
MORE THAN NUMBERS

Why better data adds up to saving the lives of women and children



© World Vision International 2014

All rights reserved. No portion of this publication may be reproduced in any form, except for brief excerpts in reviews, without prior permission of the publisher.

Published by World Vision International.

For further information about this publication or World Vision International publications, or for additional copies of this publication, please contact wvi_publishing@wvi.org.

World Vision International would appreciate receiving details of any use made of this material in training, research or programme design, implementation or evaluation.

This report has been written by Rachel Coghlan drawing on research by Isis Sunwoo (consultant) and edited by Kate Eardley. We are grateful for comments and input from staff across World Vision.

Managed on behalf of Child Health Now by Emma Edwards. Senior Editor: Heather Elliott. Production Management: Katie Klopman, Daniel Mason. Copyediting: Audrey Dorsch. Proofreading: Amber Hendrickson. Cover design and interior layout: Lara Pugh.

Cover photo © World Vision/Sopheak Kong.

Inside photos © World Vision staff.

p. 3 Mozambique/Antonio Matimbe

p. 8 India/Daniel Mung

Executive summary

As a global community, and as individual countries and organisations, we have made progress that should be celebrated. An estimated 90 million lives have been saved in the past two decades due to our collective efforts to improve child survival. We are losing fewer children every year to measles, malaria and other childhood diseases. But we are still losing too many to the most preventable of causes.


As we gear up for the final push to the deadline of the Millennium Development Goals (MDGs), 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 31 December 2015 to achieve our goals of reducing child mortality by two-thirds since 1990, and maternal mortality by three-quarters. Discussions are already well underway on what comes after the MDGs, and there is strong support for an ambitious target to end preventable maternal, newborn and child deaths within a generation. This is achievable only if we find ways to reach those babies, children and mothers who remain outside the scope of mainstream health systems and funding. We must find out who is still being left out – and why.

Every year, around the world, how many children die unseen, invisible, unregistered and unable to access the kind of health services that could save their lives? The reality is we don't know. The most educated guesses put the number of invisible and unreached people at between 250 and 500 million in developing countries.¹ How many of these are children? We should not have to guess. We should know where they are and how to reach them with health interventions.

We are not currently counting the most vulnerable children because there are significant gaps in the type of health information collected by countries. Only 20 per cent of countries have strong health information systems that count all births and deaths and track causes of death, alongside major household surveys. These are mostly more developed countries. Yet that is not where the majority of child deaths occur.

It is the right of every mother and child, everywhere, to be counted and included in government provision of services. When everyone is counted, governments and donors can more confidently invest in policies and programmes that target and reach the most vulnerable communities. We know that this will save more lives. In Uganda, it's a matter of a sick child being able to see a doctor or not. In Indonesia, it's a matter of the government providing enough funding for all children in one community to be immunised or not. In Afghanistan, it's a matter of a mother knowing what help to get when she goes into early labour and how to access it.

What we know for sure is that many child deaths and illnesses never reach a health facility and frequently go unreported. This makes expanding the reach of current information systems and investing in the collection of information at the community level, by communities, critical. World Vision works with communities to enable them to improve the well-being of their children. Key to this work is measuring, tracking and reaching the most vulnerable, often the invisible or unseen, children. We equip midwives with mobile phone health monitoring technology in Afghanistan and help community-based health workers in Indonesia to register the information of children attending public festivals, then follow up by placing stickers on houses with children under the age of 5 so health volunteers can easily identify houses that need continued support and attention.



It is the **right** of every **mother** and **child**, everywhere, to be **counted**.



We need political **champions** willing to stand up for **children**.

If we are going to end the preventable deaths of children under 5, we need to see more of these initiatives supported, integrated into national information systems and scaled up by governments. We need to see 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. We 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.

Every child has the right to be counted; the invisible deserve to be given visibility; and the most vulnerable children deserve to be given the opportunity to survive to fulfil their potential.

We believe the following steps need to be taken by national governments, donors, and global institutions, to fulfil the vision for counting every child and closing the health equity gap. These are steps not just to realise the future potential of millions but for immediate action to accelerate efforts towards the health-related MDGs.

