

# **Regional communication strategy for the prevention and control of birth defects**

**WHO Regional Office for South-East Asia**



**World Health  
Organization**

Regional Office for South-East Asia



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# Acronyms

ASHA	Accredited Social Health Activists
BCC	Behaviour Change Communication
CDC	Centers for Disease Control and Prevention
CNA	Communication Needs Analysis
COMBI	Communication for Behavioural Impact
ICBDSR	International Clearinghouse for Birth Defects Surveillance and Research
IEC	Information, Education and Communication
IFA	Iron-folic acid
MDG	Millennium Development Goal
NCD	Noncommunicable Diseases
NTCC	National Tobacco Control Cell
OPV	Oral Polio Vaccine
RMNCAH	Reproductive, Maternal, Newborn, Child and Adolescent Health
SIFPSA	State Innovations in Family Planning Services Project Agency
THCU	The Health Communication Unit
WHO	World Health Organization

# Birth defects: an urgent public health priority

Over the past two decades, there has been a significant decline in infant and child mortality in most countries in the World Health Organization's (WHO) South-East Asia Region. This successful public health achievement has contributed to progress in achieving Millennium Development Goal (MDG) 4 – a reduction in the child mortality rate by two thirds as compared to the 1990 level. However, neonatal mortality has been declining at a slower rate than overall child mortality and it contributes to 55% of under-five mortality in the Region. At the same time, mortality from birth defects has remained constant, resulting in birth defects assuming a greater proportional cause of neonatal and infant mortality. In developed countries that have reduced child mortality, the child mortality due to birth defects is as high as 25% to 30%.

Birth defects, or congenital anomalies, are structural or functional defects that arise before birth. As per the “March of Dimes global report on birth defects: the hidden toll of dying and disable children” (2006), it is estimated that every year, nearly 8 million children worldwide are born with a serious birth defect of genetic or partially genetic origin. Additionally, hundreds of thousands more are born with birth defects of post-conception origin, caused by factors such as maternal exposure to environmental agents including alcohol, tobacco, medications and environment teratogens; infections such as rubella and syphilis; and micronutrient deficiencies including inadequate folate and iodine, which can harm a developing fetus. Birth defects also significantly contribute to fetal loss through spontaneous abortions and stillbirths, the burden of which remains unknown.

The impact of birth defects is relatively higher in low- and middle-income countries where more than 94% of the births with serious birth defects and 95% of the deaths of such children occur. The higher burden of birth defects in less developed countries is due to factors such as the poor status of women's health and nutrition, inadequate care

of women during pregnancy and childbirth, and presence of adverse social determinants including poverty, high fertility and the greater frequency of consanguineous marriages.

The actual burden of birth defects is not known in the countries of the WHO South-East Asia Region due to inadequate epidemiological or surveillance information. However, as per the March of Dimes global report, the burden of birth defects is quite significant: the estimated prevalence of selected birth defects per 1000 live births in the Region is the highest in India (64.3), followed by Sri Lanka (62.2), Maldives (60.8) and Timor-Leste (60.3). The absolute number of birth defects is the highest in India because of a large annual cohort of births (about 26 million). Birth defects can be fatal, in utero or soon after birth. According to the “Global burden of disease estimates for 2012”, in the Region, the proportion of child mortality due to birth defects ranges from close to 29% in Thailand (which has achieved low levels of child mortality) to less than 6.4% in India. Babies with serious birth defects, who would have previously died, now survive due to advancing technology; this results in an increasing number of infants and children with lifelong disabling conditions. Such children require long-term medical and supportive interventions, putting an additional burden on health systems that are already stretched in developing countries.

## WHO's response

Birth defects were an agenda item in the 125th, 126th and 127th sessions of the WHO Executive Board, following which the Sixty-third World Health Assembly in May 2010 adopted resolution WHA63.17. The resolution requests WHO to support Member States in developing national plans for implementation of effective interventions to prevent and manage birth defects within their national maternal, newborn and child health plans; strengthening health systems and primary care, including improved vaccination coverage for measles and rubella and food fortification strategies for the prevention of birth defects; and, promoting equitable access to such services. The WHA resolution further urges Member States to raise awareness among all relevant stakeholders including government officials, health professionals, civil society and the public about the importance of birth defects as a cause of child morbidity and mortality. Member States are expected to set priorities, commit resources and develop plans and activities for integrating effective interventions that include comprehensive guidance, information and awareness raising to prevent birth defects, and care for children with birth defects into existing maternal, reproductive and child health and social welfare services for all individuals, and effective interventions to prevent tobacco and alcohol use during pregnancy.

In response, the WHO Regional Office for South-East Asia in consultation with Member States developed a regional strategic framework for the prevention and control of birth defects (2013–2017). The framework proposes the goal of a significant reduction in preventable birth defects in the South-East Asia Region, to contribute to the achievement of MDG 4 and beyond, through the following strategic actions:

- (1) establishing or strengthening national policies and programmes for birth defects prevention and control;
- (2) developing and strengthening national birth defects surveillance, monitoring and evaluation mechanisms;

- (3) integrating birth defects prevention and control strategies into public health, maternal and child health, nutrition and other relevant programmes;
- (4) expanding and strengthening national capacity for implementation of birth defects prevention and control programmes; and
- (5) developing and expanding national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes.

## Setting the agenda for prevention and care

Prevention of birth defects contributes to reduction in fetal losses (spontaneous abortions and stillbirths) and neonatal and child deaths, as well as a reduction in long-term morbidity and disabilities associated with birth defects. Experience from high-resource countries shows that up to 70% of birth defects can be prevented, and that affected children can be offered life-saving care that can reduce the severity of their disability and improve the functional outcomes. Effective evidence-based interventions that exist for the prevention of birth defects are listed below.

- A large majority of birth defects are attributed to the poor preconception and periconception health status of women. Improvements in maternal iron, folic acid and iodine status, and increased awareness of the impact of antenatal exposure to teratogens on the developing fetus will significantly reduce the number of stillbirths and lower the prevalence of birth defects in live births.
- Food fortification and supplementation with folic acid has been demonstrated to prevent many neural tube defects.
- Rubella immunization prevents congenital rubella syndrome.
- Appropriate management of diabetes during pregnancy reduces chances of birth defects such as facial clefts.
- Public health education and preventive health-care services can address the in utero effects of alcohol and tobacco (by discouraging its use during pregnancy) and can reduce the incidence of Down syndrome (by discouraging childbearing in women over 35 years of age).
- In populations where thalassaemia and other haemoglobinopathies are prevalent, strategies such as premarital screening and counselling to prevent marriage between carriers and prenatal diagnosis followed by

termination of pregnancy have been used to reduce the incidence of these birth defects.

- Improvements in the care of children with birth defects can be achieved even with limited resources. Affordable medications, surgical treatments and community-based rehabilitation can help children with birth defects to lead productive and meaningful lives.

Prevention and care of birth defects must be integrated into existing public health programmes that focus on safe pregnancy and childbirth, newborn and child health, and related programmes such as immunization and nutrition.

## Interventions that can be integrated into existing and emerging programmes

- **Adolescent health programmes and preconception care services:**
  - discouraging consanguineous marriages;
  - discouraging pregnancy at advanced maternal age;
  - folate supplementation during adolescence and periconception period;
  - immunization (rubella vaccine);
  - prevention of noncommunicable diseases (NCD) (diabetes and obesity) through healthy lifestyles promotion, screening and treatment; and
  - premarital counselling.
- **Anaemia and micronutrient deficiency management programmes:**
  - supplementation of folic acid and B vitamins; and
  - food fortification (iodized salt, staple food fortification with folic acid and B vitamins).
- **Reinforcing and improving antenatal care services:**
  - no self-medication;
  - screening and management of syphilis;
  - prevention of exposure to tobacco and alcohol; and

- screening and management of diabetes and obesity during pregnancy;
- antenatal screening and prenatal tests for birth defects.
- **Improved perinatal care:**
  - asphyxia prevention and management; and
  - neonatal screening for birth defects.

## The power of communication in prevention of birth defects

Several birth defects are related to maternal risk behaviours such as exposure to alcohol and tobacco, as well as sociocultural factors such as consanguinity. Health communication activities can be effective in modifying such risk factors for birth defects. Communication is also required to make people aware of preventive and curative services for birth defects.

An enabling environment for a new intervention is crucial to support behaviour change and encourage individuals and communities to sustain such behaviours. Public campaigns should focus on alleviating the stigma related to birth defects and sensitively address cultural and religious issues such as consanguinity or myths and misconceptions around birth defects. This is achieved through community mobilization and media campaigns. At the same time, it is important to carry out advocacy with policy- and decision-makers to position birth defects in the national health agendas of countries. Cooperation should be sought from governments (health and other sectors), institutions and civil society to address these issues. The importance of synergy to enable joint action within and between various programmes and departments is essential for a coordinated multisectoral response to birth defects prevention and management.

Health communication is an important component of reproductive, maternal, newborn, child and adolescent health (RMNCAH) and related programmes being implemented in Member States. Some countries in the Region have used health communication more effectively than others. Programmes such as immunization, poliomyelitis eradication and HIV have effectively used communication activities to achieve the desired results. Communication initiated for a specific programme may also influence related programmes, simply because audiences, issues and techniques overlap significantly. "Snowballing" also creates a momentum; for instance, one national programme may affect another within a country and have desirable spin-off benefits.

Communication for the prevention and control of birth defects has been recognized as an important element in the regional strategic framework for the prevention and control of birth defects. The regional framework recommends integration of prevention and communication activities for birth defects into existing public health programmes, as far as possible, for synergistic effect. Strategically planned communication can help influence policy-makers and opinion leaders to bring about policy changes, as well as encourage structural changes within the community to improve healthy behaviours. However, to be effective, communication activities must be well-designed, well-planned and aligned to national priorities and community needs in order to achieve the desired effects.

Strategic communication is the program's steering wheel, guiding it towards its goals. Strategic communication is also the glue that holds the program together or the creative vision that integrates a program's multi-faceted activities.

– O'Sullivan, G.A., Yonkier, J.A., Morgan, W., and Merritt, A.P. *A Field Guide to Designing a Health Communication Strategy*, Baltimore, MD: Johns Hopkins Bloomberg School of Public Health Center for Communication Programs, March 2003, p. 4.

Advocacy and community mobilization, when supported by behaviour change communication, influence people's perceptions, beliefs, and attitudes and can lead to changes in social norms towards prevention and management of birth defects. At the same time, communication campaigns can strengthen other health programmes that offer opportunities to integrate birth defects prevention, including:

- RMNCAH, immunization, nutrition, and environmental health programmes;
- food fortification programmes, with folic acid as well as supplementation, can help prevent neural tube defects;
- preconception care programmes for adolescents and women of reproductive age, including rubella vaccination and education on the use of alcohol and tobacco and premarital counselling initiatives;
- clinical and community genetics services.

Advocacy and community mobilization are integral to prevention strategies because health communication can promote increased awareness about an issue, change the prevailing attitudes and beliefs of communities, generate a groundswell of demand for services, and garner institutional support for desirable behaviours. Some specific advocacy and community mobilization activities are listed below:

- raising awareness about birth defects with a focus on surveillance, prevention and management of birth defects;
- providing information to people on:
  - referral services for treatment, surgery, care and rehabilitation;
  - community rehabilitation services; and
  - family support programmes.
- leveraging social support and pressure groups; and
- disseminating advice and information, including case-based counselling about management of maternal risk factors for birth defects (such as diabetes and body weight at conception and during pregnancy).

Communication activities can target certain policy-level actions that may facilitate greater involvement of various sectors and stakeholders for the prevention and control of birth defects; such as:

- positioning birth defects in a manner that synergises with existing health programmes including RMNCAH, smoking and alcohol prevention, nutrition and immunization;
- establishing national and subnational mechanisms for surveillance of birth defects at hospital and population levels to determine and monitor the prevalence and distribution of birth defects in the country;
- focusing on intersectoral issues such as:
  - professional education of doctors, nurses and other cadres of service providers to develop their expertise in diagnosis, treatment, rehabilitation and genetic counselling;
  - staple food fortification; and
  - judicious use of pesticides in agriculture.

Ultimately, the outcomes of any communication and advocacy initiative are modifications not only in individual and group behaviours, but changes in social norms, values, attitudes and opinions. For changes in behaviour to occur, incentives and “triggers” need to be identified and used appropriately; for instance, the birth of healthy babies, or less time and money spent on health care of babies born with birth defects.

In summary, health communication programmes seek to generate awareness about the importance of birth defects prevention, strengthen preventive and care-seeking behaviour, improve community engagement, advocate for policy change, and reinforce existing programmes and campaigns. At the programme level, communication about birth defects supports healthy behaviours, reinforces knowledge and practices, increases demand or support for health services, and refutes myths and misconceptions. Communication requires support from the health system and, when combined with other strategies to address birth defects, can sustain changes in individual and community health behaviours. At the population level, wide-spread implementation of a communication strategy across programmes that target all women of childbearing age, newborns, adolescents and children, offers opportunities for multiple intervention points for the prevention and management of birth defects.

The “Regional communication strategy for the prevention and control of birth defects” has been prepared to strengthen the regional strategic framework for the prevention and control of birth defects developed by the WHO Regional Office for South-East Asia, in collaboration with Centers for Disease Control and Prevention (CDC), Atlanta, and in consultation with Member States. The communication strategy will be useful for programme managers to implement national programmes for the prevention and control of birth defects in the countries.

Effective implementation of the regional communication strategy depends on multiple factors and many sectors: strong political will, a vibrant and responsive environment of change, and commitment to human, financial and infrastructural resources as well as to policy frameworks and supportive legislation.

## Goal and objectives

The overall goal of the regional communication strategy is to provide support for implementation of national programmes for birth defects, as guided by the regional strategic framework for the prevention and control of birth defects.

The specific objectives of the communication strategy are to:

- orient programme managers to the importance of communication for prevention and control of birth defects;
- provide guidance for developing country-specific communication strategies and plans to support development and implementation of national programmes for prevention and control of birth defects;
- build understanding and capacity of programme managers on the use of communication tools and techniques for advocacy, behaviour change and community mobilization for birth defects prevention; and
- provide guidance on how to implement, sustain, monitor and evaluate the communication activities for prevention and control of birth defects in the countries.

