



international
stillbirth alliance

Strategic Plan 2021-2025

19 February 2021

Introduction

There are an estimated 2 million stillbirths each year, of which about half occur during labor and delivery and half occur in the antepartum period. Most stillbirths occur in sub-Saharan Africa and South Asia and in remote and rural areas. Stillbirth is also more common within marginalized populations in all countries, for instance among Black Americans in the USA and Indigenous families in Australia. The burden of stillbirth includes both the tragedy of preventable death and the bereavement and other effects of stillbirth that occur after the death. These include grief, trauma, stigma, and economic and financial challenges felt by parents, other family members, and also health workers who provide care to these families. These effects are exacerbated by poor quality or non-existent bereavement support.

To date, there has been more global focus and progress on ending newborn death than on ending stillbirth. Despite the heavy mortality burden, stillbirth was absent from the Millennium Development Goals and is still missing in the Sustainable Development Goals. Stillbirth remains largely invisible in global, regional, and national policies and programs, underfinanced and in urgent need of attention. However, ISA recognizes that stillbirth lies on a continuum of adverse pregnancy outcomes. Many of the interventions to prevent newborn death can also reduce stillbirth, many of the approaches to respectful bereavement care after stillbirth may also be relevant for care after newborn death, and in many cases, there is misclassification between stillbirth and newborn death. For all these reasons, global action for stillbirth prevention and support naturally overlaps with newborn death prevention and support. Therefore ISA has revised its mission statement to include newborn death.

The International Stillbirth Alliance (ISA), founded in 2003 by three bereaved mothers in the USA, is the only organization that focuses on stillbirth and neonatal death at a global level and integrates bereaved family members, clinicians, researchers, and policy makers. ISA has 122 members from 26 countries in the Americas, Europe, Africa, Asia, and Oceania. About 50% are health professionals, 40% are organizations, primarily parent support organizations with several research institutes and professional organizations, and the remainder are individual parents, students, and other supporters. ISA has achieved a great deal with virtually no funding apart from membership fees and donations and despite lacking any paid staff. Run only by a volunteer board, ISA has increased its impact over its 18 years of existence, including the signature ISA Annual Conference, which has been held for 15 years in countries ranging from Vietnam and South Africa to Uruguay, the Netherlands and Antigua. This document outlines our strategic plan for our work through 2025, with bold goals to deliver real change.