National governments should:

- Ensure a consistent focus on addressing inequalities through improved counting and targeting of the most vulnerable children and the subsequent use of this data in policy setting, programme design, progress monitoring and reviews.
- Expand the health information system by systematically scaling up promising community-level approaches that generate data and analysis, particularly in areas of low information untouched by existing surveys and mapping, to help identify the most vulnerable, inform decision-making, improve health service delivery and have a positive impact on health outcomes.
- Increase investment in systems for civil registration and vital statistics towards universal and effective coverage.
- Institutionalise maternal death surveillance and response, and ensure that information gathering is structured to facilitate community participation in death-review processes.
- Bridge the gap between decision-makers at all levels and caregivers, families and communities by supporting community-based monitoring systems such as social audits and citizen report cards.
- Take explicit steps to prioritise local- to national-level accountability, including through civil society participation in planning, review and accountability mechanisms.

National and donor governments and international agencies should:

- Review and refocus existing efforts to accelerate progress towards the MDGs with a view to better counting and reaching the most vulnerable children.
- Give particular priority to the most vulnerable in the post-2015 development agenda, including through a high-level goal to end preventable maternal, newborn and child deaths and a strong commitment to significantly reduce the numbers of stunted children worldwide.
- Ensure that the monitoring of any new development goals includes strong metrics on equity beyond income and includes a commitment to disaggregate country health data at minimum by age, gender, location, ethnicity, income quintiles and disability.

- Commit to the scale-up of effective civil registration and vital statistics systems towards the achievement of universal coverage.
- Invest in and expand mechanisms for health monitoring, review and accountability, spanning local to global levels, that include effective participation from communities, civil society and all relevant stakeholders.

Finishing the job: Saving lives with better data

In the small remote place of Bawomataluo in South Nias district of Indonesia, the front door of every house with a child under 5 shows a sticker containing the information of the child's weight, height and date of weighing. Volunteers and midwives in the community update this sticker every month and keep a database in the form of a book complete with every child's picture, date of birth and nutritional status. Before this mapping exercise began, coverage of health services was low, and nobody knew exactly how many children were in the area. With this community monitoring programme, every child and pregnant woman is accounted for, and health volunteers can use this information to better target essential health services and counselling.


The simple process of counting every child and monitoring their health status may be common practice in rich countries, but in poor, remote communities like Bawomataluo, such lists are rare and scores of children fall through the cracks, uncounted and invisible. Locally driven data can plug vital information gaps so that health services can target these most vulnerable children. Communities worldwide must be part of the effort to count every mother and every child.

Extraordinary progress has been made in saving children's lives: the number of children dying each year under the age of 5 has fallen from over 12 million to 6.6 million in the past two decades.² But at a time when major advances in global child health are being rightly applauded, millions of children around the world die unseen, invisible, unregistered and unable to access the kind of health services that could save their lives. An estimated 18,000 children under 5 still die every day, many from conditions that could have been prevented or effectively treated. Two million will die on the day they are born. Four million more won't make it to their fifth birthday.

We are in a time of unprecedented investment in health, globally and nationally. The Millennium Development Goals (MDGs) have presented an extraordinary global opportunity where the political community's focus has been on saving lives and reducing poverty. This political attention has brought with it financial investment and has led to the progress seen in recent years. But success stories in striving to reach the health-related MDGs are coupled with stories of groups of children who are missing out completely in the great strides being made. Too often, the poorest and most marginalised children will be excluded from the success stories.

The current MDGs have been equity-blind – the aggregated numbers used to assess global and national progress in achieving the MDGs have meant that some countries have been able to achieve their targets without addressing the needs of their most vulnerable children. Current measures of child health mask inequalities between the best off and worst off. Vast numbers of children are born but never counted, their fundamental right to an identity violated. Children and mothers die because we don't





Closing the health equity gap is a **necessary** foundation to **end** preventable child deaths. It also has the potential to **deliver** great economic **returns**.

always know where they are and how to reach them. There are big holes in the type of health information collected by even the richest countries. This makes it difficult to understand who suffers as a result of health inequality, and it means that governments everywhere are likely to be underestimating the magnitude of inequalities between and within countries. In poor countries in particular, this means we are losing the lives of mothers and children who could be saved by simple and cost-effective health interventions. The groups who suffer most – such as children not registered at birth, children with disabilities, orphaned children, children of ethnic minorities, stateless children and children born without the help of skilled birth attendants – are those who are generally not counted, remain invisible to health services and systems and are being left out of progress. This lack of information on who and where the most vulnerable children are has significant implications for the planning, resourcing and delivery of health services.