## Strategic actions

### 1. Communication needs analysis

As a preliminary step in the development of a communication strategy or plan, a communication needs analysis (CNA) should be carried out with the main stakeholders to obtain information about communication tasks, existing initiatives and possible opportunities. The WHO Regional Office for South-East Asia carried out a CNA with Member States as a first step to develop the “Regional communication strategy for the prevention and control of birth defects”. The objectives of CNA were to:

- assess the variety and scope of existing communication activities for advocacy, community mobilization and behaviour change within existing health and related programmes in countries; and
- identify opportunities to integrate communication for prevention of birth defects with ongoing programmes and initiatives.

A questionnaire was developed and shared with all Member States. The analysis of the assessment has been used to contextualize the regional communication strategy. A country-level CNA may be commissioned by programme managers to understand the climate of communication and behaviour change prior to launching campaigns or undertaking advocacy initiatives.

A summary of findings from the South-East Asia Region CNA is placed at **Annex 1**.

### 2. Audience analysis and engagement

The audience for the intended health communication may be defined as: groups of people who are targeted as distinct recipients of information about issues related to birth defects at different stages of communication. These people are the main stakeholders for

the birth defects prevention programme. There are various categories, or “segments”, of audience within the different levels. Audiences among the community can be segmented on the basis of a variety of factors and characteristics, including (but not limited to) demographics, socioeconomic status, level of education, their awareness of and knowledge about the topic of interest, and their willingness and motivation to engage in prevention efforts. Stakeholders at policy and programme levels, including the service providers, form part of the overall audience of intended communication activities. Since they may have a greater “stake” in the implementation of a programme and its outcomes, they are usually easier to engage than audience segments in the community.

It is important to be clear on what is needed from the identified audiences, or audience segments, and what power and influence they have to bring about the desired change.

After the main audience and audience segments have been identified, they need to be effectively engaged to improve their knowledge, augment their influence to bring about a desired change, or encourage them to adopt the desired behaviours. For this, different segments of audience need different messages and approaches, as well as different channels of communication.

There are several stages of audience engagement. The objective of communication programmes is to move a targeted audience, or segment of an audience, from one stage to the next. Stages of audience engagement, based on the transtheoretical model, are:

- *pre-knowledgeable* stage: at this stage, audiences are unaware of the problem or of their personal risk;
- *knowledgeable* stage: audiences are aware of the problem, and become knowledgeable about desired behaviours for prevention of health risk;
- *approving* stage: audiences start viewing the desired behaviours favourably;
- *intending* stage: audiences intending and prepared to personally take the desired actions;
- *practising* stage: audiences start practicing the desired behaviours;
- *maintenance* stage: audiences have been able to sustain action (desired behaviour) for a period and are working to prevent relapse; and
- *advocating* stage: by this stage, audiences begin advocating such behaviours to others, thus having a multiplier effect.

In summary, knowledge of the audience and how to progressively engage them for the desired effect is crucial for designing effective communication strategies and plans.

### 3. Developing messages for communication

#### Evidence-based messages

Once stakeholders and audiences have been identified, the development of message content is the next important step. The content of the messages should be based on evidence. Informative, evidence-based messages are particularly helpful for programme managers to convince administrators, decision-makers, stakeholders, donors and partners about the importance of investing in birth defects prevention.

In the context of birth defects, the availability of adequate information is a challenge in the South-East Asia Region. However, relevant data can be obtained from vital registration systems, health management information systems and national health surveys such as demographic and health surveys, multiple indicator cluster surveys and behavioural health surveys. Other means of gathering data and information relevant for health communication actions include rapid communication needs assessment, special surveys, and face-to-face interviews with key people. Government reports, proceedings of meetings and conferences can provide insights into policy and programme implementation, but are not substitutes for “hard” data.

A set of evidence-based messages is used in the WHO factsheet on congenital anomalies (Fact sheet No. 370, updated January 2014. <http://www.who.int/mediacentre/factsheets/fs370/en/index.html>)

- Congenital anomalies (also referred to birth defects) and preterm births are important causes of childhood death, chronic illness and disability in many countries.
- Congenital anomalies affect approximately 1 in 33 infants and result in approximately 3.2 million birth defect-related disabilities every year.
- An estimated 270 000 newborns die during the first 28 days of life every year from congenital anomalies.
- Congenital abnormalities may result in long-term disability, which may have significant impact on individuals, families, health-care systems and societies.

- The most common severe congenital anomalies are heart defects, neural tube defects and Down syndrome.
- Although congenital anomalies may be genetic, infectious or environmental in origin, most often it is difficult to identify the exact causes.
- Many congenital anomalies can be prevented. For example, vaccination, adequate intake of folic acid and iodine, and antenatal care are keys for prevention.

Another example of a key message from CDC, Atlanta, is given below.

“About one in every 33 babies is born with a birth defect. Not all birth defects can be prevented. But a woman can take steps to increase her own chance of having a baby with the best possible health”. <http://www.cdc.gov/ncbddd/birthdefects/index.html>

## Persuasive messages

To change people’s behaviour, the message should not only be evidence-based but also have several inherent qualities to be able to persuade people to adopt a healthy behaviour or give up health risk behaviours. The following factors are essential qualities of an effective communication strategy. (Adapted from The Seven C’s of Effective Communication)

- (1) *Command attention*: the message should attract the attention of the identified stakeholders and audiences.
- (2) *Cater to the heart and head*: the message should have factual information and emotional appeal to persuade audiences to adopt the healthy behaviours that the programme wants to promote (e.g. babies who are healthy and without birth defects has an emotional appeal for all women).
- (3) *Clarity*: the message should be simple and easy to understand – the words in the message should be clear and chosen with care and sensitivity.
- (4) *Communicate a benefit*: the message should communicate some tangible gains to the targeted audience (e.g. consumption of supplementary folic acid and other micronutrients is good for the health of women and their babies).
- (5) *Create trust*: the message and communication should reassure audiences that behaviour change is to their benefit (e.g. birth defects are preventable).

- (6) *Convey a consistent message*: the message should convey one idea at a time (e.g. pregnant women should have regular antenatal check-ups).
- (7) *Call for action*: in addition to factual information, a persuasive message should contain a clear action that audiences can undertake. (e.g. “if you are planning to become pregnant, take 400 micrograms of folic acid every day before and during pregnancy’ or “don’t drink alcohol, smoke or use drugs if you are planning to become or are pregnant”).

Simply communicating a persuasive message does not lead to the desired behaviour change. The message, and the audience, must pass through a series of steps to result in the desired effect on the target audience.

- (1) *Get the audience tuned in (exposure)*: the message must receive due attention from the target audience. Use of cartoons and graphics, interesting pictures, catchy slogans and useful information may attract their attention. At the same time, *the message must be kept simple and direct* making it easy for the audience to understand.



- (2) *Help maintain audience interest in the message*: getting one-time attention may not be enough for the target audience to remember or act upon messages. Therefore, the message has to be repeated for the audience to register, remember and recollect it.



- (3) *Get audience to think about the message*: words and pictures in the message should encourage the audience to reflect on what has been communicated; for example, *understanding why* smoking and drug use are bad for the unborn baby; *what to do* if someone smokes in the room.



- (4) *Help audience to acquire and practice the desired behaviour*: for example, reminding pregnant women to take folic acid tablet, regularly.



- (5) *Facilitate attitude change in the audience*: beyond receiving the factual information, the audience should feel convinced that it is in their best interest to adopt the desired behaviour (for example, a family member or a health worker should not only understand and agree with the messages, she should be convinced enough to include in her communication and advice).



- (6) *Help the audience store the message in memory*: if a message has been powerful enough and the audience has been carried through these stages, then the message will be stored in their long-term memory, well after the campaign is over.



- (7) *Retrieval of the message from memory when relevant*: audience is able to retrieve the persuasive message from past experience and apply it in the future (for example, at the next pregnancy), when needed.



- (8) *Help audience decide to act on the message (intention)*: for example, a health worker or an informed relative will advise and support the woman to take folic acid tablets to prevent birth defects in her unborn child.



- (9) *Support audience to act on the message (behaviour)*: for example, the health worker actually provides tablets of folic acid, after explaining the reason and benefits, and the woman actually consumes tablet.



- (10) *Audience integrates the behaviour into lifestyle*: for example, community members quit using tobacco or seek de-addiction for drug users. Women planning pregnancies take folic acid regularly.



- (11) *Audience recruits others to adopt the healthy behaviour*: audience spreads the message and influences others to adopt healthy behaviour (for example, to take folic acid when planning pregnancy).

The Health Communication Unit (THCU) at the Center for Health Promotion, University of Ontario, Canada developed this Health Communication Message Review Tool to help assess or create health communication messages.

## 4. Selecting channels of communication

Based on understanding of audience segments and development of evidence-based and persuasive messages, the next important task is to identify the appropriate channel/medium of communication to deliver the identified message/s to the target audience. It is important to use culturally acceptable communication channels and optimize multi-channel opportunities. Various communication channels may be used in a phased manner to reinforce one another and maximize the impact on audiences.

A variety of communication channels/media are available (listed below), which have been used in countries for RMNCAH and related programmes.

- *Interpersonal communication channels* focus on either one-to-one or one-to-group communication. One-to-one channels include peer to peer, spouse to spouse, health clinic worker to client, and opinion-maker to community. An example of one-to-group communication is a community-based outreach worker meeting with a women's group. Interpersonal channels use both verbal and nonverbal communication (e.g. charades, role-plays and skits).
- *Community channels* help spread information and messages through existing social networks, such as the family or community groups (e.g. meetings, mother's groups, faith-based groups). These channels are effective when dealing with community norms. They optimize participation and present opportunities for audience members to reinforce one another's behaviour.
- *Mass media* reach large audiences. They are particularly effective for agenda-setting and contribute to the establishment of new social norms. Formats range from educational to entertainment and advertising, and include television, radio, and print media such as magazines, newspapers,



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outdoor and transit boards, the internet, and direct mail. (O'Sullivan GA, Yonkler JA, Morgan W, Merritt AP. A field guide to designing a health communication strategy. John Hopkins Bloomberg School of Public Health/ Center for Communication Programs, 2003)

- *Information and communication technology (ICT)*: short messaging services (SMS) (i.e. text messaging) via mobile phone keep health workers apprised of the latest developments in obstetric care and counselling. Distance learning initiatives, eHealth and mHealth are examples of ICT that have been adopted by low- and middle-resource countries. However, basic literacy, availability of electricity, access to technology and computer literacy are barriers to the widespread use of ICTs in some countries.
- *Social media*: with widespread Internet use, social media such as Facebook and Twitter, websites, blogs and online networks have become dynamic platforms for health message dissemination. With interconnectivity becoming more common, it is now possible to access health-care providers and health workers in virtual settings. In fact, some countries in the Region are experimenting with eHealth and mHealth. In resource-constrained



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situations, the use of the Internet and online learning and information exchange platforms is governed by factors such as availability of electricity, terrain-related difficulties and affordability. In situations where the internet is available on laptops, smart phones and tablets, information may be one click away; however, users still need to access them, and understand and retain what they read and download. Messaging and information-sharing principles for social media remain similar to those of campaigns, although a stricter gatekeeping policy is necessary to ensure meaningful communication. (Adapted from The Health Communicator's Social Media Toolkit. CDC, 2011).

The decision of programme managers to use either or all of these channels (whether together or in a phased manner) depends upon the audience size – for instance, if women of reproductive age require targeted messages on birth defects prevention at the subnational level, then a mix of interpersonal, mass media and community-based media may be selected. However, if a national campaign on smoking and alcohol is being mounted, then messages about harm caused to a fetus if the mother smokes or consumes alcohol prior to or during pregnancy may be included.

A table summarizing the characteristics of each communication channel and tips on their use is given in **Annex 2**.

## 5. Communication campaigns

A communication campaign is a method of delivering messages to broad audiences. It is critical to understand that awareness alone seldom leads to a change in behaviour or practices. At the outset of the campaign, it is important for all involved – including the campaign planners and implementers – to be aware of the change that they seek to bring about. Formative research is used to ensure that proposed messages and concepts will resonate with the target audience, and to find out which channels are most appropriate for their dissemination.

Competing priorities may overshadow the importance of birth defects prevention initiatives; therefore, vigorous and sustained communication campaigns are necessary for keeping the issue at the forefront of the health, development and social welfare sectors. Nevertheless, programme managers have the option of embedding campaign activities within existing programmes for RMNCAH, and related programmes such as school health, immunization and nutrition, for a sustainable effect. In situations where there are multiple campaigns going on, there is a risk that birth defects prevention messages may be lost or be ignored by audiences. Hence, the timing and scheduling of specific campaigns for birth defects must be chosen strategically since it is a new area of public health.

Creative and innovative campaigns, using multiple channels, are important to sustain the audiences' interest in issues related to birth defects. Another important strategy is to engage members of the community, especially those who are directly concerned with birth defects issues, while developing and delivering the messages (for example, engaging young females in the development of social media messages).

It must be remembered that mass media campaigns are expensive. Despite the expanding penetration of electronic media, some sections of the target audience might not be exposed for a variety of reasons including lack of time, situation of electricity supply, low literacy or language barriers. For better impact, mass media campaigns should be supported by community-based communication initiatives that are based on knowledge of audience behaviour and are persuasive in nature.

The multiplicative power of campaigns i.e. the likelihood of particular messages interacting with other campaign elements and being seen by many more people, is often useful in order to reach out to diverse audiences. For example, in Maldives, the antenatal counselling package consists of two to three leaflets on different health topics. Similarly, the NCD Unit of the Sri Lanka Medical Association conducts workplace

awareness programmes during which a set of leaflets is distributed (on healthy diet, exercise and physical activity, avoiding tobacco use, etc.) at the time of organizing exhibitions and screening programmes.

When planning communication campaigns, programme managers need to keep the following points in mind.

- Be strategic and comprehensive in planning and implementation.
- Include an organized set of communication activities such as evidence-based and persuasive messages, media products and campaigns.
- Use various media/channels of communication (both interpersonal and mass media), community events and diverse contact opportunities.
- Involve communities, networks and organizations; reflect community values and create a sense of ownership of issues related to birth defects.
- Use campaigns not only to inform audiences, but to persuade and drive behaviour change.
- Provide technical support and guidance so that campaigns are conducted in a time-bound manner depending on needs and available resources.
- Be on the lookout for campaigns linked to other health programmes (such as RMNCAH, nutrition, immunization, tobacco and alcohol prevention).
- Reach out to an optimum number of people from various audience segments.
- Optimize innovative dissemination opportunities (especially in a multi-channel environment and in media-dark areas).

