## GONE TOO SOON; CAN SOMETHING BE DONE?



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#### TRIBUTE TO THOSE GONE TOO SOON

Some of the children who died before their 5th birthday



#### GONE TOO SOON

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Photography Courtesy of World Vision Uganda

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#### GONE TOO SOON; CAN SOMETHING BE DONE?

One in every 19 Ugandan children dies before the first birthday, and one in every 11 children dies before the fifth birthday. To some people these are mere statics but to many families these are children with names. In November, 2012, the Child Health Now advocacy campaign conducted an exercise where mothers were asked to share stories of their children's deaths. In this publication, we share some of stories and look at some of the names and faces in the statistics.

## **GLOBAL TRENDS**

The number of children dying each year under the age of 5 has fallen from 12 million to fewer than 7 million in the past two decades – a dramatic 42 per cent reduction. But there is still a long way to go. A staggering 4.4 million children died in 2011 from conditions which are preventable or treatable: pneumonia, diarrhoea, malaria, birth complications and newborn infections.

(Extracted from "Within Reach - Ending preventable child deaths"(World Vision International 2013)

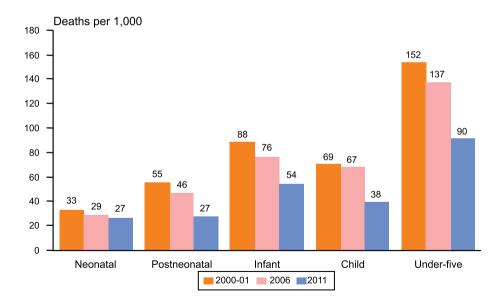
## INFANT AND CHILD MORTALITY TRENDS IN UGANDA

(Extracted from the Uganda Demographic Household Survey 2011)

- One in every 19 Ugandan children dies before the first birthday, and one in every 11 children dies before the fifth birthday.
- Infant mortality declined from 88 deaths to 54 deaths per 1,000 live births between the 2000-01 UDHS and the 2011 UDHS.
- Under-5 mortality from 152 deaths per 1,000 live births to 90 deaths per 1,000 live births between the two survey periods.
- Child mortality is higher in rural areas than in urban areas.
- The neonatal and postneonatal mortality rates were 27 deaths per 1,000 live births, each. The perinatal mortality rate was 40 deaths per 1,000 pregnancies.



Data extracted from the Uganda Demographic Household Survey 2011



### WHY UGANDAN CHILDREN DIE?

During the World Vision's Global Week of Action held on 13th -20th November 2013. One of the activities carried out was the production of the Under-five Mortality Quilt. Mothers, fathers and community members in 29 selected districts participated by telling stories of how their children died of preventable diseases the previous year (November 2011 – November 2012). According to the participants, the biggest cause of death among children below five years is: Malaria, Measles, Pneumonia, Diarrhoea, newborn infections and preterm complications. Majority of the people did not know the disease that killed their children.

#### DISTRICTS VISITED

A map showing districts visited during the Under-five mortality quilt production



In every district visited, parents voluntarily shared information about the death of their children. This activity was therapeutic to some mothers who had never had an opportunity to express their loss.

They provided information on the probable cause of the deaths, name of child who died, child's age at death and village. The wider community participated by making recommendations and demands to leaders in their communities and the government which when adopted could help prevents deaths among children. 1,180 cases were reported on the quilt.

KEY

Districts visited by World Vision Uganda



(L) A mother provides information about the death of her child on a quilt card. (R) A father places his card on the quilt cloth.

CHILD HEALTH NOW | GONETOO SOO



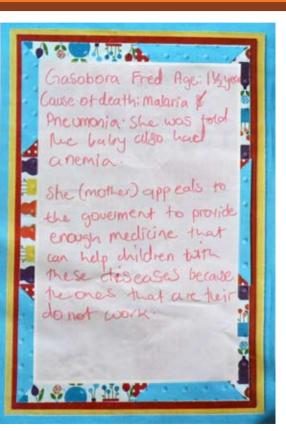
A mother receives support from her friends as she writes on her quilt card

