

PREVENTING
AND ADDRESSING
STILLBIRTHS

ALONG THE
CONTINUUM
OF CARE:

A GLOBAL ADVOCACY
AND IMPLEMENTATION GUIDE

PREVENTING AND ADDRESSING **STILLBIRTHS** ALONG THE CONTINUUM OF CARE:

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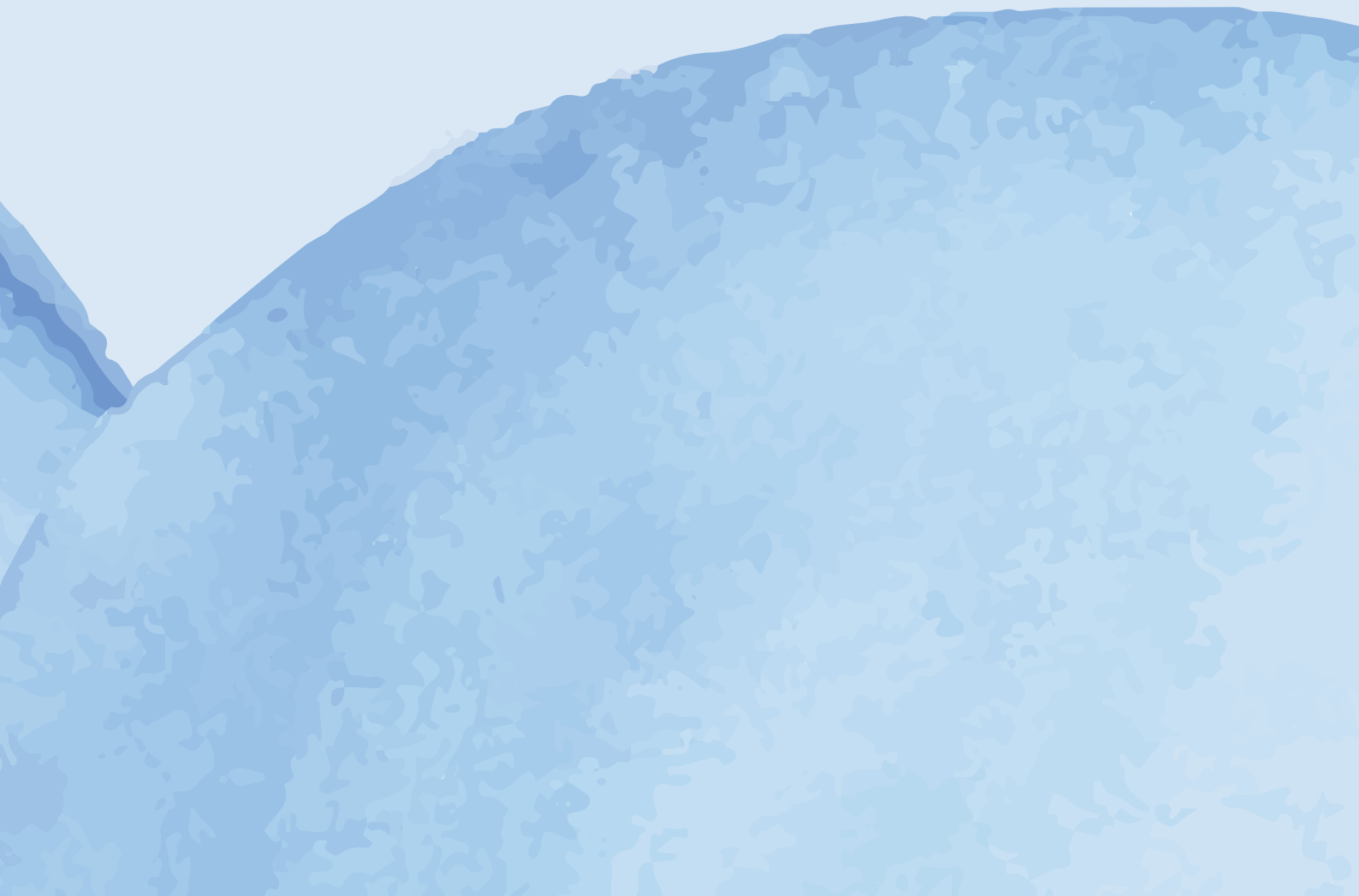
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THE VISION

We envision a world in which preventable stillbirths no longer occur, and care for families and health workers after stillbirth is compassionate, high quality and culturally appropriate.