Finishing the unfinished business is not just about moving closer to global aggregate and national average targets. It is about ending preventable child deaths. And now, for most countries, it is mostly about who is still left out – and why.³

In 2007 a series of papers published in *The Lancet* drew attention to the ‘scandal of invisibility’ in which the poorest and most vulnerable people in society went unregistered, uncounted and uncared for.⁴ This could be affecting between 250 and 500 million of the poorest of the poor in developing countries.⁵

Closing the health equity gap

Finishing the job of the MDGs and ending preventable child deaths means having health services that reach babies, children, mothers and families everywhere. It is the right of every mother and every child to be counted and to have access to good-quality health care. We must focus much more on the lives of individual mothers and children, not just on the national or global aggregates. This means addressing the reasons that mothers and babies die, supporting more families with information to prevent child stunting, and extending basic health, water and sanitation services to neglected areas. Going the extra mile will be tough, and it means finding measures to reach children who suffer from not just one but multiple deprivations. This can include children in the poorest families in rural areas, or children with disabilities within internally displaced or refugee populations.

Closing the health equity gap is a necessary foundation for accelerated progress to end preventable child deaths. Investing in health and closing the health equity gap within and between countries also has the potential to deliver great economic returns. The 2013 Lancet Commission on Investing in Health reported that reductions in mortality accounted for about 11 per cent of recent economic growth in low- and middle-income countries.⁶ A cost-benefit analysis by the Lancet Commission reveals that spending just US\$23 a head in the poorest nations, an extra \$25 billion, would yield a \$216 per capita increase in economic growth. The 2012 Copenhagen Consensus, a research-driven examination of the smartest solutions to global challenges, found that all five of the top development investment opportunities were in health or nutrition, as were four of the next ten.⁷

The risk of social exclusion and inattention to vulnerable populations is ever present. The omission of equity considerations is not only bad for women’s and children’s health. It also misses an important opportunity to accelerate progress. Equity-focused initiatives themselves could lead to faster decreases in mortality, enhanced cost-effectiveness, and reduced inequality.⁸

Without tackling inequalities, the task of ending poverty cannot be achieved. As a result, there is much discussion on the importance of addressing health inequalities to achieve the ‘unfinished business’ of the MDGs and establish an equitable, sustainable development agenda to follow. Drawing attention to the ‘wide and often mutually reinforcing disparities’ that are evident within countries, a recent Issues Brief on Promoting Equality prepared by the UN Technical Support Team for the Eighth Session of the Open Working Group on Sustainable Development Goals, went on to point out that these inequalities will make the attainment of universal, or ‘zero-based’ goals in any new development framework especially challenging.⁹

Significant discussions are underway with regards to strengthening important methodologies such as vital registration systems, household surveys and routine data collection at the facility level to improve health equity monitoring. However, existing monitoring systems do not go far enough to capture smaller groups of children suffering multiple deprivations, who remain invisible to health services and excluded from progress to save lives. Health information systems in many countries have remained focused on meeting the data needs of central governments, donors or global databases, largely without locally driven views and experiences. Significantly more work is needed to ensure that health information systems are counting and reaching the most marginalised groups.

Reaching the children who slip through the cracks will require greater input from people and communities themselves, reflecting their distinct needs. Since many child deaths and illnesses never reach a health facility and frequently go unreported, the collection of information at the community level, by communities, is critical. Local innovations that empower communities to conduct their own data collection and monitoring can help generate rich information which reflects these needs, and can complement conventional data collection methods and plug information gaps in the health status of women and children. Communities can help to gather information on children and mothers who fall through the data cracks, to understand who and where they are, what health services they have access to and what they are dying from.


A new movement for better data

In reaching the health-related MDGs and the goals to be agreed as part of the next development framework, data on inequalities present a major constraint – such data are very poor or non-existent in many countries, particularly for factors of health and well-being that go beyond income, and for the poorest and most marginalised social groups. Health information systems should be designed with a focus not just on generating data for data’s sake but on improving the health of individuals in the community and achieving health equity. The question we raise in this report is, *How do we strengthen systems to measure not just more, but to measure smarter, in a way that captures the realities of every child and engages the most marginalised groups?* This is the only way we can save the lives of mothers and children who are missing out on current efforts.

The call for more and better data is not new, but the debate being generated by the ‘data revolution’ proposal presents a significant opportunity to strengthen the systems we use to monitor progress in child health.

