4. ADVOCACY

Introduction to stillbirth advocacy

Ending the tragedy of preventable stillbirths and ensuring respectful and supportive care after stillbirth – including bereavement care and care in subsequent pregnancies – will not happen through programmes and interventions alone; it will require addressing systemic causes, increasing awareness, changing policy and making investments to redress inequities and improve quality of care. This level of change requires advocacy.

This chapter provides a foundation level of knowledge about advocacy plus guidance on the development of advocacy strategies for stillbirth prevention and support. It includes fundamentals of advocacy, how to determine the priorities for stillbirth advocacy and how to build a strategy for stillbirth advocacy. Alongside are case studies, suggested messaging and examples of policy instruments that can be used in building a concrete argument for action. Additional case studies are provided in an online repository. The list of topics addressed in these case studies is presented in Annex 2.

Fundamentals of advocacy

Advocacy is the process of influencing decision makers to adopt or change policies or other measures to better achieve a desired objective – usually to solve a problem. Advocacy action can range from direct political lobbying to petitions, large rallies and more. An advocate is a person who argues for, recommends or supports that objective through advocacy. Many people engage in advocacy in their work and daily lives, whether it is convincing a health minister to adopt a new programme or to invest in a new area of work, or arguing for better water supply in the local community.

Types of stillbirth advocacy

For stillbirth prevention and support, there are three main types of advocacy: technical, political and awareness-raising (or "voice"). Each type has a different purpose, requires engagement with different actors and demands different tactics – but all three are needed to make stillbirths important on the political agenda. Table 4.1 describes the types of advocacy, with target audiences, and example tactics and tools to use for each approach. More examples are provided in the online repository.



Wilson Center's Maternal Health Initiative and the UNFPA for a discussion on the role that midwives play in achieving Universal Health Coverage (UHC). The event will highlight the barriers to UHC, the contribution of midwives to sexual, reproductive, maternal, and newborn health, and strategies to fill the service gaps worldwide. Source: White Ribbon Alliance

TABLE 4.1: TYPES OF ADVOCACY WITH TARGET AUDIENCES, EXAMPLE TACTICS AND TOOLS FOR EACH APPROACH

ТҮРЕ	AIM	TARGET AUDIENCES	EXAMPLE TACTICS
	Raise awareness of stillbirth prevention and support; increase demand for action from key stakeholders	Politicians or influencersMediaAffected parents	 Develop strong, culturally relevant messages to fight stigma and deliver messages through inspiring champions. → Use the <u>Parent Voices Initiative</u> advocacy toolkits
VOICE		• Community leaders	 Partner with affected parents and leverage their powerful voices to advocate for change. Elevate parents' voices by creating a platform to share their experience and expertise (op-eds, panels, conversations, meetings with officials). Support parent education and training on advocacy and integrate them into health policy planning and implementation. Facilitate anonymous sharing of stories where required (e.g. via online submissions). Identify parent groups through the Parent Voices Registry
TECHNICAL	Introduce or improve implementation of a relevant policy or measure – such as including new data points for stillbirths, using data to identify populations with disproportionate stillbirth risk, adjusting health workforce training programmes to incorporate stillbirth awareness	 Staff in ministries (such as health, finance, education) and departments of civil registration and statistics) Local government Other relevant institutions 	 Request a meeting with officials to share data through presentations or briefs. Consider using the UNICEF stillbirth profiles Suggest possible changes or interventions, such as inviting officials on a learning visit to a clinic that has implemented key measures. Draw from recommendations in the Every Newborn Action Plan (ENAP) Make an investment case. Build from The Lancet Ending Preventable Stillbirths Series
POLITICAL	Increase government prioritization of and funding for stillbirths; mobilize the apparatus of government to support action on stillbirth prevention and support	Politicians Decision makers who set the political agenda or approve budgets	 Present decision makers with evidence of demand for action. Consider using national commitments to Every Women Every Child Ensure ownership of and accountability to international agreements (such as the ENAP or the Sustainable Development Goals) in relation to the current state of progress at the national level. Clarify that the government is responsible for meeting agreed global targets. Use national strategies and targets relating to stillbirths