Since it is difficult to attribute behaviour change to a single campaign, periodic evaluation must be used to assess the impact on audiences' knowledge and behaviour. Evaluation methods show whether the audience has actually experienced the campaign and attended the meetings. While designing a campaign on birth defects prevention, expected outcomes should be considered so that achievement of objectives and impact of the campaign may be assessed. Some examples of population-level programme outcomes are: women seeking preconception care and counselling treatment for children with birth defects; stakeholders advocating for policy change; and, inclusion of rubella vaccination in immunization programmes.

Some examples of good campaign practices from the South-East Asia Region are given in **Annex 3**.

## 6. Communication for advocacy

Advocacy “is the deliberate process, based on demonstrated evidence, to directly and indirectly influence decision makers, stakeholders and relevant audiences to support and implement actions...”.<sup>1</sup>

A situation analysis of birth defects in South-East Asia<sup>2</sup> raised an all-important question: why have birth defects not received the attention they deserve to date from policy-makers, funding organizations and health-care providers? The document reiterates that there is a misperception that these disorders are rare and require expensive technological interventions. In fact, many birth defects for which the cause is known can be prevented by simple health-care actions.

While describing birth defects as a public health challenge, the WHO Situation Analysis states:

“Every child who has a preventable birth defect is a failure of medical care and public health systems that ignore available preventive measures. The failure to prevent birth defects is caused, in large measure, by lack of organized effort and political will that are required to implement the necessary interventions.”

– Birth Defects in South-East Asia – a Public Health Challenge. Situation Analysis

An advocacy priority, therefore, should be to place birth defects on the policy radar and into the prevention and health-care provision landscape of countries. Advocacy with stakeholders about the extent to which death and disabilities are caused by birth defects, and that preventive strategies are available for certain birth defects, will help convince them that attention to birth defects will contribute to outcomes of the existing high-priority maternal and child health programmes.

### Objectives and functions of advocacy

The main objective of advocacy for birth defects prevention is to gather resources and investment to improve health outcomes for women and infants. Effective advocacy seeks

1 United Nations Children’s Fund. Advocacy toolkit: a guide to influencing decisions that improve children’s lives. New York: UNICEF, 2010. [http://www.unicef.org/evaluation/files/Advocacy\\_Toolkit.pdf](http://www.unicef.org/evaluation/files/Advocacy_Toolkit.pdf) - accessed 31 December 2014.

2 World Health Organization, Regional Office for South-East Asia. Birth defects in South-East Asia: a public health challenge: situation analysis. New Delhi: WHO-SEARO, 2013. Document No. SEA-CAH-13. [http://apps.searo.who.int/PDS\\_DOCS/B4962.pdf](http://apps.searo.who.int/PDS_DOCS/B4962.pdf) - accessed 31 December 2014.

the support of government and nongovernment actors, national and international donor agencies, and public–private partnerships to incorporate birth defects initiatives into RMNCAH programmes in ways that promote resource-sharing and collaborative action.

At the policy and planning levels, advocacy is carried out to draw attention to birth defects as an integral part of RMNCAH programmes on national and subnational agendas. This is the first step toward the implementation of policies and legislations that facilitate birth defects prevention.

Strategic and sustained advocacy can bring about changes in the laws, regulations and organizational policies that govern institutional change (for example, in clinic-based or school health settings). For example, advocacy for prevention of birth defects can be directed to specific policy changes that strengthen iron–folic acid (IFA) supplementation around the periconception period and food fortification programmes, among others.

At the community level, advocacy actions targeting stakeholder groups aim to remove stigma and negative attitudes towards birth defects, and promote treatment and care for children born with birth defects.

For greater investment in health promotion and partnerships, as well as to gain support from legislators, health administrators and professional bodies, strategic and sustained advocacy engagement with a large number of stakeholders is essential.

In summary, advocacy helps strengthen birth defects prevention programmes by the following means:

- informing decision-making and policy changes that facilitate the inclusion of birth defects prevention on national and subnational health agendas;
- fighting stigma and discrimination by working with specific audiences (e.g. elected leaders, opinion-makers and the media) and facilitating equitable access to health care;
- helping communities to recognize the need to change practices, and the need for designated services (and to demand such services); and also by influencing public opinion and facilitating informed choices; and
- empowering health-service providers to raise issues related to birth defects prevention with clients and communities.

## Policy-level advocacy

Advocacy at the policy level is essential for:

- designing appropriate programmes for the prevention and management of birth defects;
- allocation of budgets for health and welfare programmes (especially in the women's and child-care sectors) that cover birth defects screening, treatment and rehabilitation;
- mobilization of relevant partners and additional funding; and
- implementation of public health actions that support the prevention and control of birth defects at national and subnational levels.

Evidence-based advocacy with the health ministry can lead to:

- establishment of committees, task forces or other mechanisms that focus on birth defects, and developing policies, plans, and programmes;
- facilitating work with related ministries including education, agriculture and food safety;
- implementation of required services for prevention and management of birth defects and monitoring of their quality;
- supporting evaluation of birth defects prevention programmes and service provision;
- investment in health communication activities to support national programmes for birth defects:
  - conducting public events and media campaigns;
  - placing messages on birth defects into important health-related days and into programmes on maternal and child health, smoking and alcohol prevention, and immunization; and
  - mobilizing resource persons from the government to speak to the media and community groups.

The key steps for policy-level advocacy are as follows.

Step 1: *Identifying the policies and programmes* that are most aligned to birth defects prevention and which require strengthening or effective implementation.

Step 2: *Identifying potential “advocates” at all levels* including government, nongovernment and community. Health ministry officials and programme officers responsible for maternal and child health can play an important role by directly implementing advocacy actions so as to influence policy-makers, institutions or civil society. Advocacy within the different departments of the health ministry, with the ministries of agriculture, food safety and social welfare, as well as with academic/research institutions and within health-care settings, is important.

Step 3: *Planning and implementing activities* for advocating with policy-makers and planners, including:

- assessing the political climate of the country and identifying parliamentarians and legislators who might support the cause;
- collecting technical evidence and data to highlight the magnitude of the problem;
- using powerful arguments (such as economic cost to the country, and best practices that have worked within the country and other countries) is effective in convincing policy- and decision-makers;
- identifying cost-effective interventions that can be integrated into existing maternal and child health programmes (such as immunization, food fortification and smoking and alcohol prevention); and
- keeping key stakeholders updated on the status of prevention initiatives, information on what seems to be working, and good practices to help them in decision-making and further planning.

Step 4: *Monitoring and evaluation* of advocacy activities

The process of monitoring and evaluation, and its importance, are described in Section 9.

## **Role of health workers and other advocacy groups**

Trained and motivated health workers are an asset to prevention programmes. However, their participation is dependent upon clear briefings, assignment of roles and responsibilities, health systems support, their sense of self-efficacy and their grasp of the tasks that they are designated to perform.<sup>3</sup>

<sup>3</sup> March of dimes: global report on birth defects: the hidden toll of dying and disabled children. March of Dimes Foundation. New York: White Plains, 2006. <http://www.neonatology.org/pdf/MODBDExecutiveSummary.pdf> - accessed 31 December 2014.

The importance of health workers in the South-East Asia Region is evident from the CNA findings.

- India reported involvement of accredited social health activists (ASHA) in interpersonal communication and the work of village health sanitation and nutrition committees at the subnational level.
- Timor-Leste highlighted communication activities by health volunteers who disseminate information to the community, focusing on women in the reproductive age group and pregnant women.

These groups are potential advocates within the health system. However, they need capacity-building, mentoring and systems support to strengthen advocacy for prevention of birth defects.

Other advocacy groups, such as patient/parent support organizations, play an important role in advocating for care and support for patients and their families. They are effective campaigners for the prevention of birth defects. Advocacy groups mentioned by Member States during CNA included professional bodies, elected leaders, community-based groups and opportunities provided by religious leaders during prayers. These groups would need to be sensitized and engaged in a systematic, organized and sustained manner through campaigns, advocacy and community mobilization.

## Advocacy with families and communities

Families and communities have played various roles in advocacy, ranging from influencing policies and legislation to helping members of the community access services and educating them about health issues. Advocacy activities conducted for the general population may also reach out to families through public events and the distribution of educational materials such as brochures, pamphlets, posters and videos. Not all advocacy activities are expensive – interpersonal communication and group meetings, for example, are cost-effective and require little to no additional funding, especially if they are conducted in collaboration with ongoing initiatives.

*Networks and alliances* are free spaces that promote the exchange of ideas and experiences. There are many informal networks that already exist in communities within the maternal and child health arena. These are spaces where opinions are exchanged and discussions take place, and practice information and implementation experiences are shared, rather than formal structures that support decision-making. Networks are useful for building a climate of change and getting advocates together for the cause of birth defects prevention. Alliances are usually formed around a common issue, and may vary from loosely defined alliances to those that are highly structured.

## Media advocacy

The media is a powerful ally, and working alliances should be formed with the media. Raising issues of birth defects in the media should be a systematic process rather than through one-off events that feed the media with stories. Media should be kept informed of scientific developments and prevention initiatives, and provided access to resource persons who can explain birth defects-related issues. (Some tips on media advocacy are provided in **Annex 4**).

## Advocacy challenges

It is important to address any roadblocks that a programme manager might encounter when planning an advocacy initiative. A few difficulties that are commonly faced are given below.

- Parliamentarians and high-level decision-makers are often unaware of community needs, especially if birth defects are not at the top of the agenda.
- Birth defects may be ignored by policy- and decision-makers due to other competing health priorities.
- In resource-constrained settings, programmes may suffer due to insufficient oversight and monitoring, leading to underreporting, misreporting and lack of accountability.
- Civil society and partners may lack the will, motivation or capacity to influence policies and monitor programme implementation.
- Communities may not know about or receive entitlements that ensure safe motherhood and healthy infants.

## 7. Behaviour change communication

One of the desired goals and outcomes of health communication is to bring about behaviour change. Country-specific behaviour change communication (BCC) strategies that recognize and address behaviours related to birth defects prevention and management need to be in place. Certain health risk behaviours among women of reproductive age are related to specific birth defects. Such behaviours include consanguineous marriage, pregnancy at an advanced age, self-medication during

pregnancy, use of alcohol and tobacco during pregnancy, and occupational exposure to environmental teratogens. Similarly, there are behaviours that protect against birth defects such as rubella vaccination before pregnancy, consumption of folic acid before and after conception, and premarital counselling. Countries in the South-East Asia Region that responded to CNA indicated several health risk behaviours that required some degree of change, while protective behaviours required reinforcement (refer to **Annex 1** for details).

Ignorance, myths and misconceptions about birth defects are common issues that interfere with treatment-seeking or the adoption of preventive services. For example, children with birth defects are often hidden and not brought to health centres owing to associated social stigma. This leads to underreporting as well as failure to obtain the required services for treatment. It is evident that the presence and availability of health services is not sufficient to deal with such social and cultural barriers.

BCC activities are designed with the aim of reducing health risk behaviours and promoting/reinforcing healthy behaviours. Adoption and maintenance of healthy behaviours requires a series of actions from being aware to adopting the desirable behaviour, and should be supported by robust and systematic technical support including:

- identifying data sources, both primary (needs assessments, surveys, interviews, field visits and participatory observations) and secondary (national, regional and local databases, published reports, scientific articles and unpublished [but evidence-based] literature);
- using research and implementation knowledge present in hospitals, professional bodies and research institutions at national and subnational levels;
- mapping existing behaviours and practices (especially those that require changing); and
- keeping policy- and decision-makers apprised of any behaviour change that may have been documented as part of the evaluation process.

When behaviour change messages are embedded in health campaigns (as described in earlier sections), they lead to several actions at the individual and community levels:

- recognition of unhealthy individual/societal norms and practices;
- encouraging individual decision-making;
- strengthening intentions to alter behaviour;
- increasing the likelihood of adopting new behaviours;
- targeting the removal of obstacles to change; and
- sustained practice of health behaviours.

Concurrent with community mobilization to raise demand for services, health workers must be closely engaged in prevention programmes. The roles and responsibilities of health workers must be clearly communicated to them, and their capacity must be built in interpersonal communication and counselling skills. Effective provider–client communication and community mobilization are important for several birth defect preventive interventions including: planned pregnancy and periconceptional folic acid supplementation, strict control of diabetes, prevention of maternal infections such as rubella and toxoplasmosis, and avoidance of recreational and medicinal drug use during pregnancy.

Motivated and sensitized health workers, researchers and experts will, in turn, be able to support the development of consumer groups, family groups, and civil society organizations which collaborate in designing and delivering services for the prevention and management of birth defects. A list of environmental factors that can positively impact provider behaviour is given in **Annex 5**.

## Understanding the process of behaviour change

Most audiences are not passive recipients of messages. How they receive a message is dependent upon the social and cultural determinants of the environment in which they live. Each recipient “filters” the message in different ways; for example, in communities that have certain beliefs about birth defects (they are a curse or a result of sins) the messages are filtered through the lens of these beliefs.

The HIC-DARM analysis presented in the communication for behavioural impact (COMBI) strategy<sup>4</sup> is applicable to a range of stakeholders and audiences, and explains

<sup>4</sup> World Health Organization. Communication for behavioural Impact (COMBI): field workbook for COMBI planning steps in outbreak response. Geneva: WHO, 2012. Document No. WHO/HSE/GCR/2012.14 p. 19.

processes that may take place from the time audiences hear about birth defects to the time they adopt the behaviour as part of their routine.

**H** – Individuals and communities **hear** about birth defects from various sources (providers, health workers, community officials and opinion leaders); therefore it is important for programme managers to provide correct information and clarify doubts and misconceptions among these groups.

**I** – Individuals and communities are **informed** about the causes of birth defects and the advantages of prevention, treatment, care and rehabilitation from various sources (relatives, community, media and providers).

**C** – After receiving information, they become **convinced** that birth defects are a serious, but preventable health issue that require early diagnosis and treatment.

**D** – Individuals and communities **decide** to do something about their conviction such as taking action

**A** – Individuals and communities **act** on their new behaviour (for example, take folic acid supplementation, access treatment, encourage pregnant women to go for antenatal care); and await reinforcement

**R** – **reinforcement** that their action was a good one (support from health-care providers, health workers, opinion leaders and community groups) and if all is well, they go on to the maintenance stage

**M** – **maintain** their behaviour (continue supplementation, check-ups, spread the word about birth defects prevention, encourage community members to seek treatment and care for birth defects).

This model also helps programme managers to address the question of what is to be done in situations where communities have been exposed to campaigns, but large-scale adoption of safe behaviours (e.g. regularly taking folic acid tablets during pregnancy, immunizing children against rubella) have not taken place to the desired extent.