Vision & mission

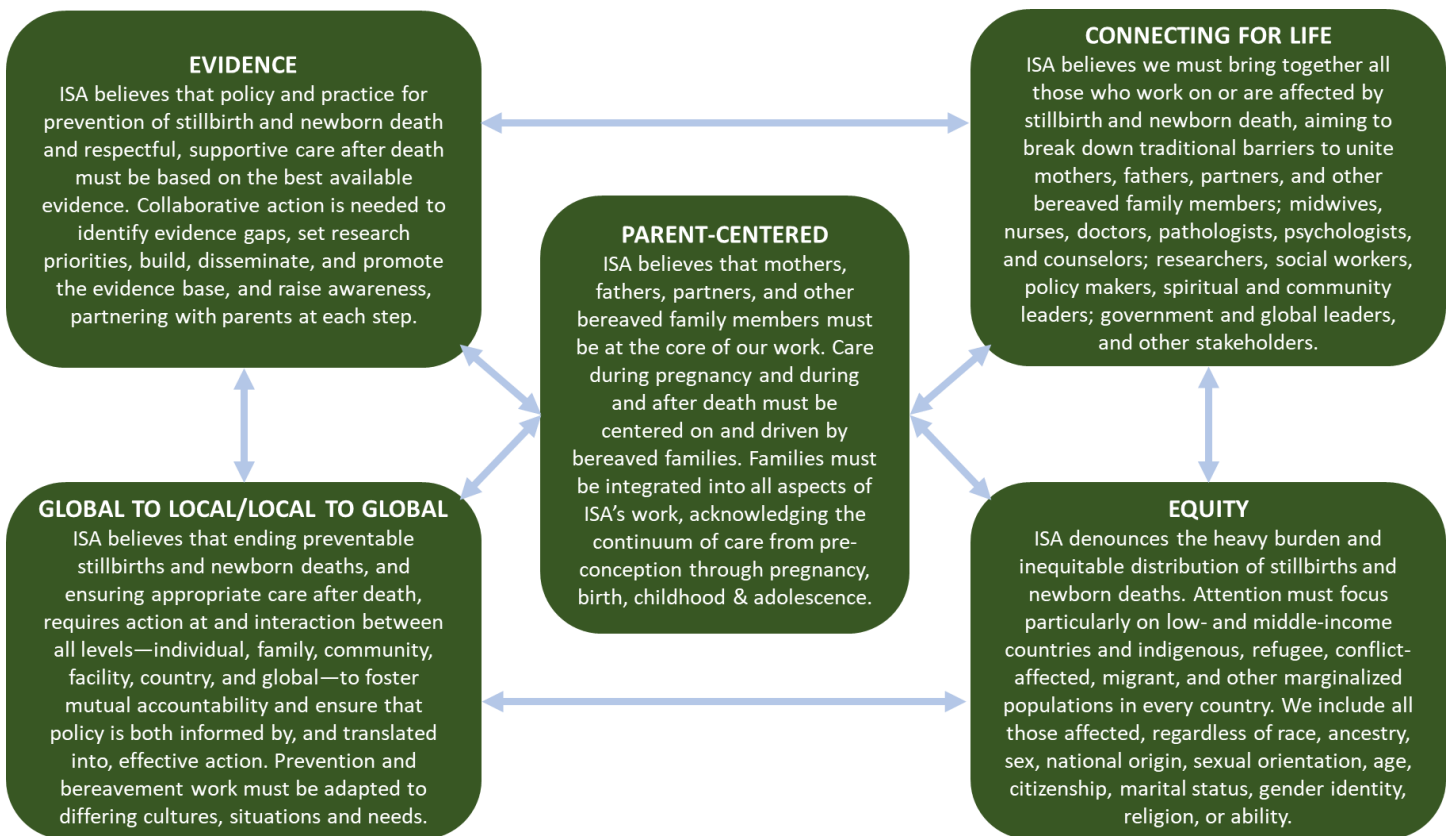
ISA's **vision** is a world without preventable stillbirth or newborn deaths, and appropriate respectful and supportive care for all who are affected.

ISA's **mission** is to promote global collaboration for the prevention of stillbirth and newborn death and for appropriate respectful and supportive care for all those affected.

Safe, wanted, healthy pregnancies and healthy, full-term babies are the ultimate aim of ending stillbirth and newborn death. However, silence about stillbirth is one of the main driving forces that keeps it a major yet neglected global public health burden. For this reason, we use the words of our vision and mission to bring stillbirth and newborn death out of the shadows.

Principles

ISA's work is driven by five principles, listed below. The strategic goals align fully with each of these principles.



Goals & objectives

ISA has five goals, listed below together with their objectives.

- The first two goals describe the levels at which we aim to have an impact (the “**where**”): both globally and within a small number of target countries, including country level, sub-national level, and community level effects.
- The third goal describes in more detail a key area in which we intend to bring about change (the “**what**”): using data to affect policy and practice.
- The fourth goal highlights some particular key stakeholder groups we aim to better integrate into our work (the “**who**”), including parents.
- The fifth goal underlies all the others as it articulates the broad strokes of “**how**” we will achieve our mission—through organizational sustainability.

These goals are inherently interlinked and infused with the principles listed above.

Goal 1 (GLOBAL): By 2025, ISA will be a leader in the global movement to end preventable stillbirths & newborn deaths & provide respectful care.