Sharing what works

The <u>UK National Bereavement Care Pathway (NBCP)</u> was successfully developed and implemented through key advocacy strategies. Below are the critical steps and how they were achieved:

- → Demonstrate the scale of the problem: The NBCP core group used reports such as annual Sands audits to provide evidence of inconsistent and suboptimal bereavement care. Subsequent parent listening events were held, profiling the real stories of parents. Regular data collection points emphasized how many families are affected, and an independent evaluation helped to demonstrate the ongoing needs.
- → Outline the direction of a solution: The NBCP core group formulated a nationally agreed pathway and gained the support of charities and national professional organizations. Awareness-raising through <u>Baby Loss Awareness Week</u> and other initiatives kept quality, respectful bereavement care on the agenda.
- → Outline how you can help implement the solution: Sands UK offered to chair the NBCP core group, lead on behalf of the collaboration and be the main voice back to the government.

More information: The NBCP for pregnancy loss and the death of a baby provides guidance and resources for health-care professionals working with families who have experienced miscarriage, termination for fetal anomaly, stillbirth, neonatal death or the sudden unexpected death of an infant. The pathway has been adopted by over 100 hospital trusts in England and is being piloted in Scotland.

Priorities for stillbirth advocacy

The priorities and focus of advocacy will depend on the main problems identified, the context, the available resources and other situation-specific factors. However, one framework to help in setting priorities for stillbirth advocacy is The Lancet Ending Preventable Stillbirths Series call to action (27), presented in Annex 3 and summarized in Box 4.1. This call to action includes targets and milestones to end preventable stillbirths, close equity gaps and improve bereavement support after stillbirth.

BOX 4.1: SUMMARY OF THE LANCET ENDING PREVENTABLE STILLBIRTHS SERIES CALL TO ACTION (27)

Mortality targets by 2030

- National stillbirth rate: 12 stillbirths or fewer per 1,000 total births in every country
- Equity: All countries set and meet targets to close equity gaps and use data to track stillbirths

Universal health care coverage by 2030

- Sexual and reproductive health care:
 Universal access to services and integration into national strategies and programmes
- Antenatal care: Universal comprehensive quality antenatal care
- Care during labour and birth: Universal effective and respectful intrapartum care

Milestones by 2025 (updated)

- Milestones in Every Newborn Action Plan (ENAP) (4, 48) and Ending Preventable Maternal Mortality (EPMM) (49, 50)
- Respectful care, which includes global consensus on a package of care after death in pregnancy or childbirth
- Reduce stigma: All countries should acknowledge the effect of stillbirths and identify mechanisms to reduce associated stigma

Guidance for developing an advocacy strategy

In this section, advocacy is broken down into its component steps, to provide a clear understanding of what goes into making a compelling case for change.

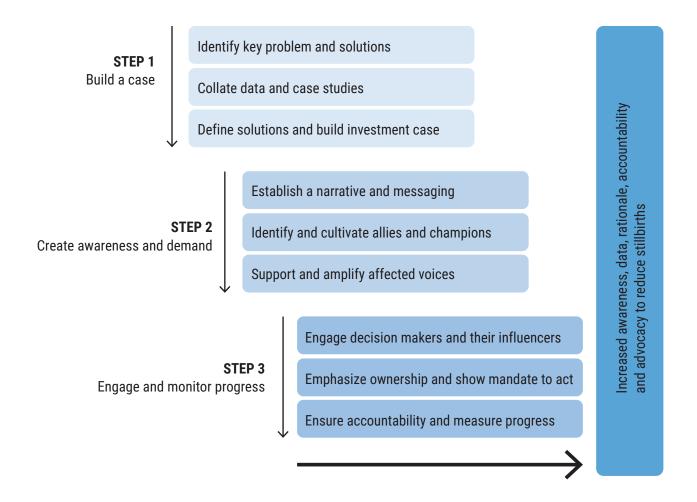
Regardless of the length of the strategy, it is helpful to consider these questions: What's the problem? What's the solution? Who makes the decisions that can solve the problem? What do these decision makers need to do and by when? How can they be influenced to make it happen?