Mounting campaigns with persuasive messages, using advocacy and initiating community mobilization techniques may help behaviour change. At the same time,

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[http://www.who.int/ihr/publications/combi\\_toolkit\\_fieldwkbk\\_outbreaks/en/](http://www.who.int/ihr/publications/combi_toolkit_fieldwkbk_outbreaks/en/) - accessed 31 December 2014.

behaviour change also requires change at the health system- and service provider-levels. For effectiveness, BCC programmes need to look at health belief systems, symptom recognition and care-seeking, provider preferences, household decision-making, health provider behaviour, and access to services.

## Interpersonal communication

Within the overall health communication campaign, interpersonal communication may be the key to changing a specific behaviour.

Use of interpersonal communication during interactions with patients and communities supports behaviour change through:

- information exchange, supported by discussions that facilitate comprehension of medical information;
- opportunities to explain benefits sensitively;
- improving adherence to treatment and advice, and doctor satisfaction;
- establishing caring relationships; and
- addressing doubts and social stigma related to birth defects, and countering blame attributed to women who give birth to babies with birth defects.

Not all health providers have interpersonal communication skills and techniques to help them communicate brief messages in a short time span. Communication skills must be incorporated into their pre-service and in-service training.

## 8. Community mobilization

*Community mobilization* is “a capacity-building process through which community members, groups, or organizations plan, carry out, and evaluate activities on a participatory and sustained basis to improve their health and other conditions, either on their own initiative or stimulated by others”.<sup>5</sup> Community mobilization for birth defects means raising community awareness about birth defects and their prevention by using

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<sup>5</sup> Howard-Grabman L, Snetro G. (2003). How to mobilize communities for health and social change. Health Communication Partnership. In: Demystifying community mobilization: an effective strategy to improve maternal and newborn health. Baltimore, MD: USAID, 2007. [http://pdf.usaid.gov/pdf\\_docs/PNADI338.pdf](http://pdf.usaid.gov/pdf_docs/PNADI338.pdf) - accessed 30 December 2014.

local resources, working with community leaders and stakeholders to invite and organize participation from those affected and interested in the issue, and by identifying current practices (both helpful and harmful), beliefs and attitudes that require modification.

Where campaigns have been initiated and advocacy initiatives are underway, programme managers need to start engaging with communities through institutions, civil society and community-based organizations. Such community mobilization is used to work with community leaders and stakeholders, and generate local resources.

## Engaging communities

Community mobilization activities should be planned in collaboration with members of the community and stakeholders.

Step 1. Work with the community to understand their needs, capacities and available resources by carrying out formative research.

Step 2. Establish credibility and trust with community networks, alliances, civil society groups and influential individuals.

Step 3. Identify both beneficial and harmful beliefs/practices in the community.

Step 4. Mobilize community leaders and stakeholders, as well as interested and affected populations. (A matrix for identifying prospective stakeholders and community supporters is placed at **Annex 6**).

Step 5. Assess the environment of change, as well as other efforts being carried out by existing health programmes.

Step 6. Based on these inputs, develop a community mobilization plan.

## Planning community mobilization activities

- Community assessments need to be undertaken to learn where the community stands on prevention and management of birth defects, efforts conducted so far, opportunities, barriers and gaps. Interview community leaders and influencers to find out which sections of the community would benefit, details on community habits (including myths and harmful practices), good practices in maternal and child care, routine habits and entertainment preferences, and media viewing/listening habits.

- Appropriate and influential members in the community should be identified. There are certain individuals present in every society and community who have the power, will and/or capacities to influence people to adopt positive health behaviours. These influencers may also be people who have frequent interactions with the community (e.g. elected or non-formal leaders, health workers, social workers, representatives of nongovernmental or grass-roots organizations, or members of faith-based groups). These people represent a cadre of “community mobilizers” who form the core of such initiatives. Involving mobilizers in every stage – from planning to implementation – is critical for the success of such initiatives.
- Identification of funding and other financial and human resources is another important step. Although the health department remains central to birth defects prevention initiatives, involving other sectors is equally important. Looking beyond the health department to non-health and welfare programmes and mobilizing creative resources within the community is an integral part of the planning process.
- Identification of the community mobilization component of ongoing campaigns for existing RMNCAH programmes should be initiated. As CNA in countries of the Region indicated, ongoing initiatives exist that may be used for community mobilization on birth defects prevention (refer to **Annex 7**).

Adding or integrating birth defects prevention into existing initiatives (such as school health or pre-pregnancy programme, as Sri Lanka has done, refer Figure 1) to sensitize communities about the importance of birth defects is always an option. However, countries should also consider launching birth defects prevention communication and advocacy initiatives – supported by community mobilization – as a stand-alone activity to draw communities’ attention to this important public health issue.

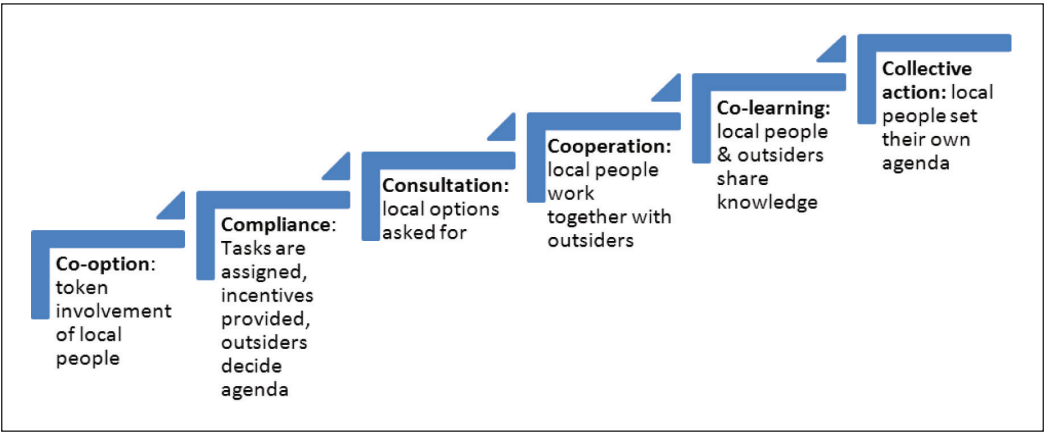
**Figure 1:** Preconception care package, Sri Lanka



## Expected outcomes of effective community mobilization

*Enhanced community participation:* Community ownership and capacity to absorb information and participate in mobilization varies among populations and groups. However, with capacity strengthening and demonstration of effectiveness, participation increases, capacities and ownership intensify and there is improvement in the quality of engagement. Figure 2 shows the degrees of participation and cooperation in community mobilization. Community mobilization efforts should seek to move communities from one level of action to another, as shown in the diagram.

**Figure 2:** Steps in community mobilization<sup>6</sup>



*Degrees of co-option:* as the diagram suggests, at the initial (co-option) stage, chosen representatives may not have much input to offer on birth defects prevention. At the next (compliance) stage, external agencies and outsiders may still decide the agenda and direct the process. At the consultation stage, local opinions are solicited; however, outsiders still analyse and decide on the course of action. At the next stage (cooperation), local people may start working with outsiders, but responsibility for the intervention still lies with outside agencies and individuals. At the co-learning stage, local people and outsiders share their knowledge to create new understanding and work together to direct the process. The ideal state is that of collective action – when local people set their own agenda and mobilize to take communication and advocacy around birth defects prevention forward, without outside initiators and facilitation.

Some tips on community mobilization are provided in **Annex 8**.

6 Centers for Disease Control and Prevention. Community mobilization guide: a community-based effort to eliminate syphilis in the United States. Department of Health and Human Services. Atlanta, GA: CDC, 2011. <http://www.cdc.gov/stopsyphilis/toolkit/Community/CommunityGuide.pdf> - accessed 31 December 2014.

## 9. Monitoring and evaluation of communication activities

Health communication is a resource-intensive component of any health programme. Therefore, it is important to continuously monitor and periodically evaluate the communication activities for advocacy, behaviour change and community mobilization to ensure that their implementation is progressing well and leading to the desired results. This improves utilization of communication materials and channels, improves the quality of campaigns, highlights areas that need to be changed and provides insights into cost–benefit. Both campaign monitoring and evaluation provide evidence of effectiveness and impact to enhance donor and stakeholder accountability.

Monitoring and evaluation activities for advocacy, behaviour change and community mobilization should be decided and financial resources identified right from the initial planning stage of the communication strategy. It is important to decide the goal and targets of the health communication plan and identify key indicators on which progress will be measured.

### Monitoring

Monitoring keeps a tab on implementation of planned communication activities in an ongoing manner, and assesses whether the activities are having the desired effect for which they were designed. There are three ways of monitoring a campaign: process monitoring, performance monitoring and outcome monitoring.<sup>7</sup> Monitoring ensures that unintended, unforeseen or unexpected events do not hamper the operations and/or outcomes of the communication campaign. Keeping in touch with audiences during the campaign by the administration of short questionnaires (in communities where literacy is not an issue), or testing the acceptance/rejection of messages through short interviews with key informants, are important to assess whether the campaign is “on track”.

### Evaluation

Evaluation helps determine if a communication campaign has worked or failed, and why. Evaluation is done at pre-agreed intervals, and not too frequently.

<sup>7</sup> O’Sullivan GA, Yonkier JA, Morgan W, Merritt AP. A field guide to designing a health communication strategy. Baltimore, MD: John Hopkins Bloomberg School of Public Health/Center for Communication Programs, March 2003. [http://www.ceecis.org/iodine/06\\_communication/06\\_03\\_jhu.html](http://www.ceecis.org/iodine/06_communication/06_03_jhu.html) - accessed 31 December 2014.

**Formative evaluation** includes pre-testing of messages and materials for planning birth defects prevention programmes and also for mid-course correction of ongoing initiatives. This type of evaluation ensures acceptance and uptake of the campaign by the targeted audience and its success. Formative evaluation findings should be documented and shared with stakeholders and donors. The CNA conducted at the beginning of this communication strategy is an example of formative assessment. Other types of formative evaluation are listed below.

- *Concept testing*: factors such as ideation, audience acceptance of visuals, and words/phrases used in the message are tested with potential target groups to design and appropriately position the campaign in the target population.
- *Message testing*: features of the messages such as comprehension, attraction, acceptability and relevance form part of the message-testing process. This process assesses the comprehensibility of messages, their strong and weak points, their relevance to audiences and whether elements of messages are confusing, sensitive or controversial.<sup>8</sup>
- *Audience analysis*: this technique gathers information about the target audiences. Audience knowledge levels, lifestyles, leisure patterns and use of mass media; their willingness and ability to participate in community mobilization activities; and, the socioeconomic and political environment are important components of formative assessment.

**Process evaluation** is used to assess the medium-term effects of campaigns that have already been launched and are underway. It tracks the quantity and quality of planned activities such as advocacy meetings, media campaigns and community meetings – both in terms of the number of people reached, and the profile of audiences who have been exposed to the campaign. This evaluation helps decide whether mid-course correction is required in order to increase chances of success and minimize wastage of resources. Process evaluation may be twinned with a mid-term implementation evaluation that measures the effect of communication activities.

**Outcome evaluation** assesses the proportion of people out of the number of people served that had a change in attitude, knowledge and behaviour. Policy changes

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<sup>8</sup> U.S. Department of Health & Human Services, Public Health Service. Making health communication program work. National Institute of Health National Cancer Institute. Pg.77. <http://www.cancer.gov/cancertopics/cancerlibrary/pinkbook/pink-book.pdf>. - accessed on 31 December 2014.

consequent to the advocacy are included in outcome evaluation. This type of assessment reassures that communication campaigns are on the right track and delivering the expected results. To evaluate outcomes, it is important to assess the extent of coverage of the communication campaign at the population level. It also quantifies achievement of short- and long-term objectives.

**Impact evaluation** assesses the impact of the programme or campaign on the audience and stakeholders. Impact evaluation goes further than outcome evaluation, as it measures what changes have occurred as a result of those outcomes; for example, the increase in proportion of women consuming folic acid or accepting rubella vaccination. This also clarifies whether any change that occurred was a result of the campaign.

It is also important to undertake costing analysis of communication campaigns.

- *Cost-benefit evaluation* measures both programme costs and results/benefits in monetary terms. Programme results, in this case, must be translated into value for money. This kind of analysis is a useful advocacy tool for funds allocation and a powerful argument for decision-makers to provide resources for campaigns.
- *Cost-effectiveness evaluation* assesses benefits in terms of impacts and outcomes (without monetary gain being assigned to them). Interpretation of findings helps stakeholders to decide if the benefit received equals the cost of the communication campaign, or whether less expensive options should be explored for greater gains.

## Monitoring and evaluation of advocacy

While monitoring measures an advocacy programme's progress in achieving specific results in relation to a strategy's implementation plan, evaluation attempts to determine a strategy's worth or significance as systematically and as objectively as possible.<sup>9</sup> Both formative and impact evaluation may be used to assess advocacy initiatives. Advocacy evaluation not only gauges factors such as effectiveness, participation and impact, but also influences advocacy processes.

<sup>9</sup> United Nations Children's Fund. Monitoring and evaluating advocacy: companion to the advocacy toolkit. UNICEF. [http://www.unicef.org/evaluation/files/Advocacy\\_Toolkit\\_Companion.pdf](http://www.unicef.org/evaluation/files/Advocacy_Toolkit_Companion.pdf) - accessed 31 December 2014.

## Monitoring community mobilization initiatives

Community mobilization may be monitored and assessed by qualitative outcomes such as: support to access health care by providing transportation; working closely with health-care workers to encourage families to seek treatment for infants with birth defects; women's participation in rubella vaccination initiatives; and, community movements to promote the use of iodized salt. If the number of women accessing the services increases, then community mobilization may be attributed as one of the contributing factors to success. Other factors include reduction in the time taken by the community for such actions, community participation in surveillance and sharing of information on birth defects, as well as spreading awareness about the issues and addressing stigma, discrimination, fears, myths and misconceptions. Measuring communities' capacity to sustain health improvements and successfully address birth defects prevention issues is important; however, development of measurement indicators requires time, as well as technical and financial resources that may not always be available at the beginning of the programme.

An example of monitoring and evaluation of a communication campaign is provided in **Annex 9**.