1. **PRESENCE:** ISA will build our global presence through participation in key global and regional initiatives, e.g., ENAP, AlignMNH, key conferences, etc.
2. **AWARENESS:** ISA will support efforts to raise awareness and reduce stigma at a global level through collaboration on key advocacy/communications/social media initiatives.
3. **RESPONSE:** ISA will lead timely responses to key global and regional events, releases, publications, etc. through joint publications/commentaries/statements, social media, etc.
4. **PARTNERSHIP:** ISA will seek out and build partnerships with women and their families and key global allies, e.g., civil society organizations, governments, global organizations such as UNICEF, WHO, ENAP, AlignMNH, FIGO, COINN, IPA, ICM, etc., particularly advocating for funder support of key actions at all levels (e.g., GFF, Gates, etc.)

Goal 2 (COUNTRIES): By 2025, ISA will have significantly contributed to ending preventable stillbirths & newborn deaths & providing respectful care in 3-5 target countries.

1. **TARGET COUNTRIES:** ISA will identify 3-5 countries to focus on that are high-burden or have substantial high-burden populations (India; one country each in sub-Saharan Africa; Oceania; Latin America; one high-income country), supporting the development of Regional Offices to facilitate country-specific work.
2. **PARTNERSHIP:** ISA will seek out partnerships with key groups within each target country or subnational setting who work on, or are involved with, prevention and/or bereavement support, including Government, UN (UNICEF, WHO country offices), parent organizations, professional associations (e.g. midwives, nurses, physicians), training institutions/hospitals, civil society and humanitarian organizations, universities, religious institutions, national working groups, and including the voices of women and their families.
3. **NATIONAL CHAMPIONS:** ISA will identify and support at least one national champion in each target country.
4. **IMPLEMENTATION:** ISA will support research, prevention, bereavement support, advocacy, political commitment, and awareness efforts in each target country, including communication to reduce stigma.

Goal 3 (DATA, POLICY, PRACTICE): By 2025, ISA will have significantly increased the translation of evidence into policy and practice through generation, adaptation, and dissemination of our own and our partners' data, tools, and programs.

1. **ACCESS:** ISA will map and increase access to existing data for global prevention and bereavement work, including the Global Scorecard, and ensure increased accessibility to parents, families, and communities.
2. **IMPLEMENTATION:** ISA will collaborate to adapt, disseminate, and integrate promising and best-practice interventions and capacity building for prevention and bereavement support.
3. **RESEARCH:** ISA will advocate for, endorse, collaborate in, and lead new research to fill identified gaps in data on prevention and bereavement support, in collaboration with parents.
4. **LIVED EXPERIENCE:** ISA will support integration of families' and caregivers' lived experience into research and the translation of evidence into policy and practice.

Goal 4 (STAKEHOLDERS): By 2025, ISA will have significantly increased the integration, voice, and impact of key stakeholder groups within global and country-level action.

1. **MODALITIES:** ISA will use multiple modalities to build connections and collaboration across all stakeholder groups, including our flagship annual conference, while also establishing other, demand-driven initiatives such as country workshops, webinars, etc.
2. **PARENTS:** ISA will increase integration and voice of affected parents within global prevention and bereavement work, especially parents from LMIC and marginalized populations and adolescents.
3. **NEWBORN DEATHS:** ISA will include newborn deaths together with stillbirths in all our work.
4. **OTHER KEY GROUPS:** Recognizing the interconnectedness of conditions associated with stillbirth and newborn death; recognizing that stillbirth and newborn death lie on a continuum of adverse reproductive, maternal and child health outcomes, including maternal morbidity and mortality and other pregnancy losses such as miscarriage and induced terminations; and acknowledging the importance of ensuring that all women have access to evidence-based information about healthy and safe pregnancy and birth, ISA will reach out to engage with particular stakeholder groups who have been less well-integrated into our work to date.

Goal 5 (SUSTAINABILITY): By 2025, ISA will have harnessed our passion, finances, management, and membership to increase our organizational sustainability.