FOREWORD



When a baby is stillborn, the impact on parents, their families and the health-care professionals who have cared for them can be devastating. The resulting grief is as strong as that for the loss of any child, yet poor acknowledgement of their birth and the pregnancies that resulted in a stillbirth, combined with stigma, blame and silence, continue to limit acceptance and legitimization of these tragic experiences across the globe. Inadequate quality of care during pregnancy, labour and birth impacts stillbirth prevention. The shared vision of the International Stillbirth Alliance and our members is to improve access to quality care across the continuum of maternity and newborn care. This includes support for parents and families, as well as those who care for them, across a range of health-care and community settings.

As many of us contributing to this foreword have lived experience of bereavement following the death of a baby, we welcome this guide and extend our thanks to the Bill & Melinda Gates Foundation for overarching funding and to the authors and contributors who have devoted their time and expertise to bring this guide to fruition.

Central to this guide are the voices, experiences and images of many bereaved parents who have collaborated each step of the way to co-produce

a unique document. To those parents and their babies, we also extend our deepest gratitude and thanks.

We hope this guide will be read and utilized by all those working to integrate stillbirth prevention and care into national, subnational and health-care facility programmes and policies – because every pregnancy and every baby counts. By taking a holistic and collaborative approach to policy development and implementation, and by including and listening to bereaved families, it is possible to ensure that all women and babies experience the quality, safe and respectful care they deserve throughout the continuum of care.

A handwritten signature in black ink, appearing to read 'Claire Storey'.

Claire Storey, Director of Bereavement, Community and Parent Voice, on behalf of the International Stillbirth Alliance Board

Marti Perhach, CEO and Co-founder of Group B Strep International

Grace Mwashigadi, Research Coordinator, Aga Khan University, Kenya

JOINT MESSAGE FROM COLLABORATING ORGANIZATIONS

Every day, over 5,000 babies are stillborn, affecting nearly 2 million families every year. Two out of five of these deaths occur during labour, most of which are preventable with high-quality maternity care. While some progress has been made in reducing the global stillbirth rate, substantial disparities persist between and within regions and countries, with the most vulnerable groups continuing to experience disparities in all countries. Timely care and support can mitigate the known impacts of stillbirths on women, families, communities and health workers. Yet such support is only sparsely available, and little progress has been made to close these gaps in access. Despite previous calls for action, progress has been slow.

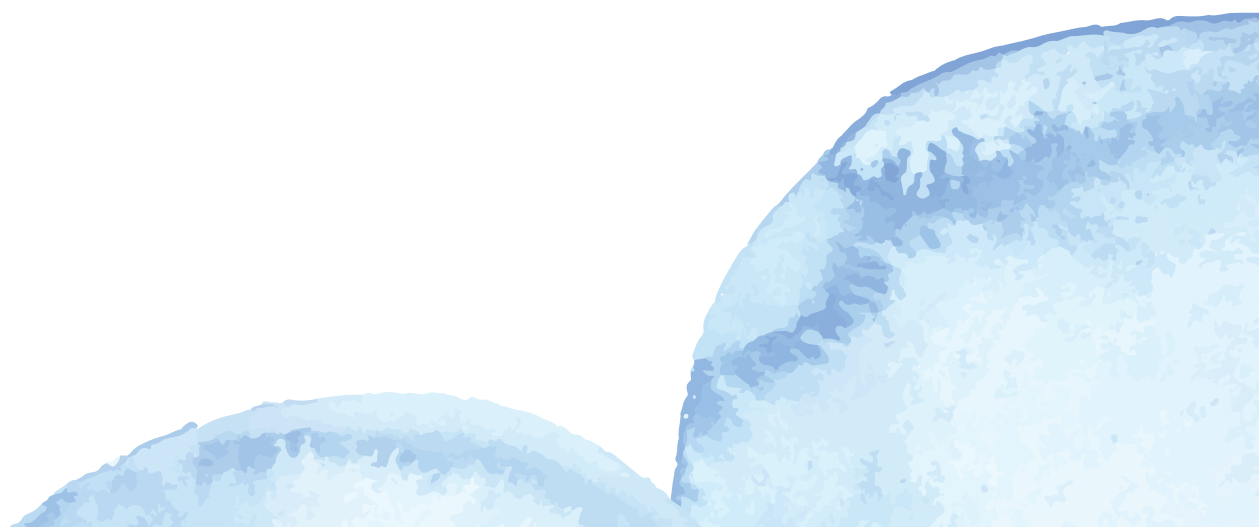
We can and must do better.