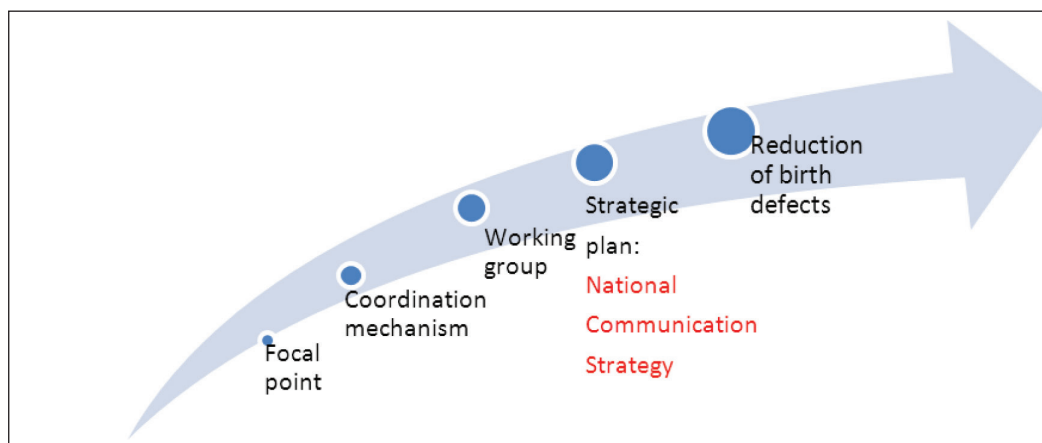
## Programme evaluation report

Once a communication and advocacy programme has been implemented and evaluated, it is important to write a programme evaluation report. This kind of report explains what worked and what should be altered in the future; it may include tools and questionnaires to help others who would like to implement or upscale the programme. The evaluation report also helps apply project learning to future initiatives, promotes knowledge gain and cross-learning opportunities, showcases programme accomplishments, points out areas that require modification, indicates transparency and integrity towards achieving project goals, and demonstrates to funders that the project optimized benefits for the time and money spent. Specifically, the report provides evidence about effectiveness, learning opportunities with regard to challenges, and serves as a formal record of the project.

## The way forward....

The “Regional strategic framework for prevention and control of birth defects” recommends a set of essential actions for developing national programmes for prevention and control of birth defects (Figure 3) that includes development of strategic communication plan. Strategic communication for advocacy, BCC and community mobilization is an essential element for the effective implementation of national birth defects prevention programmes in countries. Prevention programmes benefit from the enabling environment of change created by communication activities.

**Figure 3:** Essential actions for developing national action plan for prevention of birth defects



The way forward for implementing strategic communication for birth defects within national birth defects prevention programmes is working with RMNCAH and related programmes, such as nutrition and welfare programmes, already being implemented in the countries. The communication resources being invested in such programmes in terms of resource persons, institutions (in health as well as non-health sectors) in government and civil society could be effectively shared to integrate communication actions for birth defects prevention and management.

Pilot health communication activities may be designed, initiated and scaled up as the birth defects prevention programme gains momentum. Initiating partnerships or strengthening existing ones, and the sharing of resources, ideas and platforms may be explored by country communication strategies for birth defects prevention and management. Documentation of successful implementation and any roadblocks encountered will help increase understanding of the way communication activities strengthen prevention programmes.

## Implementation tips

Member States can use this regional strategy to develop or strengthen country communication plans. Communication plans need to be adapted to each country's situation and activities should be planned keeping beneficiaries and outcomes in view.

- Technical support for communication activities should remain with the health ministry, and programme managers may consider setting up mechanisms for information exchange and results-sharing (through meetings and/or websites) with multiple sectors and stakeholders.
- Intersectoral and private–public partnerships are important to sustain prevention activities and must be addressed by planned communication activities. Health programme managers may request other departments within the health ministry and allied sectors to include birth defects prevention into programmes for NCDs, immunization or nutrition (including food fortification) as well as social welfare programmes.
- A situation analysis may be carried out in the beginning to map existing programmes and resources, as well as to understand the communities' knowledge, perceptions and practices in relation to birth defects. This helps in development of appropriate messages and channels of communication.
- Using a mix of social marketing, advertising, mass media, interpersonal communication, health education and promotion will ensure the effectiveness of communication plans.

Advocacy, behaviour change and community mobilization activities need to be integrated with ongoing prevention initiatives in the various allied sectors to promote effectiveness and cost-efficiency.

- Setting up expert groups, collaboration with research institutes and use of existing data sets are ways to ensure success. Monitoring and evaluation of health communication activities are key supervisory functions.

A checklist for strategic communication plans is provided in **Annex 10**.

## Conclusion

The regional communication strategy provides broad concepts for the “why, what and how?” of health communication for the prevention and management of birth defects. It describes the essential elements of a holistic and integrated approach to strengthen communication activities in support of national plans for birth defects prevention and control.

The strategy recognizes that communication for advocacy, behaviour change and community mobilization cuts across many programmes in the health and allied sectors, and is dependent upon collaboration, partnerships and joint actions.

The strategy provides guidance for the development of country-specific national communication plans to strengthen the managerial and technical support functions of the birth defects nodal person within the health ministry to implement national plans for the prevention and control of birth defects.

## Resources

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## Useful links

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## Annex 1

# Findings of the communication needs analysis (CNA) in the South-East Asia Region

## Section 1: Strategic communication and mass media opportunities for prevention of birth defects

1.1 All 10 countries that participated in the CNA, reported communication activities in support of health-related programmes, including reproductive, maternal, newborn, child and adolescent health (RMNCAH), immunization, nutrition and micronutrient supplementation, tobacco and alcohol use prevention, sexually transmitted infections prevention, noncommunicable diseases (NCD) prevention, and school health programmes. All the countries stated that they broadcast health-related campaigns on radio and television. Bhutan and India mentioned monthly broadcasts; Bangladesh and Myanmar mentioned that broadcasts occurred almost every day; while Bangladesh and Indonesia also stated that broadcasts occurred on special occasions, e.g. National Immunization Day, World No Tobacco Day and World AIDS Day. Indonesia broadcast talk shows on 11 television channels with a frequency of 20 times in 2012 and 21 times in 2013; the country also broadcast radio talk shows 21 times in 2012. Timor-Leste did not mention the frequency of broadcasts.

### *Indonesia: an example of consistent print media coverage*

Indonesia reported news-related publications in 20 newspapers, 4 magazines and 1 tabloid. Immunization was reported 544 times, communicable diseases appeared 1700 times, NCDs 1161 times, nutrition-related topics 783 times, maternal and child health 1609 times, and mental health/smoking-related topics appeared 577 times.

1.2 Only Sri Lanka and Thailand mentioned that broadcasts occurred infrequently. When asked about newspaper reports, articles or public service advertisements on any of the topics related to birth defects prevention that might have appeared in the past

six months, all countries reported frequent reportage on anti-smoking and alcohol prevention as well as birth defects. Bangladesh mentioned slightly more infrequent reportage on these topics. Overall, smoking and alcohol prevention were more frequently reported than birth defects prevention.

*Maldives: popularizing tobacco control laws and antenatal counselling through health campaigns*

The law enacted for tobacco control activities is being popularized through media programmes, video spots and news articles. Antenatal counselling sessions are conducted utilizing a package consisting of 2–3 leaflets on different aspects of the issue. Measles-rubella and measles-mumps-rubella campaigns were introduced in 2006 and are ongoing.

1.3 The CNA questionnaire also sought information on birth defects/smoking/alcohol prevention advertisements that appeared in public spaces – on posters, billboards or hoardings. Of the 10 countries that responded, only Bangladesh reported not having any posters, billboards or hoardings on smoking and alcohol prevention; all other countries had public displays on these topics. Bhutan and Indonesia had displays of posters on birth defects prevention.

1.4 Apart from print, broadcast and transit media, the questionnaire requested details of community-based and outreach initiatives that had potential for synergies with communication, community mobilization and behaviour change initiatives. All countries reported outreach initiatives as follows.

- Five countries reported school health initiatives (Bangladesh, Bhutan, Indonesia, Nepal and Sri Lanka).
- Three countries mentioned birth registration programmes (Bhutan, Myanmar and Nepal).
- Three countries were advocating food fortification for birth defects prevention (Indonesia, Nepal and Thailand), including:
  - iodine fortification in salt, vitamin A fortification in wheat flour and cooking oil, and home fortification (Sprinkles) in Indonesia;
  - iodized salt, nutrition, safe motherhood, measles and rubella vaccination campaigns in Nepal; and
  - inclusion of iodine in food products such as fish-sauce and noodles in Thailand.

- Bangladesh reported community involvement in awareness generation programmes for child and adolescent health, safe motherhood and birth registration through road theatre and folk songs.
- Bhutan mentioned outreach clinics.
- India mentioned interpersonal communication efforts by accredited social health activists (mainly for NCD), initiatives by village health sanitation and nutrition committees and initiation of screening programmes for birth defects.
- Indonesia reported premarital counselling initiatives, implementation of school health programmes (from kindergarten to high school) and immunization programmes. The country also has a national campaign targeting adolescents and HIV entitled “I’m proud, I know”.
- Myanmar and Nepal reported awareness generation programmes on child and adolescent health. Myanmar and Indonesia both reported immunization, nutrition and safe motherhood programmes.
- Myanmar also mentioned child health programmes and food safety initiatives.
- Nepal reported advocacy activities to include rubella vaccination, instead of only measles, in the immunization programme.
- Timor-Leste mentioned a pilot project in Aileu that provided food for pregnant women and their families in order to increase the number of deliveries in health facilities. Corn oats are given to beneficiaries at integrated community health services to attract pregnant women to come for antenatal care. Women who delivered at a health facility were given maternity packets.
- Timor-Leste also reported health volunteers who disseminate information to the community, targeting women in the reproductive age group and pregnant women.

#### *Sri Lanka: multiple communication initiatives*

Sri Lanka reported having a regular health-promoting schools initiative and the involvement of professional organizations to conduct community-led activities. These included health tests and a preconception care package by the Family Health Bureau and units of the Ministry of Health, College of Community Physicians of Sri Lanka, and Sri Lanka College of Obstetricians and Gynaecologists. The Sri Lanka Medical Association led health walks and the NCD Unit conducted workplace awareness programmes, leaflet distribution, exhibitions, exercise and screening programmes.

1.5 As part of the CNA, Member States were asked for a brief description of any significant communication activities that may have direct or indirect bearing on prevention of birth defects (e.g. alcohol and smoking prevention, immunization, maternal and child health, and nutrition).

- Bangladesh stated that announcements<sup>10</sup> over loudspeakers on the eve of national immunization days had a significant influence on immunization. However, nothing similar had been done for prevention of birth defects.
- Bhutan reported rubella vaccination<sup>11</sup> and campaigns advocating alcohol/smoking prevention during pregnancy, weekly IFA supplementation to school children and pregnant women, and iodized salt supplementation.
- India reported initiatives for improving maternal nutrition through mass media, mid-media and interpersonal communication. Mid-media are used for alcohol and smoking activities.
- Myanmar reported smoking prevention, antenatal care, iodization of salt (universal salt iodization), IFA supplementation, nutrition education and counselling.
- Nepal mentioned vitamin A supplementation and deworming initiatives for under-five children, “polio mop-up programme”, antenatal counselling, IFA distribution to pregnant women and the measles–rubella campaign.
- Sri Lanka reported that birth defects were part of an all-inclusive preconception care package by the Family Health Bureau. The package covered the thalassaemia project, rubella immunization and iodine/food fortification.

<sup>10</sup> Announcements made over microphones in communities prior to an event.

<sup>11</sup> Mass immunization was introduced in the country in 2006 and has been up-scaled to cover all children.

- Timor-Leste mentioned dissemination of information by health staff and community volunteers to the community, verbally during consultation, during antenatal care, through health promotion, and through information, education and communication (IEC) materials.

“Campaign activities to raise awareness about harms of smoking and alcohol use, through posters, occur in the community very frequently”.

– *Quote from Thailand*

1.6 Member States were asked to rate important communication channels for prevention of birth defects (1 was assigned to the most important channel and 5 to the least important). Initiatives such as interpersonal communication/individual counselling, small group communication; family counselling, meetings organized by elected leaders/faith leaders/opinion-makers, and interactions with women of reproductive age, government functionaries, health-care providers and health workers were the most preferred communication channels. Print, electronic and social media were also mentioned as preferences. Timor-Leste rated civil society, community-based organizations and support groups as the least important channels of communication.

1.7 The assessment also included questions related to important communication and counselling opportunities in relation to birth defects prevention. The findings are given below.

- Apart from Sri Lanka, antenatal check-ups were the most favoured opportunity in all countries that participated in the CNA.
- Outpatient department clinic visits were rated highly by all countries, except India and Thailand.
- Community-based groups were preferred by Bangladesh, India, Indonesia and Nepal.
- School health activities were rated as least important by Timor-Leste.
- Other opportunities mentioned (apart from those listed in the questionnaire) were:
  - opportunities provided by religious leaders during prayers;
  - civil society involvement;
  - peak-time television broadcasts.

1.8 Respondents were asked to cite reasons why any of the options mentioned are *not* feasible opportunities for birth defects prevention. The reasons varied, and are mostly unique to the country situation.

“Indonesia has a huge population and it lies in an archipelago. Electronic media is the most effective channel to share the information to all districts and villages. Facebook and Twitter can also be effective channels. The programme needs strong policy support, health workers competency enhancement and empowerment of women’s organizations. On the other hand, interpersonal and other means of communication are not organized and therefore are not effective”.

– Quote from Indonesia

“Media programmes can be very helpful as this is accessible to everyone”.

– Quote from Maldives

- Bangladesh reported lack of proper training of health workers on counselling.
- Bhutan mentioned lack of resources for home visits by health workers.
- Indonesia stated that birth defects prevention information cannot be given in detail to school students and should be packaged and disseminated during community festivals, village fairs and other informal events. Presentations should be interesting and easily understandable.
- Myanmar and Thailand had a distinctly different perspective. Myanmar reported that it is not common/effective to give health education or health counselling during social affairs, since such issues may not be consonant with other areas of interest and priority. Thailand mentioned that “the people who come to village fairs, festivals and important days want to be entertained, enjoy and be happy. They are not interested to hear other issues”.
- Maldives reported that the country does not have support groups related to health. However, nongovernmental organizations could play a role in birth defects prevention.
- Timor-Leste mentioned competing priorities.

## Section II: Advocacy and community mobilization for the prevention of birth defects

2.1 In this section of the CNA, Member States were asked to identify primary stakeholders for advocacy on birth defects prevention.