1. **PEOPLE:** ISA will celebrate and support our greatest resource and engine: our people and their passion, including board, staff, volunteers, ISA and WG members.
2. **MEMBERSHIP:** ISA will expand, animate, and be responsive to our membership.
3. **FUNDING:** In the first 3 years of this strategic plan, ISA will make every effort to obtain the significant multiyear core funding that would enable hiring full-time staff. If successful, ISA will work to build successes into replicable models. If unsuccessful, ISA will focus the final 2 years of this strategic plan on reimagining ourselves as a sustainable, volunteer-only organization (rather than continuing to try for large grants).
4. **REGIONAL OFFICES:** ISA will support the establishment and functioning of regional offices based on principles of a shared vision/mission and mutual benefit, to best implement this strategic plan.
5. **LEADERS:** ISA will seek out and build the next generation of leaders, including parent advocates.
6. **CORE FUNCTIONS:** ISA will build and maintain sustainable core organizational functions, including: communications, website, and social media presence; finances and donations; board member recruitment; record-keeping; partnerships to support volunteer regional offices; Working Groups for advocacy, prevention, bereavement, parents, and conferences; administration; legal security; and planning, monitoring & evaluation.

Annex 1: Measuring success

One tool to measure our success in achieving our bold strategic plan is to report on our progress against some key indicators. Below are listed indicators that we have chosen to report on annually. They do not and cannot fully capture all that we hope to achieve. Our limited resources require us to focus on a relatively small number of indicators, which are a proxy for the depth, breadth, and underlying intent of our goals. **Nine are ‘external-facing’**, capturing some of the work we hope to achieve. **Nine more are ‘internal-facing’**, capturing progress on the resources we require in order to achieve our goals. **The final two indicators reflect our mission.** Though ISA cannot alone affect measures such as the global stillbirth rate, we can and must track these global indicators as they are the reason we exist.

External-facing

1. # of global, regional, or country-level initiatives (such as advisory groups, committees, campaigns, or programs) that ISA initiates or joins
2. # of conferences that ISA holds, and # delegates, both total and disaggregated by country, region, group (parent, clinician, etc)
3. # of global, regional, or country-level events other (such as conferences, workshops, or webinars) that ISA initiates or participates in (other than the ISA conference)
4. # of global, regional, or country-level initiatives or events that include parent voices due to ISA’s advocacy
5. # of articles/commentaries published by ISA
6. # of country partnerships established by ISA
7. # of national champions supported by ISA (financially or in-kind)
8. # of research initiatives that ISA endorses, participates in, or initiates
9. # of settings in which the Global Scorecard is used

Internal-facing

10. # of ISA regional offices
11. # of funding proposals ISA submits
12. Income, total and disaggregated by source (membership fees, individual donations, grants)
13. Total assets at year’s end (existing assets and income less expenses and debts)
14. # of ISA members, both total and disaggregated by country, region, member type (parent, clinician, organization), and marginalized group (LMIC, HIC, etc.)
15. # of Working Group members and proportion who are parents and/or represent LMIC and other marginalized groups
16. # of ISA paid staff, consultants, and volunteers
17. Level of security of ISA assets, including board liability, bank and PayPal accounts, website, and files.
18. Satisfaction level with ISA’s work, assessed through a short anonymous survey sent to board, ISA members, Working Group members, staff, volunteers, and other stakeholders.

Tracking the mission

19. Rates of stillbirth and newborn death globally, in target countries, and sub-nationally among marginalized populations
20. Availability and uptake of appropriate, respectful bereavement care globally, in target countries, and sub-nationally among marginalized populations

Annex 2: Risks

There are many external factors that may affect ISA's ability to achieve this plan. Some are listed below. As we progress in implementing the plan, we will need to continually review and update these risk factors and take them into account in our planning.