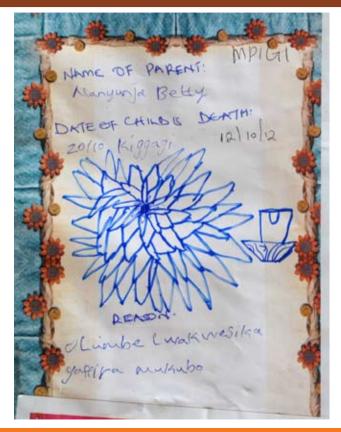




Pages 11 to 26 show quilt cards with information on cause of child death







13

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CHILD HEALTH NOW | GONETOO SOON

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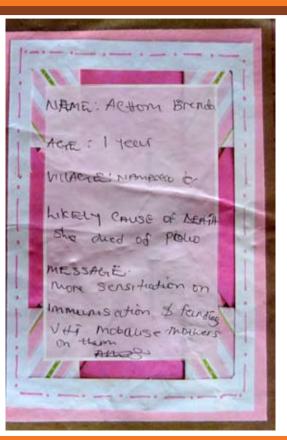
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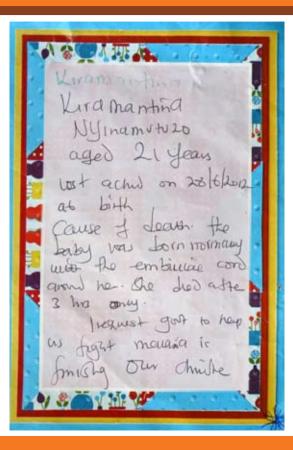


#### STORIES ABOUT CHILD DEATHS



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Maureen Nambatya from Nnindye sub-county in Mpigi district gave birth to a bouncing baby at around 8.00 am at Nkozi Hospital and was discharged. Later that evening, she noticed that her baby was not fine. He had a problem with his stomach- it was swelling.

She sought treatment from the Health workers at Nnindye Health Center III- the nearest health facility in her community. Upon arrival, the health workers accused her for using herbs on the baby, something she had not done. She was also accused of going to the health facility without the child's exercise book where medical records are kept which made it difficult for the health workers to provide timely treatment.

Maureen says she begged the health workers to consider her as the baby's health was above the missing book in vain. All this while, the baby's stomach continued to swell and the baby developed a high fever, convulsed and died.

#### Jamila Nabila of Kiwangala Villaga narrates her story below:

"One morning, my child developed severe dirrhohea. I took him to the nearby health centre but I was referred to Kitovu Hospital which is about 50km away. I did not have enough money for transport so I walked but because the distance was long, my child's condition worsened and she died before I could make it to the hospital."

#### David Kabubi from Rakai district says;

"My Joram Ssepuma developed a high fever, he was taken to hospital where a kidney infection was diagnosed by the health workers. We kept on taking him for treatment but his health just worsened. Joram was urinating blood and had a very high temperature. He was sick for a almost a month. Later on, we had Joram tested again but the Doctor's diagnosis showed that his Kidneys were fine. We did not know what our son was suffering from but we could see that he was in pain. For one year, he passed blood in his urine until he died. Grace Aneno from Lagoro village in Kitgum district lost her first baby, Julius Omara on October, 5th 2012. He was only 4 years old.

Grace says Julius had strange swellings on his chin which were causing him too much pain. She took him to a nearby herbalist who provided some herbs but the pain intensified. She took him to Akuna Labek Health centre 11- about 5kms away from her village where the nurse prescribed some antibiotics for the baby.

Two days later, she realized that Julius health was not improving. She went to the health centre where the In- charge told her that they did not have drugs to offer for such a case. She was referred to Kitgum hospital- 80km away where she was advised to buy the drugs from a pharmacy but could not afford to meet the cost of Ug. Sh. I 5,000.

Later she embarked on a journey to Kitgum town hospital. She had to walk with the sick child, with no food. She spend some nights with relatives and well wishers along the route. Unfortunately, the baby past away before they could reach the hospital. After dying, black smelly fluids started coming out of the dead body. She took it back home for burial and to date, the disease remains a mystery to all the concerned friends and family.

Betty Ocen Olal's son Geoffrey Ocen passed away on 11th March 2012 in Aboke sub-county, Oyam District. Widowed in 2012, Betty is HIV positive with four children under her care. Geoffrey too was HIV positive and died of oppountistic infections.