Creating an advocacy strategy is an iterative process. Even though the steps are presented here in a specific order, they can be carried out in a different order or done simultaneously. Also, certain steps can be repeated or skipped.

Effective advocacy must build a case, create awareness and demand and engage decision makers and monitor progress (Figure 4.1). However, as advocacy is an iterative and continuous process, these steps may not be linear. For example, it may be helpful to map actors before building a case, so that actors can help to build the case.



FIGURE 4.1: STEPS FOR EFFECTIVE ADVOCACY



Advocacy can also be used to pursue smaller goals, such as obtaining an invitation for a stillbirth parent to speak at a national health conference, as a means of tackling bigger goals, such as adding a stillbirth target to a national health strategy. However, even smaller goals such as this will require funding, including for travel and incidentals, and support for the stillbirth parent (as they address relived trauma).

Step 1: Build a case

ASK:

What is the problem?	Conduct a situation analysis
What is the goal?	Identify key objective(s) for solving the problem
What information is available to explain the problem and build a case for change?	Gather evidence, including collating data and case studies
the problem and band a case for change.	Define solutions that will help support the call for action

ACT:

Build an investment case, including key asks for decision makers

Identify problems and possible solutions

Stillbirth prevention and support is multifaceted, involving many actors, challenges and opportunities (see Chapter 2). It can be difficult to identify a single problem to centre an advocacy strategy, as there are likely several interrelated problems. Identify these problems and break them down into smaller, actionable objectives. Setting out which objectives need to be tackled first will help to define the "asks" – the specific actions that the decision makers will need to take. A situation analysis can help.

To carry out a situation analysis, it is important to consider the specific problems in each setting and what information is available. Some issues might be data limitations, lack of awareness about stillbirth, unheard voices of those affected, limited funding allocation and weak strategies to quantify and address the causes of stillbirths.

It is crucial to partner with affected parents in the process of developing a situation analysis and as the key asks are being defined.



REFLECTION

What are the common problems for stillbirth prevention and support in your setting? Do the examples given here apply? Are there others as well? Consider equity: do any of the problems systematically affect any population group(s) more than others?



RESOURCES

- Every Newborn Toolkit Section V: Situation analysis tools: Country examples and lessons learnt (51)
- ISA webpage on advocacy



Group Work National Dialogue – Pakistan. Source: White Ribbon Alliance

Collate data and case studies

Collating data and case studies involves compiling key data related to the problem identified and analysing and presenting the data in a way that can be understood by – and influence – decision makers. It is helpful to use real-world examples or case studies to illustrate the problem, as data alone are unlikely to lead to action. Politicians and decision makers see large amounts of data every day, so case studies and data must be accompanied by specific asks.

RESOURCES

- United Nations Inter-agency
 Group for Child Mortality Estimation (UN-IGME) country and regional profiles
- Guidance for how to develop case studies



To define solutions to the problem, the policy opportunities and gaps must be identified. This means understanding a country's policies and targets related to stillbirths. Global initiatives for stillbirths and newborn deaths can also be used to leverage country and subnational action. There



are two key global initiatives in which stillbirths are embedded:

- 1. Every Newborn Action Plan (ENAP) (4, 48) adopted as a World Health Assembly resolution (WHA 67.10) in 2014, which focuses on ending preventable stillbirths and newborn deaths.
- Ending Preventable Maternal Mortality (EPMM)
 (49, 50), launched in 2015, which aims to end preventable maternal deaths.

ENAP and EPMM include global and national targets for mortality and coverage (meaning access to quality health care throughout the continuum), as well as recommendations for how countries can reduce mortality and morbidity and close subnational equity gaps with harmonized workplans coordinated by WHO. Annex 4 presents the ENAP and EPMM mortality and coverage targets along with guiding questions to consider in creating an advocacy strategy. In reviewing these global initiatives, ask the following questions:

Does your country/district/facility have national or subnational stillbirth targets?