In its latest report, *Never Forgotten: The Situation of Stillbirth Around the Globe*, The United Nations Inter-agency Group for Child Mortality Estimation describes the dire situation of stillbirths around

the globe. It makes clear that, to drive change in preventing stillbirths, there must be sound policies and targeted investments along the continuum of care.

From the team of volunteers representing United Nations organizations, donors, academics, professional associations, facility directors, administrators, clinicians, parent organizations and others who have been working on this global stillbirth advocacy and implementation guide, we hope to aid and empower readers to use this guide to inspire the change needed to end preventable stillbirths and ensure respectful and supportive care for every woman and family after stillbirth. By taking immediate action as a global community of champions, we can ensure quality and respectful maternal and newborn care along the continuum of care and make the vision of this guide a reality.

We hope you will join us.



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ACRONYMS

CRVS Civil registration and vital statistics

EmOC Emergency obstetric care

EmONC Emergency obstetric and newborn care

ENAP Every Newborn Action Plan

EPMM Ending Preventable Maternal Mortality

HIC High-income country

ICD International Classification of Diseases

ICM International Confederation of Midwives

IMPROVE Improving Perinatal Mortality Review and Outcomes Via Education

ISA International Stillbirth Alliance

ISA-SAWG International Stillbirth Alliance Stillbirth Advocacy Working Group

LMIC Low- and middle-income country

MOH Ministry of Health

MPDSR Maternal perinatal death surveillance and response

NBCP National Bereavement Care Pathway

PMNCH Partnership for Maternal, Newborn and Child Health

PVI Parent Voices Initiative

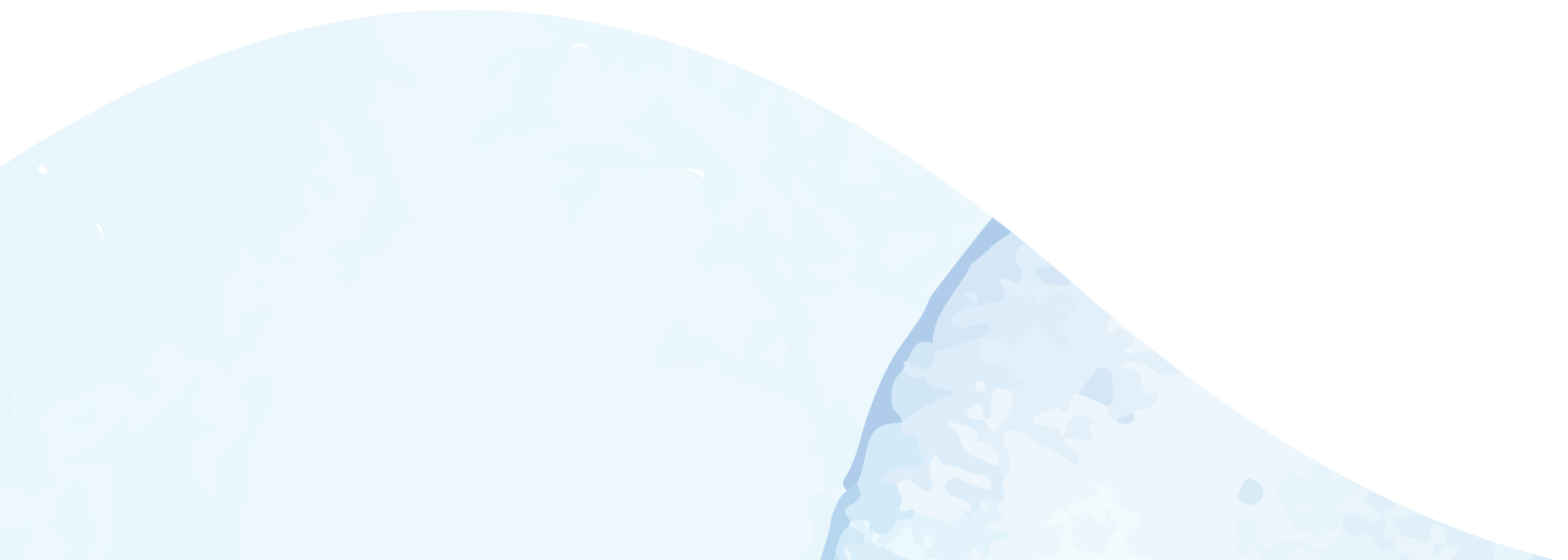
RMNCAH Reproductive, maternal, newborn, child and adolescent health