While pregnant, Betty did not seek antenatal care therefore was ignorant about the prevention of mother to child transmission of HIV. After delivery, she was advised to breast feed the baby exclusively for six months only. After six months she introduced solid foods to the baby which were not nutritious. The baby fell ill, it had severe head ache, diarrhea and was vomiting. It became malnourished. By the time Betty sought treatment, the baby was too sick to survive death.



Twenty one year old Aida Nalumu's baby Patricica Nakamyuka died at the age of two to what Aida describes as negligence in the home and at the health centre.

One fine morning, Aida left Patricia at home unattended too and went to the saloon to have her hair washed. Minutes later, her neighbour's child came looking for her with bad news. Patricia had chocked on a maize cob and was in critical condition.

Patricia was taken to St. Francis Health Centre IV in Buikwe but the health workers could not treat her. She was referred to Mulago hospital where the doctor whose shift had just ended refused to treat the baby saying the doctor in the next shift would see them. Patricia later died that evening before she could be attended to. David Egesa, 35, lost his granddaughter a few hours after she was born to 15-year-old Prossy Nabwire. When Prossy discovered she was pregnant, she left Kampala where she was working as a house help to live with her grandfather. Unfortunately, she never got any antenatal care services. During delivery, she was helped by Traditional Birth Attendant who failed to resuscitate the bay when it failed to breathe on its own.

## RAISING HANDS FOR CHILD SURVIVAL

World Vision Uganda through the Child Health Now Campaign which aims at contributing to the reduction of preventable deaths among children below five years, participated in the first Global Week of Action.

One of the activities carried out was the production of the Under-five mortality quilt which was presented to Members of Parliament, Civil Society Organizations and the Media on 20th November, 2012. The quilt was a platform for the communities to tell their leaders the major cause of child death in their communities and recommended solutions.

They also raised their hands as a way of showing their support and commitment towards preventing child death.

"Count me in- I want Children to survive 5!" was the slogan used throughout the Global Week of Action.



Pages 31 to 40 show some of the people who raised their hands for the survival of children in the visited districts.



























# PROPOSED SOLUTIONS FROM THE COMMUNITIES TO END CHILD DEATHS

In order to reduce the number of Children in communities dying of preventable diseases, communities recommended the following:

- Advocating to the Districts to include activities of Maternal and Child Health Nutrition in the District work plans.
- Continuous capacity building for health workers in several health related packages especially for children and mothers should be provided.
- Encourage health workers to work in hospitals full time and attend to patients efficiently.
- Extending health care services to communities.
- Government should equip health centres with enough drugs and skilled health workers.
- Government to provide drugs for some diseases like sickle cells.
- Government to set up buffer stocks especially of rare drugs to avoid stockouts.
- Government to setup more blood centres.
- Implementing the ICCM (Integrated Community Case Management) which helps to identify, treat, and refer cases of children with the common Child illness like Malaria, Pneumonia and Diarrhoea which are the lead causes of child mortalities.



- Increasing sensitization of mothers on Maternal and child Health Nutrition issues using Mother support groups.
- Increasing the number of skilled health workers delivering ANC services to Women of Child Bearing Age.
- Increasing the rate of follow-up of pregnant mothers and their new born by the Village Health teams.
- Provide ambulances to take patients to health centres especially those that are so far.
- Strengthening the Primary Health care system at community level. Especially VHTs to mobilize community members for outreaches like Immunization, de-worming and others.
- Subsidizing the prices of medicine sold at the hospitals.



## ADVOCACY PRIORITIES FOR CSOs

- Increased government expenditure on health to 15% as per the Abuja Declaration and commitment made by the Government of Uganda. Within the Health Sector, Maternal and Child Health should be prioritized by allocating adequate fund.
- Increased community involvement in health systems strengthening and promoting accountability through Local Level Advocacy approaches (e.g. Citizen Voice and Action used by World Vision).
- Increased coverage of key interventions for child and maternal health.
- Government should review and implement appropriate policies with a particular focus on child health.
- Children, mothers and community members should be empowered with information to claim for their right to quality health service.



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#### COUNT ME IN - I WANT CHILDREN TO SURVIVE 5!