- Covid-19-related delays and shortfalls in donations
- Differing situations in settings where we hope to have impact, including different levels of ENAP engagement, degree of education and empowerment of women, and pace of cultural or social change.
- Inability to raise the required funds or obtain the required donated expertise and time.

Annex 3: Implementation of this strategic plan: The “how”

Our 5-year strategic plan outlines what we want to achieve between 2021 and 2025. We will review the plan twice annually, once prior to the annual General Assembly and once at the end of the year, discussing successes as well as roadblocks and reasons for the roadblocks, reporting against indicators, and specifying plans for the coming year. A financial report should accompany the review.

To turn this plan into action, we will create an annual workplan identifying specific actions, individuals who will lead and carry out these actions, time frames, and required resources, including a budget. The workplan for each year will answer many of the questions stakeholders raised in their review of the strategic plan about how we intend to achieve our goals.

Annex 4: Definitions

- **Advocacy.** A set of methods for doing any type of work that focuses on influencing and changing key decisions and the policies and programs they determine. For ISA, which is focused on prevention and bereavement support, advocacy is a method of influencing decisions and policies that affect prevention and bereavement support. Other methods for achieving change include research, communications, and training.
- **Bereavement care.** This should be respectful, supportive, compassionate, and culturally acceptable, driven by families' lived experiences, and informed by the best available evidence.
- **Burden.** By the 'burden' of stillbirth/newborn death, we mean both mortality (stillbirths and newborn deaths), and all other adverse outcomes associated with these deaths, including grief, stigma, mental illness, financial and economic costs, and other outcomes. Reduction of this burden entails both preventing the deaths and providing appropriate care after death occurs.
- **National champion.** An individual who is a citizen of the country who has, or has the clear potential for, national leadership in facilitating high-impact changes in national or subnational policy and/or practice. The individual has, or has the clear potential for, national recognition, strong links to key national decision-makers at multiple levels, deep understanding of the national situation, needs, and decision-making processes, a track record of successful advocacy to make needed changes in policy and/or practice, and the ability and strong desire to devote their time and effort to meaningful country-level improvements. This individual can be from any relevant background, including policy maker, health worker, or parent.
- **Newborn death/neonatal death.** Newborn or neonatal death is the death of a baby after live birth, through the 28th day of life. This is often disaggregated into early newborn death (on days 0-7 of life) and late newborn death (on days 8-28 of life).

- **Partner.** ISA considers a partner to be a formal or informal organization with whom ISA collaborates toward a shared objective. ISA partners should work in accord with ISA’s principles.
- **Preventable.** Most stillbirths and newborn deaths are preventable. ISA considers a preventable death to be any death that could have potentially been avoided with any known or hypothetical change in policy or practice at any level (from the individual to the global).
- **Prevention.** Includes evidence-based interventions to reduce stillbirths and newborn deaths. These include family planning and interventions to reduce preterm birth.
- **Stillbirth.** Stillbirth is the death of a baby before birth or during labor & delivery. Countries define stillbirth differently. While ISA respects variation in global, national, and local definitions of stillbirth, ISA considers all deaths from 20 gestational weeks on to be stillbirths.
- **Support.** Support by ISA could include making connections between key individuals and organizations, providing in-kind support such as help with strategic planning or preparation for a meeting or webinar, collaboration on research or with publications, and, when and if our financial situation allows it, this may also include financial support, for instance to attend an international meeting.

Annex 5: Acronyms

- ENAP. The [Every Newborn Action Plan](#)
- AlignMNH. [Collective Action for Maternal Newborn Health](#)
- WHO. The United Nations’ [World Health Organization](#)
- ICM. The [International Confederation of Midwives](#)
- UNICEF. The [United Nations’ Children’s Fund](#)
- IPA. The [International Pediatric Association](#)
- COINN. The [Council of International Neonatal Nurses](#)
- FIGO. The [International Federation of Gynecology and Obstetrics](#)
- PVI. ISA’s [Parent Voices Initiative](#)
- COCOON. [Continuing Care in Covid-19 Outbreak](#)