Paying particular attention to the inequalities holding back progress in child health and development, the report of the High-Level Panel of Eminent Persons on the Post-2015 Development Agenda made a powerful case for focusing on excluded and disadvantaged populations, calling for a transformative shift to ‘leave no one behind’:

Since many **child deaths** and **illnesses never** reach a health facility and frequently go **unreported**, the **collection of information** at the community level is **critical**.



‘A **data revolution** for sustainable development’ should gather information to **shine a light** on the **most vulnerable** groups who would otherwise remain **hidden**.

The next development agenda must ensure that in the future, neither income nor gender, nor ethnicity, nor disability, nor geography, will determine whether people live or die, whether a mother can give birth safely, or whether her child has a fair chance in life.¹⁰

Recognising that efforts to tackle inequalities depend hugely on the availability of the right data, the panel proposed that a ‘data revolution for sustainable development’ should gather information disaggregated by gender, geography, income, disability and other categories to shine a light on the most vulnerable groups who would otherwise remain hidden. Putting that spotlight on those communities means many lives could be saved through more targeted interventions to improve health outcomes.

Similar calls for a new approach to data, in the context of the next development agenda in particular, have been articulated by a wide range of stakeholders across a number of processes. The independent Expert Review Group on Information and Accountability for Women’s and Children’s Health (iERG), in their 2013 report *Every Woman, Every Child: Strengthening Equity and Dignity through Health*, called for a ‘new movement for better data’ and for a post-2015 development target related to civil registration and vital statistics (CRVS).¹¹ The UN Issues Brief on Promoting Equality suggests,

Methods for the practical measurement of inequalities include strengthening current household surveys and vital registration systems with more extensive disaggregation of data and data collection on poorly-covered populations. 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.¹²

The good news is that these innovative ways of collecting more and better data allow for better targeting of resources and interventions and mean that many more lives can be saved. This is in contrast to traditional means of data collection and monitoring, which have generally been top down, externally controlled and deeply extractive. Information systems in many countries have focused on meeting the data needs of national governments, donors or global databases, largely without locally driven views, ideas, experiences and solutions. National and global databases and registries are critical, but nationally aggregated data from surveys and censuses cannot provide detailed, current, local information useful for individuals, communities, local authorities and health service providers. Information generated at the community level gives authorities a far better chance of accommodating the poorest and most vulnerable groups in their health services.

Reaching the children who slip through the cracks will require greater input from citizens reflecting children’s real and distinct needs. Individuals, families and communities can play a significant role in shaping and monitoring health systems, but to extend current health information systems to the local level will require political champions who can help drive changes to existing models and methods.

More than a data revolution: An accountability revolution to transform communities

Community involvement in data generation and monitoring can do more than contribute to revolutionising data. Local monitoring can help drive accountability at local, national and global levels. It can serve to empower communities, improve community and government relationships and transform government systems to deliver benefits for the most marginalised women and children. True accountability means counting every woman and every child and is the only way we will be able to measure tangible progress in saving lives.

Presenting the findings of *A Million Voices Survey*, which captured the views of more than 1 million citizens across 190 countries, including women and excluded groups such as children, people with disabilities and displaced people, the Administrator of the United Nations Development Programme, Helen Clark, reported that the world's people


...want to continue to have a say, to ensure that their views are taken into account, to monitor the real-time progress in their countries, and to hold their governments accountable for results.... They have called for a revolution in data – so that regularly updated, reliable and disaggregated data is available about their communities, countries and world. They see a data revolution as the foundation for an accountability revolution.¹³

The elements of equity, participation, empowerment and accountability were largely missing from the MDGs and their targets. In the less than two years remaining before the end of the MDGs, and as we advance the post-2015 and sustainable development agendas, we are faced with an imperative to agree on a transformative agenda for action where health metrics and human rights stand together. All governments, institutions and organisations must recognise that, like the children in Bawomataluo, Indonesia, every child has the right to be counted and reached by health services. The invisible deserve to be given visibility, and the most vulnerable deserve the opportunity to survive beyond 5 years of age and to reach their full potential.

The invisible children: Slipping through the data cracks

The children and families who have not benefitted from gains in child health and survival in the past two decades are neither randomly nor evenly distributed within countries. It is the most disadvantaged groups who tend to fare consistently worse on all indicators to measure progress towards the MDGs and who are left behind in their country's overall improvements. In the most extreme cases, not being counted means lives are lost as government services completely bypass those communities living on the margins. Income levels go a long way to explaining the gaps in health equity. From 2006 to 2011, income inequality increased within most countries around the world. Income poverty often means sub-standard living conditions, poor diets, exposure to the most illnesses and the fewest opportunities to overcome these adversities.