UN-IGME United Nations Inter-agency Group for Child Mortality Estimation

UNFPA United Nations Population Fund

UNICEF United Nations Children's Fund

WHO World Health Organization



USING THIS GUIDE



Purpose of the guide

This guide is intended to provide technical resources and practical guidance for stillbirth advocacy and programme planning at national and subnational levels. The guide does not present new information but rather brings together existing resources, global guidance and toolkits in one place to inform planning, investments and programmes aimed at ending preventable stillbirths and improving care for all women and families who experience stillbirth. In doing so, gaps in available resources are also highlighted.



Target audience

The target audience of this guide includes:

- Country-level and subnational governments and stakeholders, including ministries of health, civil registration authorities and national statistics offices.
- Health-professional organizations including national medical, midwifery and nursing associations and other relevant bodies.
- Hospital and health facility directors, managers and administrators.

It is anticipated that the guide will also be useful for parents, parent organizations, community leaders, individual clinicians and others who advocate for stillbirth prevention and respectful and supportive care after stillbirth to be integrated along the continuum of maternal and child health care.



Stakeholder level definitions

The content in this guide is sometimes aimed at specific stakeholder levels. The following definitions have been used:

- **Policy level:** Includes those who work in ministries or United Nations agencies in-country and make or directly influence policy.
- **Mid-level:** Includes those who work in ministries or United Nations agencies in-country but do not make or directly influence policy.
- **Local level:** Includes those who do not work in ministries or United Nations agencies, whose work is based in communities (villages, cities, towns).



Types of resources included

Included in this guide are links to global guidelines, toolkits, key initiatives, training resources, data sources and publications about stillbirth and care along the continuum of maternal and child health. Case studies from a wide range of geographical contexts are also included to illustrate what can be achieved.

A colour-coded system has been used to organize specific features of the guide:

- Blue boxes: reflections, definitions of key terms and key data and their sources (the latter presented as “Data highlights”).

- Large lavender boxes: case studies, often presented as “Sharing what works”.
- Green boxes: resource links, presented as “Resources”
- Aqua boxes: links for further information, presented as “Learn more”.
- Orange boxes: content specific to bereavement care.



Navigating the document

This guide includes hyperlinks to external web resources, as well as internal hyperlinks to specific sections of the guide itself. To return to your place

in the guide when using internal hyperlinks, press *ALT+left arrow* (PC) or *Command+left arrow* (Mac) on your keyboard.



Feedback and updates

The International Stillbirth Alliance Stillbirth Advocacy Working Group (ISA-SAWG) welcomes feedback on this guide, as well as suggestions for additional resources to be included in future updates, to sawg@stillbirthalliance.org.