 If yes, what are they? Do they align with ENAP and EPMM national and subnational targets? Use the <u>UN-IGME latest data</u> to determine different scenarios for reaching these targets by 2030. Does your country/district/facility have national and subnational maternal and newborn health coverage targets?

- If yes, what are they? Do they align with ENAP and EPMM national and subnational targets?
- If there are no targets for stillbirth, maternal and newborn health, consider incorporating the development of these targets in the advocacy strategy.

Has your country/district/facility set targets to close equity gaps?

 If yes, what are they? If there are no equity targets, consider incorporating these in the advocacy strategy.

Finally, the solution(s) will also need to address any challenges that could stand in the way of success. It will be important to identify and map objectives to achieve the solutions, and to note possible challenges. If the objectives are very long term, unpack them into subobjectives with more short-term, interim targets.

RESOURCES

• The Lancet Ending Preventable Stillbirths

Series presents a case for a triple return on investment in stillbirth prevention that also prevents maternal and newborn deaths and improves health outcomes. Find the triple return argument in The Lancet (52).



Step 2: Create awareness and demand

ASK: ACT:

How can I explain and share my objectives?	Establish a narrative and develop core messages based on the evidence
Who can address the problem? Who can make the decisions to solve the problem?	Identify and map key targets and audiences (allies and champions) and cultivate them
Who influences them? Who can be a champion?	Undertake a power analysis
How to support and engage affected voices?	Identify and engage champions, including affected families and health workers

Establish a narrative and messages

Once the problem and advocacy objectives have been identified, it is time to develop advocacy messages that will convey the urgency, extent and impact of the issue.

These messages will highlight the depth of the problem and set the tone of the advocacy initiative. Advocacy strategies often have a single overarching message, along with up to four supporting messages. Possible stillbirth messages – which can be adapted to specific contexts – include:

- Every stillbirth is a tragedy. There are an estimated [ADD HERE the latest data before using this guide] stillbirths annually, many of which are preventable, and most of which occur during labour and birth.
- Stillbirths are overlooked in many ways

 to the detriment of progress, and to the detriment of grieving parents. Stillbirths are undercounted in routine data, and health systems are often not equipped to support bereaved women and families.
- Women from disadvantaged groups face at least double the risk of stillbirth when compared with more advantaged groups.

Targeted policies and programmes can help to redress inequities and reduce stillbirths.

- Progress on reducing stillbirths is too slow, but our experience shows that it is possible to reduce stillbirths with strong leadership and the right investments.
- Leaders, policymakers and advocates
 must urgently seize the opportunity to
 raise the visibility of stillbirths and to better
 integrate stillbirths within women's and
 children's health policies and programmes.
 These actions have the potential to save
 millions of lives
- At all levels of society, we need increased advocacy and awareness to confront the harmful taboos and fatalism surrounding stillbirths, to reduce stigma and to ensure that bereaved women and families are supported.

For information on what leaders can do, see the <u>Leadership</u> section in <u>Chapter 5</u>.



RESOURCES

- Panel 2: Debunking myths about stillbirths in <u>deBernis et al. 2016</u> (27) is a useful starting point to help guide messaging about stillbirth facts.
- The message mapping template, worksheet and checklist created by Agency for Toxic Substances and Disease Registry may help.

Identify and cultivate allies and champions

When drafting a stillbirth advocacy strategy, it is important to identify the target audience, allies and champions and individuals or groups to be influenced. A power analysis can help in understanding the decision-making and policymaking processes, identify stakeholders involved and define to what extent they can influence the outcome (the changes we would like to see).

To conduct a power analysis, consider three key questions:

- Who can change the current situation?
 These are targets or key individuals who are in a position or have the power to bring about changes.
- Who are the influencers? These individuals have some influence on the targets and can use this influence for or against the changes we would like to see.
- What do they care about what will motivate them to agree to a call to action (the "asks")?