But as a recent Global Health Index from World Vision highlights, a country's overall material wealth alone does not guarantee good health for all people.¹⁴ Children who fall through the cracks in the health system often face not one but multiple inequalities at once, making them harder to count, harder to reach with essential health interventions



The invisible
deserve to be
given **visibility**, and
the most **vulnerable**
deserve the **opportunity**
to **survive**
beyond five years
to **reach** their
full potential.



and left out of progress in child health. The children most at risk will come from the poorest households, reside in rural locations, belong to an ethnic minority or low-caste group, and have parents, particularly mothers, with little or no education.¹⁵

The many deprivations that individual children may face mean that average measures of health will hide the inequalities between the best-off and worst-off children. The health of the most vulnerable children is therefore not routinely documented or acknowledged and they remain invisible to the health services they desperately need. It is clear that missing out on these services has an impact on health outcomes. Summary data can also be deceptive: in Nepal, the child mortality rate in Dalit communities is at least 50 per cent higher than the national child mortality rate, and in Peru, although child stunting is lower in urban areas than rural areas, poorest children in urban areas are four times more likely to be stunted than children from the least poor quintile in rural areas.¹⁶

Significant effort has gone into improving how to measure key health outcomes such as child mortality or nutrition status; coverage of health interventions such as immunisation status, antibiotic use for childhood pneumonia and presence of a skilled attendant at birth; or the quality of health care. Often ignored is a critical denominator to this equation: how well do we count populations and, in particular, children and the poor? Without knowing this information, targeting interventions where they are most needed is a haphazard task and, as this report argues, it is the most vulnerable who will miss out.

Against the backdrop that the MDG goals and indicators have neglected inequalities in child health, there is increasing concern about rising health inequality between and within countries, and attempts are being made to quantify and measure these gaps:

- The Commission on Information and Accountability for Women's and Children's Health has highlighted the limitations of aggregate national-level statistics. It has requested that the 11 indicators for women's and children's health be reported for the lowest wealth quintile, gender, age, urban or rural residence, geographical location, ethnicity and, where feasible and appropriate, that mother's education, marital status, number of children, and HIV status is also reported.¹⁷
- The Countdown to 2015 initiative includes equity analyses as a regular component of its reporting on progress towards MDG 4 (reduce child deaths) and MDG 5 (improve maternal health) for 75 countries. It provides a breakdown of 18 indicators for essential reproductive, newborn, maternal and child health interventions by maternal education, gender of the child, wealth quintiles, urban or rural location, and region of the country.
- Household surveys, including the UNICEF-supported Multiple-Indicator Cluster Surveys (MICS) and the USAID-supported Demographic and Health Surveys (DHS), are the primary data source of health coverage indicators for children and women for most countries, and they usually provide disaggregated information on urban and rural location, wealth, gender, age groups and nationally defined ethnic groups.¹⁸

The measures of inequality listed above are those best captured by existing modes of data collection. But the real faces of inequality extend well beyond the data currently being compiled. The most vulnerable children may be the most excluded from statistics and essential health services, and most at risk of losing their rights to health, protection and identity.

A recent review of interventions to improve equity in the health-related MDGs found an almost complete lack of studies addressing social and cultural issues in relation to maternal and child health. Almost all of the studies addressed income poverty, reinforcing the idea that inequality in health is mostly considered to be a matter of income and that other inequalities are neglected.¹⁹ Yet we know that economic development is not enough for improving health for all. Despite efforts to measure and analyse child health, an understanding of the realities faced by the most vulnerable children and communities continues to elude governments, policymakers and planners.

World Vision's *The Killer Gap* report identified the following vulnerable groups of children for whom information is not routinely collected and who miss out on essential health services:²⁰

- children uncounted at birth and in death
- mothers and newborns who die around the time of childbirth
- indigenous children and ethnic minorities
- refugees and displaced children
- children living with disabilities
- child labourers and trafficked children
- orphaned children.

This report adds to this list children living in urban slums as another marginalised, uncounted group.


While there is far less evidence to assess their situation, and while present data constraints limit the scope for monitoring these children, we must raise our ambition to make sure they are counted and reached with the essential health services needed to save lives.

Conventional counting methods: Can they reach the most vulnerable children?