- Ministries/Departments of health, education, and food/agriculture were acknowledged as national-level actors by all of the countries.
- Ministries/Departments of social service/social welfare, child development, and food and industry were mentioned by Nepal, Sri Lanka and Thailand.

2.2 Most countries mentioned academic/research institutions, medical colleges, corporate sector, civil society and development partners as subnational players. However, Myanmar, Sri Lanka and Timor-Leste included these as actors at the national level. Indonesia rated medical colleges and civil society as national actors, while Timor-Leste mentioned them as actors at the subnational level. Timor-Leste also mentioned development partners as national-level players.

- In addition:
  - Maldives mentioned atoll councils and the Malé City Council;
  - Nepal mentioned the Ministry/Local Development authority; and
  - Sri Lanka stated Provincial Department of Health Services.

2.2 Countries were asked to identify individuals and/or groups that could possibly be involved in advocacy and awareness generation. All 10 countries stated that policy-makers at the national level and national/subnational officials could be involved. However:

- Indonesia and Maldives did not mention elected leaders;
- Indonesia did not mention professional bodies;
- neither Indonesia nor Maldives mentioned women of reproductive age and community volunteers;
- Bangladesh, Bhutan and Maldives did not include civil society and community-based organizations; and
- Timor-Leste mentioned youth groups, peer educators, civil society and community-based organizations.

2.3 Countries were asked to cite national programmes and plans that may have the potential to incorporate advocacy on birth defects prevention. All 10 countries unanimously mentioned RMNCAH, nutrient and micronutrient supplementation programmes. While all countries stated that sexually transmitted infection prevention, NCD prevention and tobacco and alcohol prevention had potential, Bangladesh and Indonesia were not as strongly in favour (choosing the “somewhat” response). Nepal and Timor-Leste did not choose NCD prevention as an option. All countries (except Bhutan) mentioned school health programmes. Other initiatives mentioned were health promotion by departments of paediatrics, obstetrics and gynaecology, and professional bodies.

2.4 The CNA also asked countries to provide details of health outreach initiatives for communities in far-flung and difficult to reach areas that may be utilized for awareness generation on birth defects prevention. Five out of 10 countries mentioned specific initiatives catering to such populations.

- Bhutan has monthly outreach clinics for reproductive health and immunization activities.
- India mentioned mobile medical teams that visit far-flung areas.
- Indonesia described health outreach programmes (mobile clinics and adolescent-friendly health services) that operated in remote, border and small archipelagic areas.
- Myanmar mentioned an integrated township health plan that covers 60 out of 330 townships and includes maternal and child health, nutrition, emergency services and immunization. NCD are included in the plan, but not on a priority basis. The country’s Expanded Programme on Immunization Plus services also include nutrition and other activities that are related to prevention of birth defects. Myanmar is also developing national and regional plans to reduce under-five mortality.
- Thailand has introduced fortification with triferdine (iron, iodine and folic acid). This scheme is intended for pregnant women, targeting the prevention of neural tube defects.

2.5 A section of the CNA asked countries to describe the most important drawbacks and hindrances that could hamper the implementation of a communication and advocacy programme for prevention of birth defects. All 10 countries provided information on barriers to effective implementation.

Bhutan cited limited funds and resources, while Maldives stated human resource capacity constraints. Myanmar mentioned financial limitations with regard to operating costs for projects, including funds for conducting advocacy meetings and capacity-building. Electricity shortages and availability/accessibility of mass media were also drawbacks. India stated competing communication and advocacy needs. Like many neighbouring countries, Nepal mentioned fund and human resource constraints; communication and advocacy activities being perceived as an “extra burden for busy clinics” and lack of motivation among the health workforce are also major hurdles. Sri Lanka stated that although the media is an effective vehicle for birth defects prevention, it is also very expensive. Thailand’s fortification with triferdine programme is targeted to prevent neural tube defects among pregnant women. Timor-Leste mentioned the importance of community awareness for the prevention of birth defects, and the need for involvement and collaboration with many sectors. Overall, countries were of the opinion that there is superficial understanding of, and less attention paid to, prevention of birth defects.

“Since this is a new programme it will take time to establish and change policies at the national level”.

– Bangladesh

“Birth defects have not been established as a national programme as yet. Therefore sustainability is an issue. The vital registration system for newborn babies still needs improvement. Health providers lack knowledge about birth defects detection. They require information and training programmes”.

– Indonesia

### Section III: Behaviour change communication

3.1 This section of the CNA asked Member States to provide information on beliefs and practices on which the BCC section of the birth defects prevention strategy could be based. Some common myths and misconceptions related to birth defects in countries were as follows.

In Bangladesh, people tended to relate birth defects to various natural events. Bhutan mentioned that people attributed birth defects to bad deeds committed in a previous life. Likewise, Buddhists in Thailand also believe that birth defects are caused by sins in the past. In Bhutan, mothers who give birth to babies with defects are often blamed for the infant’s condition. Similarly in Nepal, birth defects are perceived as a

curse and women who give birth to such infants are faulted. In Myanmar, birth defects are related to the outcomes of bad “*karma*”.<sup>12</sup> India reported that birth defects are perceived as “God-given conditions” for which there can be no prevention or control measures. Indonesia mentioned that cutting cloth during pregnancy can cause cleft lip. Also prevalent in the country are myths, such as consuming a double banana during pregnancy can cause Siamese twins to be born or eating crabs during pregnancy can cause split hand or foot. In Maldives, it is believed that during a lunar eclipse a pregnant woman should not use knives to cut anything, as this action gives rise to birth defects in the unborn child.

3.2 Countries were also asked to cite some harmful practices prevalent in communities that could interfere with the adoption of beneficial behaviours in relation to prevention of birth defects. Bangladesh reported that belief in myths and prevalence of misconceptions prevent women from going to health workers for antenatal and postnatal check-ups. In Bhutan, belief in local healers is a hindrance that interferes with treatment-seeking. Children with birth defects are often hidden and not brought to health centres; birth defects in the country are also underreported. In Thailand, practices such as consumption of herbs during pregnancy (based on the erroneous belief that it can lead to a healthy fetus) are hindrances to the adoption of safe practices.

In India, drug use, consanguinity and elderly primigravida are harmful practices that lead to prevalence of birth defects. The poor nutritional status of populations is also a factor that leads to the occurrence of birth defects.

In Maldives, smoking, substance use and improper use of pesticides in agriculture are harmful practices that are related to prevalence of birth defects.

3.3 Countries were asked to name some good practices in communities that require strengthening in the context of birth defect prevention. India mentioned avoidance of elderly primigravida, consumption of unnecessary drugs (medication) and exposure to radiation during pregnancy. Maldives mentioned avoiding superfluous medication and the importance of early antenatal check-ups and spreading awareness of folic acid supplementation pre-, during and post-pregnancy. Nepal mentioned that encouraging women to go for antenatal check-ups was a good practice. Myanmar stated low levels of smoking prevalence and alcohol consumption among women, although they may be exposed to second-hand smoke. Thailand mentioned the importance of

<sup>12</sup> In Hinduism and Buddhism, *karma* is the sum of a person’s actions in this life and previous states of existence.

quitting smoking or drinking habits prior to conception and pregnancy. Bangladesh highlighted the need for a religious ban on consanguineous marriages, while Bhutan was the only country that referred to the importance of health messages on the subject of birth defects.

3.4 Member States were also asked to identify barriers to treatment and care-seeking for infants with birth defects. Some of the barriers mentioned earlier were repeated in this section. Bangladesh stated that some parents feel shy about taking infants with birth defects to health-care providers. Bhutan mentioned feelings of ignorance, fear, stigmatization and guilt about birth defects among communities. Indonesia also reported that stigmatization interfered with care-seeking; while India attributed non-availability of medical care and surgical interventions to non-health seeking behaviour. In Maldives, treatment and care are available only in the capital cities and treatment-seeking is hampered by delayed referrals from the atolls due to a variety of reasons. Some cases may need to be referred outside the country for treatment. Myanmar faced transportation issues, especially for people living in remote areas. Financial constraints and other socioeconomic conditions also interfered with treatment-seeking. Nepal mentioned lack of a proper referral system. Thailand reported that expensive treatment and mountainous terrain make it difficult for communities to access hospitals in some areas of the country

3.5 Countries were asked to rate key communication skills that need to be strengthened among providers and health workers, and that are likely to be most relevant for birth defects prevention (where 1 was the highest rating and 5 the lowest).

- Interpersonal communication and counselling skills were rated the highest by Bangladesh, India and Thailand.
- Only Thailand rated small group communication and interviewing skills highly. By contrast, Timor-Leste rated these skills the lowest.
- Designing awareness campaigns was rated highly by Bangladesh, Bhutan and Nepal.
- Basics of advocacy (including media advocacy) were rated highly by all countries, except Bhutan and India (4 and 3, respectively).
- Only Indonesia rated community mobilization and demand generation for services highly, followed by Bangladesh. All other countries rated this skill much lower than the others (3–5).

3.6 As a precursor to designing the regional communication strategy, countries were asked to mention some important “days” or festivals (e.g. World Health Day) where events could be held to propagate birth defects prevention. All countries, except Sri Lanka, mentioned days when health-related events could take place. Some countries mentioned days that were unique to their countries, while Indonesia provided a complete calendar of days and events.

**Table A1.1:** Health-related days mentioned by countries in the CNA

Country	Days	Events
Bangladesh	National immunization days	Village fairs
Bhutan	School Iron Day (Thursday of every week)	
	World Diabetes Day	
Bhutan, Maldives, Myanmar and Nepal	World Health Day	
India	Mother’s Day	
	Children’s Day	
Maldives	World No Tobacco Day	
	World Population Day	
Myanmar	World Health Month	
	Nutrition Promotion Month (August)	
	World Breastfeeding Week	This week could include nutrition promotion for pregnant women and under-5 children, and iodine deficiency disorders elimination activities.
Nepal	Diabetes Day	Birth Defects Day
		“365 days”
Thailand		Smoking Cessation Day

3.6.1 Bhutan, Maldives, Myanmar and Nepal mentioned World Health Day as a possible platform for conducting activities related to birth defects prevention. Other international health-related days/week mentioned by countries included: World No Tobacco Day, World Population Day, World Diabetes Day, and World Breastfeeding Week. India mentioned two days devoted to mothers and children, respectively, that could be used for birth defects prevention activities. Myanmar mentioned week-long

activities that could be conducted during World Breastfeeding Week, while Nepal suggested that a day devoted exclusively to birth defects be marked and that almost every day be observed as birth defects prevention day.

3.6.2 Calendar of health-related days (provided by Indonesia)		
(i)	25 January	: National Nutrition Day
(ii)	3 March	: National Ear Health and Hearing Day
(iii)	24 April	: Immunization Day
(iv)	8 May	: Thalassaemia Day
(v)	31 May	: World No Tobacco Day
(vi)	23 July	: National Children’s Day
(vii)	1–7 September	: World Breastfeeding Week
(viii)	12 November	: National Health Day
(ix)	1 December	: World AIDS Day
(x)	3 December	: World Disability Day

3.6.3 The final question in the CNA was about birth defects prevention sensitization, awareness generation or BCC, advocacy, and community mobilization activities that may have already been carried out by countries. This was answered by four of the 10 countries that participated in the CNA.

- Bhutan mentioned that they had disseminated messages about the harmful effects of alcohol and the importance of avoiding x-rays during pregnancy.
- India stated that the country is planning to initiate universal screening of all children for identification of birth defects.
- In Maldives, birth defects prevention sensitization meetings were held for relevant departments by the Ministry of Health and the Indira Gandhi Memorial Hospital.
- Thailand mentioned that newspapers reported issues such as the importance of prevention, preparing parents prior to childbirth, and fortification of folic acid and iodine six weeks before pregnancy.

## Annex 2

### Communication channels

A table showing the characteristics of each channel, and its advantages and disadvantages, is presented below. Programme managers may use this table to decide the “channel mix” that they intend to use in communication programmes for prevention of birth defects. This list is indicative, however, and in each country media have unique and inherent properties that need to be tapped.

**Table A2.1:** Channel communication choices

Channel	Audience reached	Advantages	Disadvantages
<b>Interpersonal channels</b>			
	Individual	Face-to-face	Difficult to control messages
Provider to client	Individual/client	May be the most credible source, as it is face-to-face	Requires expert training by a communicator
Spouse to spouse	Individual/spouse	Most participatory	Costly to scale up.
Peer to peer	Peer group	Highly effective	Takes a long time to build reach
<b>Community channels</b>			
Community media (community newspapers, local radio)	Men, women, children	Participatory, may be more credible than mass media, as it is localized Low cost	Costly to scale up. Low reach beyond the immediate community Low frequency One-way communication

Channel	Audience reached	Advantages	Disadvantages
Community activities (folk drama, group meetings, rallies, community advocacy or mobilization)	Segments of target audience	Participatory May have more credibility than mass or community media, as it engages audiences Stimulates institutionalization of community structures Encourages sustainability of effort Low cost	Costly to scale up Low reach Low frequency
<b>Mass media channels</b>			
Television	Households, families (men, women, adolescents, children)	Comes into homes, can spur family discussion Reaches a large percentage of the intended audience Delivers maximum impact (sight, sound and motion) Cost-efficient	Expensive production Initially more urban than rural May be too costly at certain times of year Prime time may be prohibitive; other time slots may not reach many audience members
Radio <sup>a</sup>	Individuals, families, adolescents	Reinforces television messages Can be highly creative Can send messages in the local language Used as a personal medium in many countries FM radio has re-established urban and periurban audience	Fragmented reach Costly to build reach when there are many different radio stations covering one area No visuals Not always easy to buy or access in all parts of a country
Mobile phones	Individuals, families, adolescents, health workers	Personal medium Expanding reach	Multiple languages may be required

Channel	Audience reached	Advantages	Disadvantages
Websites and social media	Individuals, families, adolescents	Reach, access and use are expanding Appeals to several audience segments Repeated reach-out and follow-up possible	Reach is limited in rural areas
Magazines	Men, women, youth	Segmented to reach different audiences by lifestyle, demographics and attitude	Long lead time Low frequency For literates only More up-scale
Newspapers	Well-educated men and women, policy-makers	Mass medium Timely Message length Influential Flexible sizing	For literates only Reproduction quality Poor photo reproduction Short lifespan May not be cost-efficient
Outdoor/transit (billboards, bus advertising)	Men and women	Good for identification or awareness building High traffic areas Very brief message Reinforcement of other media messages	Limited time of exposure Limited message content Not very durable

<sup>a</sup> Some countries, including India, Indonesia and Nepal, have strong community radio presence although this was not mentioned in the CNA.

