities and in ensuring that those children most in need are reached.

The children and families who make up communities around the world can and should be the duty bearers responsible for their own health outcomes. Their involvement in data collection about their lives is key to this. Local decision-makers also benefit from the use of locally generated information to inform the direction of policies and programmes. Data gathered locally can provide the evidence needed to lobby provincial and national governments for more resources for their districts. In this way, community-driven information can enable local governments and municipalities to form a vital bridge with national governments.

UNSEEN IN THE URBAN RUSH

Access to basic services and proximity to city facilities and government workers should reduce many of the challenges of accurate data collection in rural and remote areas.

But the rapid changes in the population numbers in urban centres, and the particular needs of poor children and families who live there, can increase the difficulty for governments to respond with the right levels of resources and services.

Children in urban slums grow up in informal, insecure, overcrowded settlements, which are often illegal and temporary. Families compete for access to essential resources and services such as electricity, clean water and health care. Rates of malnutrition and preventable childhood illnesses are often higher than in rural settings or the national average.

They lack access to affordable housing, basic infrastructure, full-time employment, health, education and legal protection. They are usually excluded socially and in institutional decision-making.

These hardships mean that statistical averages on which resource allocation decisions are based often conceal the reality. Aggregate figures tend to show urban children as better off than rural, obscuring the disparities among children living in cities.

With more than one billion people already living in urban slums in developing countries, and an estimated 100,000 more arriving every day, being aware and keeping track of emerging trends is vital for good urban health systems.

Sources:
 UNICEF, *The State of the World's Children 2012*; *Children in an Urban World*; IFRC, *World Disasters Report 2010*; The World Bank Group, *Urban Papers 2009*; UN-HABITAT, *Global Report on Human Settlements*.

Community involvement in data collection and monitoring can do more than contribute to revolutionising data. The meaningful engagement, participation and empowerment of families and individuals can help to transform communities, their relationships with government and local health service providers, and even government systems to deliver better services.

Among barriers to gathering better data are distrust between residents and authorities, and a low value placed on the importance of birth registration.¹⁹ Families or individuals may be reluctant to register life events and status if they fear misuse of the information, especially among people already marginalised or recovering from the effects of past abuses and discrimination. Building safeguards and trustworthy systems is essential to engaging citizens and reinforcing respect and protection of their human rights.²⁰

Yet by and large, such data-gathering efforts that do exist remain project based and authorities demonstrate varying degrees of interest for scale-up or integration with national health information systems.

At present, there are few policy blueprints for generating and monitoring data at the local level with the participation of community members. Countries developing and implementing their national statistics strategies need to reconsider this oversight.

“It’s safer in Jordan. When we first came, we lived in a tent. The children were always sick and cold. We couldn’t get medicine. It was a bad time. There are hospitals but they have too much to do and they don’t have time to listen to us.”

**NAJWAH, MOTHER,
REFUGEE.**

COMMUNITY LEADING THE WAY IN INDONESIA

Working with a local community in rural Indonesia, World Vision and a local health centre took an innovative approach to registering and tracking children under five in the area.

A local festival drew a high turnout of people from the local community, so health workers photographed and weighed all children under the age of five, creating the community’s first baseline database and compiling it into a book. They used the information to create a village map – plotting all the houses with a baby, child under the age of five or pregnant woman – so health volunteers could quickly identify households for follow-up and appropriate counselling. The map of households presented the village with a visual that more clearly illustrated where the most needs existed. Empowered by the evidence, the community and the health centre decided to move the growth monitoring centre closer to the families that would most benefit from its services.

Incredible progress has included:

- An increase by 40 per cent in the number of children attending the growth monitoring centre over a six-month period.
- Women delivering babies with a skilled birth attendant increased by nine per cent.
- An increase in exclusive breastfeeding by four per cent.

The success of the community-driven, low-technology mapping and targeting system has inspired discussions about its replication and wider use with the local District Health Chief and all the health centre chiefs in the district.



“Disabled children from faraway villages fail to access help from the clinic. They use crutches to walk and this limits them from travelling a long distance.”

GILAYIDI, 11, MALAWI

Recommendations

More than one billion people cannot access the health services they need, either because the services are unavailable or people cannot afford them.²¹

This reality isn't solely the result of national wealth – it is also a reflection of political will to gather and effectively use vital information in planning services for people who need them. There is broad agreement on the need to improve child and maternal health, meet MDGs 4 and 5, and establish a strong post-2015 health agenda. But for the millions of invisible, unseen and uncounted children, this means nothing if it doesn't begin with recording and respecting their existence.

World Vision believes that for this to happen, governments need to improve counting and use the data collected to ensure progress for better health:

- Community-driven statistics and monitoring initiatives that are supported, integrated into national information systems and scaled up by governments
- Global-level endorsement of approaches that put real people – families and communities – at the front and centre of efforts to count and reach the most vulnerable children in the most need
- Political champions willing to stand up for those children furthest from health centres and people's minds and put them at the forefront of the next development agenda
- Increased investment in effective systems for civil registration and vital statistics
- Greater attention at the highest political level to strengthen routine data collection systems locally, nationally and internationally to measure inequalities
- Commitment to ensure that children and the most vulnerable groups are involved in generating surveys and mapping
- Bridging the gap with families and communities by engaging and empowering their participation in data collection and in the planning, delivery and review of health services

Appendix

COUNTRIES WITH STRONG DATA COLLECTION SYSTEMS

- Australia
- Austria
- Belgium
- Bulgaria
- Canada
- Chile
- Croatia
- Czech Republic
- Denmark
- Estonia
- Finland
- France
- Germany
- Greece
- Hungary
- Ireland
- Israel
- Italy
- Japan
- Latvia
- Luxembourg
- Mauritius
- Mexico
- Netherlands
- New Zealand
- Norway
- Panama
- Portugal
- Romania
- Russian Federation
- Slovakia
- Slovenia
- Spain
- Sweden
- Ukraine
- United Kingdom
- United States of America
- Uruguay
- Uzbekistan

Categorisation of WHO member states according to level of information availability for equity analysis from *Integrating Equity into Health Information Systems*.

Endnotes

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World Vision is a Christian relief, development and advocacy organisation dedicated to working with children, families and communities worldwide to reach their full potential by tackling the causes of poverty and injustice. World Vision is dedicated to working with the world's most vulnerable people. World Vision serves all people regardless of religion, race, ethnicity or gender.

Child Health Now is World Vision's five-year global campaign, active in nearly 50 countries, aiming to accelerate action to end the preventable deaths of children under five.

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