Annex 6: Process of strategy development

This strategic plan was developed by the ISA board between October 2020 and February 2021. Aspects of the plan were first discussed at two board meetings in November 2020 and further refined at a board meeting in December 2020 and through emailed input in January 2021. Input to the draft was also requested from key stakeholders via email or calls with the chair, vice-chair, and/or secretary twice, first in November 2020 and again in January 2021. A total of 36 individuals from 30 organizations provided input either once or twice, including parent support organizations, research institutes, civil society and academic institutions, and others, from 14 countries in Asia, Africa, Oceania, Europe, and the Americas (see table below). A further 12 were invited to provide input but did not. The plan was revised based on all input received and is now submitted to the board for its approval at the February 17, 2020, meeting. It will then be finalized and submitted to the General Assembly in February 2021 for review.

Respondent	Organization	Country	Stakeholder group(s)	Input in Nov or Jan?
1. Alex Heazell	Tommy's, University of Manchester	UK	Parent support organization, research institute, clinician	Nov
2. Beth McClure	RTI, University of North Carolina	USA	Research institute	both
3. Caroline Homer	Burnet Institute	Australia	Research institute, clinician (midwife)	both
4. Charlotte Warren	Population Council	Global	Civil society	Jan
5. Claudia Ravaldi	Ciao Lapo	Italy	Parent support organization	both
6. Danielle Pollock	University of Adelaide	Australia	Parent, researcher	Jan
7. Danzhen You	UNICEF	Global	Multilateral	Nov
8. Diana Jepkosgei	Still A Mum	Kenya	Parent support organization	Nov
9. Fleurisca Korteweg	Martini Hospital Groningen	Netherlands	Clinician, researcher	Jan
10. Fran Boyle	Institute for Social Sciences Research, UQ	Australia	Research institute, social scientist	both
11. Guilherme de Jesús	Universidade do Estado do Rio de Janeiro	Brazil	Research institute	both
12. Hannah Blencowe	LSHTM	UK	Clinician, researcher, advocate	Jan
13. Hema Magge	Gates Foundation	Global	Research institute, funder	Nov
14. Jillian Cassidy	Umamanita	Spain	Parent support organization	Nov
15. Kapila Jayaratne	Maternal and Child Morbidity & Mortality Surveillance, Family Health Bureau	Sri Lanka	Government	Jan
16. Keren Ludski	Red Nose	Australia	Parent support organization	both
17. Kristy Kade, Elena Ateva, Diana Copeland	White Ribbon Alliance	Global	NGO	both
18. Lauren Christiansen-Lindquist	Emory University, Rollins School of Public Health	USA	Research institute	both
19. Lesley McCowan	University of Auckland	New Zealand	Clinician	Jan
20. Lindsey Wimmer	Star Legacy	USA	Parent support organization	both
21. Lori MacDougall & Irum Taqi	PMCNH	Global	Multilateral	both
22. Mary Kinney	University of Cape Town	South Africa	Researcher, advocate	Jan
23. Philippa Middleton	University of Adelaide	Australia	Clinician, researcher	Jan
24. Rafat Jan	Aga Khan University School of Nursing and Midwifery	Pakistan	Clinician, researcher	Nov

Respondent	Organization	Country	Stakeholder group(s)	Input in Nov or Jan?
25. Rakhi Dandona	Public Health Foundation of India, IHME, University of Washington	India	Clinician, researcher	Jan
26. Sofia Saterskog	Spadbarnsfonden	Sweden	Parent support organization	both
27. Steve Wall	Save the Children	Global	NGO	both
28. Sue Steen	Maple Grove Hospital	USA	Clinician, researcher	Jan
29. Theresa Shaver, Susan Niermeyer, Leah Greenspan	USAID	Global	Policy makers, research	Jan
30. Tina Lavender & Tracey Mills	University of Liverpool, LAMRN	UK	Clinicians, researchers	Jan