## Examples of communication channels being used in countries

In certain situations, mass media campaigns would need to be combined with community media (also called mid-media) events and community mobilization to generate awareness about birth defects among communities. Community media may be used to reach messages to populations during selected events and days of the year, or used whenever a health issue needs to be positioned for recall, action and behaviour change, especially in vulnerable and low-literate communities.

An example of community media is the “*Aao, batein karein*” (Come, let’s talk) campaign of the State Innovations in Family Planning Services Project Agency (SIFPSA) in Uttar Pradesh, India. The project identified a key barrier to adoption of birth spacing methods as lack of dialogue between spouses, and between the service provider and young couples. Featured themes were *Tota* (parrot) and *Maina* (mynah), two birds, one male and one female, originating from folklore. The Johns Hopkins Center for Communications Programs supported SIFPSA in Uttar Pradesh to implement this multimedia BCC initiative in a campaign mode from 1998 to 2002, through service-provider training, mass media dissemination, interpersonal communication training and distribution of materials (flip books, posters, stickers and calendars) to all workers. These were used to start a dialogue with couples. The campaign included 30 and 60 second television spots on three spacing methods (condoms, oral pills and intrauterine contraceptive devices) broadcast over national and regional channels. As aids to recall, audio versions of the television spots were broadcast during popular film-music programmes on all radio stations in the state. Additionally, radio spots and press advertisements targeting opinion leaders were developed in order to advocate family planning and to dispel fears, myths and misconceptions. To reach media-dark areas, popular folk forms including folk theatre and puppetry were performed by troupes trained to disseminate family planning messages in villages. To maximize audience outreach, SIFPSA organized exhibitions at *kumbh melas* (big fairs) in the capital city Allahabad.<sup>13</sup> The campaign stimulated dialogue on family planning between young couples, between providers and clients, and was used to raise awareness and knowledge of family planning methods and allay myths and misconceptions and also created a demand for family planning services.

Although community media initiatives may be less expensive than television broadcasts, public service announcements or radio programmes, as Table A2.1 (above) indicates, they definitely need to be planned and evaluated before they can be scaled up to other issues and settings. As the CNA findings show, most Member countries have used mass media either in the campaign mode or as one-off communication for health promotion.

13 IFPS Technical Assistance Project (ITAP). 20 years of the innovations in family planning services project in Uttar Pradesh, India: experiences, lessons learned and achievements. Gurgaon: Futures Group, ITAP, 2012. [http://futuresgroup.com/files/publications/20\\_Years\\_of\\_IFPS\\_in\\_Uttar\\_Pradesh.pdf](http://futuresgroup.com/files/publications/20_Years_of_IFPS_in_Uttar_Pradesh.pdf) - accessed 31 December 2014.

*Figure A2.1: Screenshot of a newspaper report, Thailand*



Note: this newspaper article is on the importance of preparing parents before the birth of a child, raising awareness about birth defects prevention, and the need to fortify folic acid and iodine 6 weeks before pregnancy.

## Campaign examples from the South-East Asia Region CNA

- Bangladesh stated that miked announcements<sup>14</sup> on the eve of national immunization days had a significant influence on immunization. This practice may be adapted to birth defects prevention.
- Bhutan reported advocating for alcohol/smoking prevention during pregnancy.
- India reported initiatives for improving maternal nutrition through mass media, mid-media and interpersonal communication. The country also uses mid-media activities for alcohol and smoking prevention.
- Myanmar reported smoking prevention, nutrition education and counselling.
- Nepal mentioned the “polio mop-up programme”, antenatal counselling and measles-rubella campaigns.
- Thailand stated that “campaign activities to raise awareness about harms of smoking and alcohol use, through posters, occur in the community very frequently”.

14 Announcements made over microphones in communities prior to an event

- As expressed by some countries during the CNA, mass media requires financial resources that may not always be available. Although sponsorships, donor engagement and public–private partnerships may be ways of generating funds, mass media still remains an expensive proposition for middle- and low-income countries. The media is a powerful partner and advocate for birth defects prevention, and resources have to be allocated for strategic communication, advocacy and community mobilization.

*“Indonesia has a huge population and it lies in an archipelago. Electronic media is the most effective channel to share the information to all districts and villages. Facebook and Twitter can also be effective channels. The programme needs strong policy support, health workers competency enhancement and empowerment of women’s organizations. On the other hand, interpersonal and other means of communication are not organized and therefore are not effective”.*

– Indonesia

*“Media programmes can be very helpful as they are accessible to everyone”.*

– Maldives

*“Media is the most efficient but is very expensive”.*

– Sri Lanka

## Global campaign examples

There is much to be learnt from immunization campaigns. The WHO *Global measles and rubella strategic plan: 2012–2020*, states that “Communication and social mobilization efforts aim to foster community ownership and demand for immunization, to increase coverage and to help achieve measles, rubella, and Congenital Rubella Syndrome (CRS) goals. Community awareness of immunization rights, benefits, safety and available services will promote public acceptance and participation. Experience with polio and measles programmes demonstrates the need for targeted and specific strategies to address resistance to immunization in communities, including health workers. Moreover, community and civil society demand for immunization will hold governments and programmes accountable to their commitments, thereby improving programme sustainability”.

## Examples of opportunities for incorporating birth defects prevention messages from the South-East Asia Region

- Most states in India have a regular village health and nutrition day (under the aegis of the flagship programme, the National Rural Health Mission) where birth defects prevention may be discussed.
- Community events such as World Health Day or World No Tobacco Day, national immunization day or mother's/children's days are not only valuable platforms for information sharing, but they provide publicity for messages, indicate availability of community resources, and are a form of social support to encourage change in habits and behaviour.
- Regarding community events, Myanmar has suggested that, "it is not common/effective to give health education or health counselling during social affairs. There may be other interesting/priority areas". Thailand mentioned that "the people who come to village fairs, festivals and important days want to be entertained, enjoy and be happy. They are not interested to hear other issues". In such situations, prevention messages may have to be packaged in an interesting and entertaining manner for dissemination to communities.
- Sri Lanka has a preconception care package for newly-married couples. The goal of the package is to develop reproductive health outcomes by improving the health of newly married couples through screening both husband and wife for risk factors including selected past and present medical conditions and medications, family history of selected medical conditions, sexual and reproductive health, family nutrition, lifestyle, environmental conditions, psychosocial concerns (depression/violence), and rubella vaccine/folic acid. An invitation card, guide for health workers and a book for the new couple are also part of the package.

**Figure A2.2:** Preconception care package, Sri Lanka



## Lessons learnt from implementation of health campaigns

- Large-scale media campaigns have higher population exposure and can, therefore, generate a somewhat increased response when compared to smaller communication initiatives.
- A health campaign can effectively use agents of change (e.g. teachers, health professionals, group leaders) to disseminate information about a health topic. Interactions with these groups promotes healthy behaviour change and provides social support to those who are making changes.
- Messages disseminated via the mass media can stimulate opinion leaders to discuss health topics and these efforts can percolate down through community networks. The media can also be used to reinforce existing norms – such as promotion of anti-smoking habits among adolescents and women of reproductive age, encouraging referrals for birth defects, and improving care-seeking behaviour.
- Effective communication campaigns do not merely disseminate information; they often create an environment where people adopt healthy behaviours. However, presentation of facts and the prominence given to information influences public opinion on health topics.
- Campaigns use a mix of interpersonal communication and media. Interpersonal communication through support groups, interactions and lectures builds capacity and provides essential information and health education. Within organizations and institutions, “gatekeepers” (those who make policy-decisions, control resources and plan activities) are key campaign targets. The mass media often enhances gatekeepers’ knowledge and generates popular support for campaigns (refer to the example of the *Aaon batein karein* campaign in Uttar Pradesh, India).
- Campaigns have an agenda-setting function. Both campaigns and advocacy activities promote “agenda-setting” (whereby a topic gains importance in people’s minds). The need for agenda-setting with regard to birth defects was expressed by countries during the CNA.
- Factors such as simplicity of the message, judicious use of visuals and statistics, appeals to low-literate audiences, mix of channels, duration (the length a message is retained in the campaign), how much audience participation it generates, how much receiver control is necessary (print media messages can be re-read by the audience, whereas radio and

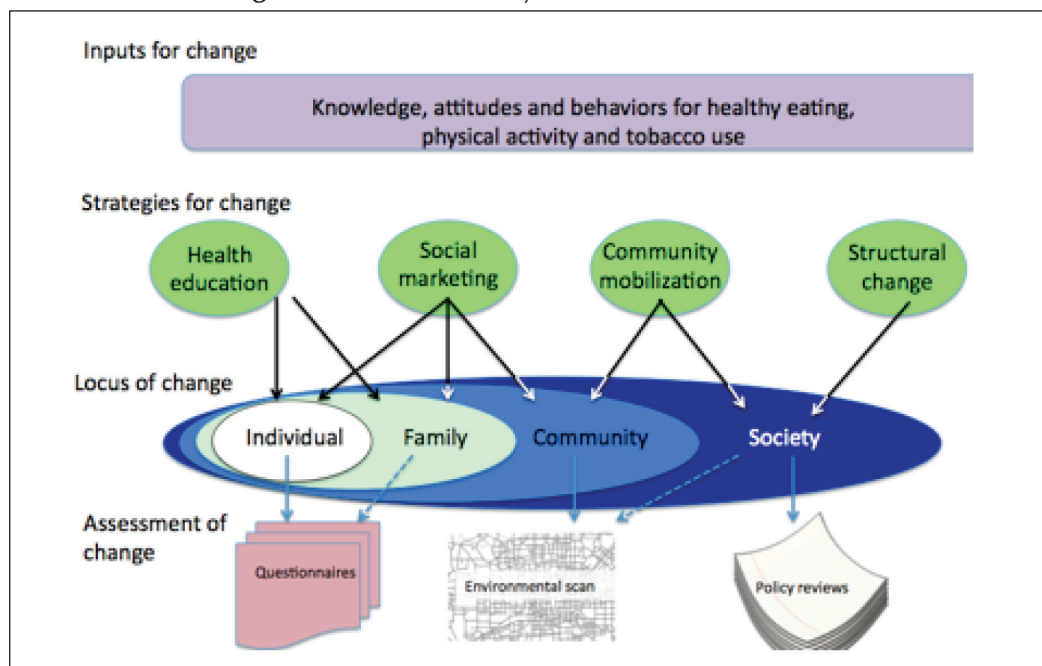
television programmes are viewed only during transmission) are key to successful campaigns.

- In some instances, listener's clubs (e.g. the *Kalyani Clubs*<sup>15</sup> in India, that discuss the popular health magazine *Kalyani* broadcast by Doordarshan) are ways to reinforce mass media campaigns by using interpersonal communication. Repetition of campaigns facilitates recall among audiences and enhances message preservation.<sup>16</sup>

## An example of social marketing campaign outcomes

Successful interventions are often a combination of social marketing, health education and behaviour change. The Oxford Health Alliance<sup>17</sup> is piloting the Community Interventions for Health (CIH) project, which brings together all these aspects. A conceptual model of the intervention is given in Figure A2.3.

**Figure A2.3:** Community interventions for health



15 Role of Kalyani clubs. <http://www.ddindia.gov.in/devcom/Program%20Column%202/Documents/9a225acd543f4b63ba3801ba5f3a058bROLEOFKALYANICLUBS.pdf> - accessed 31 December 2014.

16 National Collaborating Centre for Methods and Tools. Developing health communication campaigns. Hamilton, ON: McMaster University, 2010. <http://www.nccmt.ca/registry/view/eng/75.html> - accessed 31 December 2014.

17 Community interventions for health. Oxford Health Alliance, 2013. <http://www.oxha.org/publications/community-interventions-for-health-ci-h/> - accessed 31 December 2014.

Although the example is based on prevention of NCD, the intervention model shows the interrelationship of communication and social marketing. CIH aims to develop and showcase sustainable interventions addressing poor diet, tobacco use and lack of physical activity, and to demonstrate their effectiveness in preventing disease in a way that is both practical and scientifically rigorous. CIH is taking place in three sites around the world, located in Hangzhou in China, Kerala in India and Mexico City in Mexico. The goal of CIH is to promote individual behaviour change, through structural interventions and community mobilization, supported by health education and social marketing. While structural interventions emphasize improving health by changing the physical, social and economic environments within communities, community mobilization organizes communities around social, environmental and policy change toward healthier lifestyles. Critical components of the CIH intervention strategy are community coalitions, health education and social marketing/media. The model posits that health education, without support from structural interventions and community mobilization, has little or no impact on behaviour change in the long term, and states that social marketing has been found to be effective in addressing the gap between knowledge and behaviour.

## Annex 3

# Examples of good practice in the South-East Asia Region

### Networking among institutions and experts

An approach used by the WHO Regional Office for South-East Asia to develop capacity for promoting newborn health has been the creation of a network of “centres of excellence” in Member States for the utilization of regional resources. A network of centres of excellence (from Bangladesh, India, Indonesia, Nepal, Sri Lanka and Thailand) was established and their capacity built for developing and contributing to the neonatal-perinatal database. Tools were developed for data collection, and standardized through a consultative process with the network. Each site in the present regional network would then develop a national-level database network in the subsequent phase. Since then, national networks of institutions have been established / initiated in Bangladesh, India, Indonesia, Maldives, Myanmar and Nepal.

The network serves as a platform for creating, sharing and disseminating of knowledge and experience; builds education and training capacity of health-care professionals in the Region and within the countries; and, will engage policy-makers in newborn health advocacy at the regional, national and subnational levels. The network will endeavour for evidence-based policies and programmes, greater resources (domestic and external), and greater accountability for results by all stakeholders.

Following the release of the regional strategic framework for the prevention and control of birth defects, by the WHO Regional Office for South-East Asia in collaboration with CDC, Atlanta, birth defects have been integrated within the regional neonatal-perinatal database and newborn health-related activities of the regional network.

## Communication within the regional network

Currently, the focus of the regional network is on the development, distribution and application of knowledge through the following pathways:

- establishing national neonatal-perinatal networks for strengthening newborn care, education and training in Member States and in the Region;
- managing the integrated regional neonatal-perinatal database including birth defects and stillbirths;
- disseminating educational and training tools on newborn health such as e-courses, webinars, standard treatment protocols, neonatal-perinatal databases and recent WHO guidelines; (See snapshot of weblink below.)
- disseminating the regional strategic framework for the prevention and control of birth defects and supporting priority actions to initiate preventive strategies for birth defects and surveillance in countries. (A participatory approach is being pursued, to initiate a momentum of knowledge sharing and collaborative learning amongst members of the network on the important public health issues of birth defects and newborn health in the South-East Asia Region.)