Health information systems generally use data gathered from population-based sources such as household surveys, vital registration and censuses, from facility-based sources such as hospital service records and individual patient records, and from surveillance systems to monitor health inequalities.

Routine data from facilities can provide continuous information at lower administrative levels such as districts, but health information systems are generally too weak to collect and utilise quality data, and these sources fail to capture groups – often the poorest and most marginalised – who do not access health facilities and thus go uncounted. There are several types of surveillance systems, including outbreak disease surveillance systems, which aim to track cases of diseases that could become epidemics, as well as their risk factors. Many low- and middle-income countries have established demographic surveillance sites, where information is collected for a particular defined population over a long period of time.²¹ These surveillance systems produce higher-quality data but for limited geographic areas that are not representative of national populations.

Amidst enthusiasm to realise the 'data revolution', there is much discussion on the role of household surveys as one of the most valuable sources of information for areas



Children who fall through the cracks in the health system often face not one but **multiple inequalities** at once.

There has been no **systematic attempt** to estimate the numbers of **children missing** from surveys.

covered in the new development framework and as the primary source of information on child mortality for most countries. Nationally representative household surveys are the method of choice for measuring reproductive, maternal, newborn and child health in low- and middle-income countries and for assisting in national and global decision-making for health interventions. This is likely to remain the case for the foreseeable future.^{22,23} The MICS and DHS programmes have contributed greatly to strengthening national capacities to collect high-quality data on a wide range of development indicators, including more than 20 MDG indicators.²⁴

But the ability of household surveys to monitor whether the poorest and most marginalised children are being reached with essential health services is limited. The sample size of DHS surveys (15,000 households) and MICS surveys (10,000 households) is enough to produce reliable information on most indicators at the national, rural/urban and regional levels but not at lower administrative levels such as districts and within communities for small population groups. To identify and highlight the experiences of smaller numbers of marginalised groups, household surveys can be used to oversample particular groups.²⁵ But oversampling and adding questions to surveys makes them time-consuming and costly, and the added value of producing information at lower levels needs to be balanced with the logistical challenges.


While household surveys are critical for data collection, now and in the future, the majority of the poorest and most vulnerable children, families and communities are simply not in the survey sampling frame and will continue to go uncounted with these methods alone. The design of household surveys neglects individuals who are not in households, such as children living on the streets; those who are in institutions, including refugee camps; and mobile or landless populations. Surveys will also under-represent many of the hardest-to-reach and vulnerable groups, including urban-slum dwellers and those in fragile or multiple-occupancy households.²⁶ Children facing multiple deprivations are even less likely to be captured by the sampling frames of surveys due to their small numbers.

The lack of recognition of the plight of the world's most vulnerable children and the inability of existing counting methods to give them visibility, means there has been no systematic attempt to estimate the numbers of children missing from surveys, where they are located or how to reach them with essential services.

Local-level data collection and monitoring: How communities can extend the health information system to reach the most vulnerable

To date the greatest improvements in health have been made amongst communities that are the easiest to reach, while millions of children and families continue to suffer and die in remote, hard-to-reach or hard-to-count locations. But many health information systems are designed and implemented without measuring and understanding the specific characteristics and contexts in which the most marginalised children and groups live. Without this information, these vulnerable groups will continue to miss out on the efforts under the MDGs and other similar agreements.

Health information is too important to be left to statisticians and politicians. Strengthening health information systems is also about imagining and creating a better world for all.²⁷



Community-based systems are a necessary investment to strengthen and expand the reach of national health information systems.

In light of this, community-based systems are a necessary investment to strengthen and expand the reach of national health information systems. Established methods for generating and using data to monitor progress in the health of women and children can be complemented with innovations that empower families and communities to conduct local-level monitoring. Communities can help to gather information on children and mothers who fall through the cracks in the data system – to understand who and where they are, what health services they have access to and what they are dying from. Since many deaths and illnesses never reach the level of the health facility and frequently go unreported, the collection of information *at the community level, by communities*, is paramount. Political will, local government engagement and the participation of communities are critical factors in developing innovative methods suitable for local conditions and experiences.

Community-based systems can be extremely cost effective as a solution to improving data collection. In the case of the community-based monitoring system (CBMS), an approach involving community members and local officials that is being implemented to track poverty and development issues at the household level in 14 countries across Africa, Asia and Latin America, the per-household cost of carrying out CBMS is much lower than the cost of household surveys undertaken by national statistical offices. The cost of CBMS in Vietnam is only around US\$0.30 per household, and in the Philippines it is \$0.70.²⁸ Local governments generally bear the cost of implementation. Commitment from local governments and municipalities is key to overcoming capacity and resourcing blocks.