Key targets for stillbirth advocacy include:

- Senior health policymakers in government and United Nations agencies (decision makers/ influencers)
- Programme officers and senior policymakers in other agencies outside the health sector
- Parliamentarians (focused on budget allocation, accountability, representation)
- Civil society, including affected parent organizations (to encourage outside pressure on government to act)
- Donor agencies
- Non-government organizations
- Professional associations for obstetricians and other doctors, midwives, nurses and other health professionals (to shape guidelines and protocols and work with government to act)
- Media (for evidence-based message dissemination)

<u>Table 4.2</u> provides examples of advocacy targets and possible tactics.

RESOURCES







TABLE 4.2: IDENTIFYING AND UNDERSTANDING ADVOCACY TARGETS

TARGET	WHO INFLUENCES THEM	WHAT THEY CARE ABOUT	POSSIBLE TACTICS
Ministry official	Department ministers, think tanks and universities, prominent former ministers and staff, donors, development and implementing partners	Creating good policy, strong evidence to justify action	Produce a report co-authored by a leading institution; organize a meeting with health-care professionals and affected parents to present an investment case and solutions
National politician	The media, other legislators, important constituents, regional politicians and peers	Getting re-elected, their image – what the electorate thinks of them	Organize a meeting with other sympathetic legislators; write a letter signed by significant national champions; put an op-ed in the media
Local politician	Community leaders, faith leaders, voters, the media	A vibrant community, re-election	Write an op-ed in the local paper co-authored by a parent and a faith leader

Support and amplify affected voices

The role of champions – affected parents or prominent people who care about an issue – can be very influential and helpful to the success of an advocacy strategy. This is the case particularly for stillbirths, given the associated strong cultural taboos and stigma. Engaging and supporting a champion to speak out and talk to the target audience directly or through other modes, such as the media, can help raise awareness of the issue and reduce some of the stigma that hampers progress. Politicians are often influenced by real examples of the issue, and messages conveyed

in meetings between champions and decision makers can be very effective. The ISA PVI provides recommendations on how to achieve this (see Sharing what works).

RESOURCES



- Saving Newborn Lives Champions Toolkit,
 2nd edition and Toolkit Forms (editable)
- Raising Parents' Voices Stillbirth Advocacy
 Toolkit: Parents' Version Kenya
- Raising Parent Voices Advocacy Toolkit India Providers' Version

Sharing what works

The ISA Parent Voices Initiative (PVI) aims to raise the voice and participation of parents bereaved by stillbirth to strengthen advocacy for stillbirth prevention and bereavement support. Its two advocacy toolkits provide brief, simple advocacy training for stillbirth parent support organizations and health-care workers. In Kenya, the advocacy toolkit for parents who have experienced stillbirth aims to help parents advocate for themselves and other affected parents among providers, family and friends, and community leaders for quality care. In India, the advocacy toolkit for health-care providers in health facilities aims to raise their awareness about stillbirths, improve care after stillbirth and foster champions, paving the way for parents to advocate on their own behalf.

Step 3: Engage and monitor progress

ASK: ACT:

What is the best tactic or combination of tactics to achieve maximum influence?	Engage decision makers and their influencers Determine the type of engagement: meetings, forums, reports and papers, petitions, mobilization
What actions need to take place by when to implement these tactics?	Develop an action plan with clear targets and responsibilities; make sure to emphasize ownership and show mandate to act
When are good opportunities to implement tactics?	Set out the timeline – use relevant events, anniversaries and other "hooks" that will help emphasize the objectives
How do we monitor progress and determine next steps?	Document actions through reports, blogs, event summaries, social media reports and feedback to relevant stakeholders

Engage decision makers and their influencers

The next stage of an advocacy strategy is engaging the decision makers, either directly or through their influencers or issues they care about. Use the investment case together with the increased awareness built through messaging to pressure decision makers to act. Annex 5 presents example activities to engage decision makers and their influencers.

Remember the target: it is key to tailor the "ask" to what the decision maker can do. For example, a health official cannot decide the government's health budget, which is up to the finance minister. A legislator cannot solve the issue of stillbirths, but they can ask questions of the ministers to push ministries to collect better data or organize a government review of stillbirths.