Our vision for counting every child

Community participation in data collection and monitoring can generate accurate and rich information to complement national statistics and plug information gaps. Communities can help collect information on the health status of the poorest and most marginalised children that surveys cannot and can ensure that governments are in touch with the realities of people in the community. This means health systems and government services can be better designed and implemented to meet the needs of all portions of the community. Local-level approaches to data generation can support not only the flow of information from the community level through to the national level and back again but can create opportunities for real dialogue between marginalised groups and authorities at each level.

At present, there are no policy blueprints for generating and monitoring data at the local level with the participation of community members. We have identified four fundamental principles for expanding current health information systems to ensure that all children are counted, visible and reached with essential health services, and for putting equity at the heart of the numbers and statistics. By putting these principles into action, governments can expand their data systems to better capture information about the most vulnerable and improve their targeting of the most marginalised communities.

1. **Every child matters:** All mothers and children have the right to be counted from birth to death.
2. **The poorest and most marginalised children deserve special attention:** Local information on inequalities in health supports efforts to count the uncounted children.


3. **Local authorities should be partners in generating and using local information:** To count and reach the most marginalised children requires engaged and committed local authorities and leaders.
4. **Beyond data – community empowerment and accountable institutions:** Generating local information can be a participatory empowering process for communities and an opportunity for governments, communities and individuals to work together to reduce health inequality.

Local people generate information in many ways, through mapping, scoring, comparing and measuring. The methods and innovations are varied; they range from simple approaches, such as community scorecards and focus-group discussions, to high-tech systems, such as mobile phones and geographic information systems. Innovations in community monitoring are being carried along by the ever-increasing role of information and communication technologies. Recent advances in mobile phone technologies have increased the opportunities for bringing community participation and empowerment to data collection.

Citizen report cards and scorecards have emerged as powerful tools for monitoring, advocacy and accountability. Information can be collected by community health workers, community volunteers, village health committees, women's groups or local health providers. Community members can also be part of the process of analysing, validating and disseminating information.

Whatever the approach, any community health information system should have clear channels of information dissemination and feedback loops between the community and the service providers/governments. It should be designed with a focus not just on extracting data for data's sake, but on improving the health of individuals in the community, and achieving equity in a participatory, accountable way. Good policy choices for empowering the poorest and most vulnerable groups can best be made when local authorities work together with communities, who are given the opportunity to participate in health planning and implementation.

The elements of equity, participation, empowerment and accountability were largely missing from the MDGs and their target indicators. In the less than two years remaining before the expiry of the MDGs and as we advance the next development agenda, we are faced with an ideal opportunity to agree upon a transformative agenda for action where data and statistics are not only part of an information system for governments and agencies, but are behind the faces of real people, are part of an empowering process for local people and will lead to better child health outcomes. Achieving the vision for counting and reaching every child, every newborn and every mother is possible but it will take concerted effort and action from governments, donors, institutions, communities and families. We must focus on those children who are currently furthest from health centres and people's minds, ensuring the realisation of every child's right to be counted and to count.



Community participation in data collection and monitoring can **generate accurate and rich information** to complement national statistics and **plug information gaps.**

Endnotes

- 1 R. Carr-Hill (2012). *Measuring Inequalities: The Population Denominator Problem*, submission for the Global Thematic Consultation, Addressing Inequalities, The Heart of the Post-2015 Development Agenda and the Future We Want for All.
- 2 UN Inter-Agency Group for Child Mortality Estimation (2013). *Levels and Trends in Child Mortality 2013 Report*, UNICEF, New York.
- 3 UNICEF (2013). *Committing to Child Survival: A Promise Renewed, Progress Report 2013*, UNICEF, New York.
- 4 P. Setel et al. (2007). 'A Scandal of Invisibility: Making Everyone Count by Counting Everyone', *The Lancet*, Vol. 370, Issue 9598, pp. 1569–1577.
- 5 R. Carr-Hill (2012).
- 6 D. Jamison et al. (2013). *Global Health 2035: A World Converging within a Generation*, The Lancet Commission on Investing in Health. The Lancet, London.
- 7 Ibid.
- 8 Independent Expert Review Group (2013). *Every Woman, Every Child: Strengthening Equity and Dignity through Health*, World Health Organization, Geneva.
- 9 UNICEF, UN Women, UNDP and OHCHR (n.d.). *TST Issues Brief: Promoting Equality, Including Social Equity*. <<http://sustainabledevelopment.un.org/index.php?menu=1680>>
- 10 United Nations (2013). *A New Global Partnership: Eradicate Poverty and Transform Economies through Sustainable Development. The Report of the High-Level Panel of Eminent Persons on the Post-2015 Development Agenda*, United Nations, New York, p. 7.
- 11 Independent Expert Review Group (2013).
- 12 UNICEF, UN Women, UNDP and OHCHR (n.d.).
- 13 V. Russell (2013). 'World Leaders Must Heed Calls for Bold Development Goals, Says UNDP Chief', *Public Finance International*. <<http://www.publicfinanceinternational.org/news/2013/09/world-leaders-must-heed-calls-for-bold-development-goals-says-undp-chief/>>
- 14 World Vision International (2013). *The Killer Gap: A Global Index of Health Inequality for Children*, World Vision International, UK.
- 15 M. Woodhead, P. Dornan and H. Murray (2013). *What Inequality Means for Children: Evidence from Young Lives*, Young Lives, Oxford.
- 16 Ibid.
- 17 Commission on Information and Accountability for Women's and Children's Health (2011). *Keeping Promises, Measuring Results*, World Health Organization, Geneva.
- 18 J. Requejo et al. (2013). 'Measuring Coverage in MNCH: Challenges and Opportunities in the Selection of Coverage Indicators for Global Monitoring', *PLOS Medicine*, Vol. 10, Issue 5, pp. 138–145.
- 19 M. Malqvist et al. (2013). 'Targeted Interventions for Improved Equity in Maternal and Child Health in Low- and Middle-income Settings: A Systematic Review and Meta-Analysis', *PLOS Medicine*, Vol. 8, Issue 6.
- 20 World Vision International (2013).
- 21 World Health Organization (2013). *Handbook on Health Inequality Monitoring: With a Special Focus on Low- and Middle-Income Countries*, World Health Organization, Geneva.
- 22 J. Bryce et al. (2013). 'Measuring Coverage in MNCH: New Findings, New Strategies, and Recommendations for Action', *PLOS Medicine*, Vol. 10, Issue 5, May 2013.
- 23 A. Hancioglu and F. Arnold (2013). 'Measuring Coverage in MNCH: Tracking Progress in Health for Women and Children Using DHS and MICS Household Surveys', *PLOS Medicine* Vol. 10, Issue 5, May 2013.
- 24 UN System Task Team on the Post-2015 UN Development Agenda (2013). *Statistics and Indicators for the Post-2015 Development Agenda*, United Nations, New York.
- 25 E. Samman and L. Rodriguez-Takeuchi (2013). *ODI Background Note: Old Age, Disability and Mental Health: Data Issues for a Post-2015 Framework*, Overseas Development Institute, London.
- 26 R. Carr-Hill (2012).
- 27 C. AbouZahr and T. Boerma (2005). 'Health Information Systems: The Foundations of Public Health', *Bulletin of the World Health Organization*, Vol. 83(8), pp. 578–583.
- 28 C. Reyes and E. Due (2009). *Fighting Poverty with Facts: Community-Based Monitoring Systems*, International Development Research Centre, Ottawa, Canada.

WORLD VISION IS A CHRISTIAN RELIEF, DEVELOPMENT AND ADVOCACY ORGANISATION DEDICATED TO WORKING WITH CHILDREN, FAMILIES AND COMMUNITIES WORLD-WIDE 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.

INTERNATIONAL OFFICES

**World Vision International
Executive Office**
Waterview House
1 Roundwood Avenue
Stockley Park
Uxbridge, Middlesex
UB11 1FG, UK

**World Vision Brussels & EU
Representation ivzw**
18, Square de Meeûs
1st floor, Box 2
B- 1050 Brussels, Belgium
+32.2.230.1621

**World Vision International
Liaison Office**
7-9 Chemin de Balxert
Case Postale 545
CH-1219 Châtelaine
Switzerland
+41.22.798.4183

**World Vision International
United Nations Liaison Office**
919, 2nd Avenue, 2nd Floor
New York, NY 10017, USA
+1.212.355.1779

www.wvi.org

www.childhealthnow.org