Once messages are developed, champions identified and tactics defined, put together a messaging grid that identifies the medium

for specific messages. Such platforms might include social media (such as Twitter, Instagram, Facebook), a policy brief or an op-ed in the press (Table 4.3). Consider the timing of the messages. For example, it may be best to build the case over time, using many steps.

RESOURCES



- <u>Launch Toolkit</u> for The Lancet Ending Preventable Stillbirths Series.
- ISA Stillbirth Advocacy Working Group (ISA-SAWG) Ending Preventable Stillbirths scorecard – tracking global progress against The Lancet call to action. See the 2018 scorecard published on pages 88–89 of the 2019 Every Newborn Progress Report (53).
- Joint technical brief on the Stillbirth
 Situation and Way Forward in the Middle
 East (read more about how this brief was
 developed in <u>Sharing what works</u>).

TABLE 4.3: EXAMPLE OF A MEDIA GRID

OBJECTIVE	AGENT	MESSAGE CONTENT	DELIVERY METHOD	TIMING AND FREQUENCY
Increase awareness and urgency on stillbirth reduction	Affected parents Health-care professionals	Stillbirths are overlooked and progress is slow (include data)	Series of tweets, Instagram posts, Facebook posts, TikTok videos (and/or other social media platforms)	Once – at launch of advocacy strategy
Increase awareness of inequities leading to increased stillbirth risk	Academic institutions Professional organizations	(For example) Stillbirth disproportionately affects families living in rural and remote areas	Reports, infographics, radio or TV interview, social media	Once – at launch of advocacy strategy
Reduce stigma around stillbirth	Affected parents Health-care professionals	We cannot reduce stillbirths if we cannot talk about them	Radio or TV interview, social media, inclusion of parent panels in community and religious events	At launch of advocacy strategy and in the six months leading up to new MOH budget

MOH: Ministry of Health

Sharing what works

The WHO Regional Office for the Eastern Mediterranean (WHO EMRO), United Nations
Population Fund Arab States Regional Office (UNFPA ASRO), United Nations Children's Fund
(UNICEF) Headquarters and Regional Office for the Middle East and North Africa (UNICEF
MENARO) have jointly developed the Technical Brief on Stillbirth Situation and Way Forward
to raise voices as one. In the combined regions of the Eastern Mediterranean, Arab States,
and the Middle East and North Africa, around 380,000 babies are stillborn every year, with a
rate of 19 stillbirths per 1,000 total births, which is higher than the global average of 14 per
1,000 total births. UNICEF Headquarters has contributed with data consolidation and analysis
as the countries covered by three organizations in the region are slightly different. Due to
the COVID-19 pandemic, virtual meetings and discussions have been held between the three
agencies, and a regional webinar was organized by the three agencies to raise awareness
of the stillbirth situation, the main challenges and the way forward. The brief is available in
English, Arabic and French on the UNICEF website.

Ensure accountability and measure progress

An advocacy strategy should tell a story. It should show how planned activities will bring about desired changes. Identify these and include milestones to track progress. Annex 6 provides an action plan template. Review this action plan and milestones and set indicators for each objective. Through discussion and feedback on which messages and tactics are working and which are not, the strategy can be improved.

Finally, at the end of the process, take time to evaluate the strategy – the outcomes achieved, effort involved and lessons learned, to help inform the next strategy. Advocacy work is not easy; celebrating even small achievements can keep momentum going and signify that efforts are making a difference.

RESOURCES



- The Global Health Advocacy
 Incubator provides a wide range of advocacy guidance and tools.
- The Partnership for Maternal, Newborn and Child Health (PMNCH) has mapped various advocacy toolkits – including some specifically for stillbirth – which provide further guidance and ideas for how to do advocacy. See Annex 7.
- The Australian <u>National Stillbirth Action</u> and <u>Implementation Plan</u> (54) is another highly useful resource. (Read about its development in the <u>online repository</u>.)