## Intersectoral collaboration for prevention of birth defects

During the CNA, when countries were asked to cite national programmes and plans that may have the potential to incorporate advocacy on prevention of birth defects, all 10 countries unanimously mentioned RMNCAH and nutrient and micronutrient supplementation programmes. Almost all countries stated that sexually transmitted infection prevention, NCD prevention, tobacco and alcohol prevention and school health programmes had the potential for intersectoral collaboration. Other initiatives mentioned were health promotion by departments of paediatrics, obstetrics and gynaecology, and professional bodies.

## SOUTH-EAST ASIA REGIONAL NETWORK ON NEWBORN HEALTH & BIRTH DEFECTS



WHO Collaborating Centre for Training and Research in Newborn Care  
WHO Collaborating Centre for Training in Clinical Laboratory Genetics for  
Developing Countries

Department of Pediatrics  
All India Institute of Medical Sciences, New Delhi

Supported by  
World Health Organization, Regional Office for South-East Asia &  
National Center on Birth Defects and Developmental Disabilities, CDC, USA

### Joining hands to make a difference



- Every year, of the 3.0 million neonatal deaths globally, 1 million occur in the South-East Asia Region accompanied by an equal number of stillbirths. With a high coverage of evidence based interventions, the majority of these deaths can be averted.

- Globally, it is estimated around 10 million babies, are born with congenital malformations, of which 2.3 million babies, are born in the South-East Asia Region. Elective termination of pregnancy for foetal anomalies (ETOPFA), stillbirths, spontaneous abortions, survival, comorbidity and long-time disability add to the high burden of birth defects.

- WHO-SEARO supported the newborn leadership of the SEA Region to form the Regional Network for Strengthening Newborn Health and Birth Defects Surveillance and Prevention. This Regional Network is being coordinated by the WHO-Collaborating Centers for Newborn and Genetics at All India Institute of Medical Sciences (AIIMS), New Delhi.

- The aim of this Regional Network is to develop linkages for an integrated **neonatal-perinatal database** including stillbirths and birth defects (**SEARNet**), learning resources, packages for newborn care and standard treatment protocols to manage common newborn conditions in small hospitals and the development of guidelines for the prevention

and management of birth defects. These would contribute to strengthening newborn health interventions in the national maternal, newborn and child health programs of the Region.

- The Integrated Neonatal-Perinatal Database focuses on generating prospective information leading to new insights on neonatal/perinatal morbidity and mortality in the Region and occurrence of various birth defects. Standard protocols for recording and reporting of data on newborn conditions, birth defects and stillbirths have been developed. Capacity building in Member States has been ongoing. All the Member States have attended the Regional Network meeting and are committed to establishing national networks in their respective countries. **National Networks for Newborn Health and Birth Defects** have been initiated in Bangladesh, Myanmar and Nepal.
- The purpose of this newsletter is to share updated information among the members. We request you all to kindly share any information you wish to be disseminate through this newsletter.

**Table A3.1:** Examples of intersectoral communication from the CNA

Country	Examples of intersectoral communication
Maldives	<ul style="list-style-type: none"> <li>• Birth defects prevention sensitization meetings held for relevant departments by the Ministry of Health and the Indira Gandhi Memorial Hospital</li> </ul>
Myanmar	<ul style="list-style-type: none"> <li>• Smoking prevention</li> <li>• Nutrition education and counselling</li> </ul>
Nepal	<ul style="list-style-type: none"> <li>• “Polio mop-up programme”</li> <li>• Antenatal counselling</li> <li>• Measles-rubella campaign</li> </ul>
Sri Lanka	<ul style="list-style-type: none"> <li>• Birth defects were part of an all-inclusive preconception care package by the Family Health Bureau (including thalassaemia, rubella immunization and iodine/food fortification).</li> </ul>
Timor-Leste	<ul style="list-style-type: none"> <li>• Information dissemination by health staff and community volunteers to community, during consultations, antenatal care, etc.</li> <li>• Through health promotion and IEC materials.</li> </ul>

## Tobacco control programme in Bhutan

Tobacco control policy and gross national happiness audits in Bhutan are vital mechanisms for health in all policies. The process is implemented through intergovernmental and multisectoral committees or task-force platforms, involving actors from civil society, consumer groups and academia. The platform enables the health sector to seek support from other sectors, and to make necessary decisions in the process of policy development. The Tobacco Control Board was created in Bhutan, comprising 13 members representing different governmental and other agencies.

Intersectoral action is evident in the enforcement of tobacco control policy, whereby the measures of reducing tobacco use in the country are integrated into the plans of other sectors. Community leaders and district officers also play a crucial role in monitoring tobacco control measures. This range of intersectoral action may have contributed positively towards reducing tobacco consumption and maintaining low prevalence rates of tobacco use in Bhutan, thereby effectively helping compliance with the provisions of the WHO Framework Convention on Tobacco Control (WHO FCTC). The case-study clearly demonstrates the feasibility of using intersectoral mechanisms in policy development and gains from improving the efficiency of cooperation and coordination between sectors.<sup>18</sup>

18 World Health Organization. Learning from intersectoral actions for implementing health in all policies: a compilation of case studies. Geneva: WHO, 2013. p. 10.

## Tobacco control programme in India<sup>19</sup>

This case-study describes how intersectoral action for health has contributed to the WHO FCTC in India. WHO FCTC was ratified by India in 2004, and provides the foundation to manage tobacco control programmes and elicit the cooperation of related sectors. A high-level governance structure, the National Tobacco Control Cell (NTCC), has been established by the Ministry of Health and Family Welfare in collaboration with the WHO Country Office for India for overall policy formulation, planning, implementation, and monitoring at state level. To drive the implementation of the WHO FCTC by different sectors, high-level coordination committees have been established at national, state and district levels. State tobacco control cells (STCC) are present at the state level.

The ministries that have contributed towards tobacco control at national and state level include: human resource development, information and broadcasting, home affairs, labour and employment, railways and finance. In addition, the parliament, judiciary, civil society and media have also been significant allies for the achievement of tobacco control.

The implementation of the smoking ban is an interesting example of multisectoral collaboration and communication. Immediately after the Supreme Court of India ruling on a ban on smoking in public places, NTCC sent letters to all central government departments, and several workplaces in the public and private sector to inform them about the act. NTCC advised all the state finance secretaries to increase value added tax on all tobacco products. Similarly, an advisory was sent to all states to enforce the Food Safety and Standards Regulations – thereby prohibiting production, sale and storage of food products containing tobacco or nicotine (such as *gutkha*, pan masala and *zarda*). In this manner, several agencies were involved in intersectoral action that supports implementation of this important law.

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19 WHO Country Office for India. 2012–2013.

## Annex 4

### Tips on media advocacy

Programme managers for birth defects in the ministries of health should be prepared for working with the media. Some tips on media advocacy are given below.

- Develop a database of journalists who regularly cover health, economic and social development issues, not only at the state level, but also at the subnational level.
- Develop a media strategy – decide the message, choose a credible source, and choose the medium that is most likely to advocate the cause (whether it is print, radio, television or web-based).
- Select spokesperson/persons who will meet the media from time to time. Spokespersons could be well-informed individuals within the health ministry or a resource person who has credibility.
- If a reporter calls with a story he/she heard has about, do not brush it away. Check information sources and the stand that the ministry is going to take on the story before speaking to the media. If an official finds it difficult to answer the question, remember to call back with the information requested once it has been sourced. Respect the fact that reporters work to deadlines and need to get accurate information in a timely manner. If the information reaches after the deadline, it is a missed opportunity to advocate for birth defects in the media. Many such missed opportunities may lead to the media not trusting you for accurate and credible information.
- As we have learnt, media campaigns are expensive but effective. Therefore, attempts should be made to get time on television channels and radio (especially on important health-related days) to conduct talk shows and

panel discussions. These can then be uploaded on the ministry website or as a video on YouTube<sup>20</sup> so that a wider audience can see the programmes.

- Events at the national, subnational and community levels are good ways to keep the media informed and sensitize them about the importance of prevention. When hosting events, make sure that a media kit consisting of some printed materials (a press release, fact sheets and Frequently Asked Questions), and photographs are ready for media persons. Ministry officials and resource persons should be briefed in advance to give short interviews and sound-bites that the media can use during broadcasts. Sometimes, blogs on websites (ahead of the event and afterwards) keep the issue alive in the minds of a section of the audience.
- Other important media opportunities are feature articles and opinion pieces that can be printed in newspapers, and public service announcements on outdoor media, radio and television.<sup>21</sup>

“To gain the highest, most effective media coverage, an advocate’s message needs to have solid content, framed to draw media attention. Journalists are always looking for a fresh breakthrough such as the newest research..... Translating an individual’s story into the broader public issue is another useful strategy for framing messages.... It is always best to present a solution to the issue, suggesting practical steps decision makers can take”.

“A gripping story can also be told through compelling visuals, photos, videos or symbols. Using quotes that shape the argument from credible messengers such as academics or decision makers will also boost the advocate’s credibility and gather media attention. Hard-hitting numbers – used accurately and responsibly – draw a clear picture. Showing sources and methodology goes a long way towards transparency, and secures an organization’s credibility”.

– From: Advocacy toolkit: a guide to influencing decisions that improve children’s lives. UNICEF, New York, 2010. Pg. 54-55

20 Centers for Disease Control and Prevention. Birth defects count. Video National Center on Birth Defects and Developmental Disabilities. BirthDefectsCOUNT@cdc.gov. <http://www.cdc.gov/ncbddd/folicacid/global.html> -accessed 31 December 2014. *Summary: there are more than 300 000 babies born with neural tube defects worldwide each year. Fortification of food staples with folic acid is a cost-effective public health intervention to ensure more babies are born without neural tube defects. The purpose of the video is to raise awareness of and document the public health success story of folic acid fortification.*

21 World Health Organization. Advocacy for mental health. (Mental Health Policy and Service Guidance Package). Geneva: WHO, 2003. [http://www.who.int/mental\\_health/resources/en/Advocacy.pdf](http://www.who.int/mental_health/resources/en/Advocacy.pdf) - accessed 31 December 2014.

## Annex 5

### Environmental factors that influence provider behaviour

The following table illustrates some of the environmental factors that may positively impact provider behaviour.

**Table A5.1:** Multiple environments that influence practitioner behaviour<sup>22</sup>

Immediate environment	Interaction with patients and staff members
Personal environment	People with meaningful relationships with the practitioner; personal preferences and values, etc.
Educational environment	The opportunities for education that exist: basic education system, higher education system, health-care personnel education system and continuing education, as well as other learning opportunities that are available, both formal and informal.
Professional environment	Colleagues, professional associations, certifying bodies, licensing or credentialing system and its regulations, etc.
Community environment	How the practitioner (professional) is perceived in the wider local/regional community, in the media and among opinion leaders and decision-makers in health and health care.
Administrative environment	Rules, regulations and laws that govern provider behaviour, working conditions, facilities, health-care education programmes, etc.
Sociocultural environment	The traditions and culture of wider society.
Economic environment	The history of, and prevailing economic conditions in, the country, especially as they affect health-care personnel
Political environment	The dominant ideologies, political structures, etc. that set limits on types of political actions that are acceptable

<sup>22</sup> Ibid, Pg.15

Several such environmental factors that influence provider behaviour were mentioned by countries during the CNA.

- India attributed non-availability of medical care and surgical interventions to non-health seeking behaviours.
- In Maldives, treatment and care are available only in the capital cities and treatment-seeking is hampered by delayed referrals from atolls due to various reasons. Some cases may need to be referred outside the country for treatment.
- Myanmar faced transportation issues, especially for people living in remote areas. Financial constraints and other socioeconomic conditions also interfered with treatment-seeking.
- Nepal mentioned lack of a proper referral system.
- Thailand reported that expensive treatment and mountainous terrain make it difficult for communities to access hospitals in some areas of the country.

## Annex 6

### Stakeholder identification matrix<sup>a</sup>

Matrix for identification of prospective stakeholders and community supporters					
Individual/ organization name	Why they would want to support birth defects prevention	Skills and resources they bring to the community mobilization effort	How they should be recruited	Pre- involvement orientation and information needs	Observations and notes

<sup>a</sup> Centers for Disease Control and Prevention, Department of Health and Human Services, Community mobilization guide. Atlanta, GA: CDC, 2011. p.15. <http://www.cdc.gov/stopsyphilis/toolkit/msm/see-msm-cbo.pdf> - accessed 31 December 2014.

## Annex 7

### Community mobilization examples from the South-East Asia Region

Country	Community mobilization initiatives mentioned in the CNA
Bangladesh	Community involvement in awareness generation for child and adolescent health, safe motherhood and birth registration through road theatre and folk songs.
Bhutan	Dissemination of messages about the harmful effects of alcohol during pregnancy and the importance of avoiding x-rays during pregnancy. Rubella vaccination, campaigns advocating alcohol/smoking prevention during pregnancy, weekly IFA supplementation to school children and pregnant women, and iodized salt supplementation.
India	Universal screening of all children for identification of birth defects planned. Initiatives for improving maternal nutrition through mass media, mid-media and interpersonal communication. Alcohol and smoking prevention campaigns use mid-media.
Maldives	Birth defects prevention sensitization meetings were held for relevant departments by the Ministry of Health and the Indira Gandhi Memorial Hospital.
Myanmar	Smoking prevention, antenatal care, iodization of salt (universal salt iodization), IFA supplementation, nutrition education and counselling.
Nepal	Vitamin A supplementation and deworming initiatives for under-5 children, “polio mop-up programme”, antenatal counselling, IFA distribution to pregnant women and measles-rubella campaign.
Sri Lanka	Birth defects were part of an all-inclusive preconception care package for newly married couples, developed by the Family Health Bureau. The package covered the thalassaemia project, rubella immunization and iodine/food fortification.
Timor-Leste	Health volunteers disseminate information to the community, especially women in the reproductive age group and pregnant women. Youth groups, peer educators, civil society and community-based organizations are involved in health promotion.

Country	Community mobilization initiatives mentioned in the CNA
Other relevant findings	<p>Bangladesh stated that miked announcements (announcements made over microphones in communities prior to an event) on the eve of national immunization days had a significant influence on immunization. However, nothing similar had been done on prevention of birth defects.</p> <p>Community-based groups were the preferred channel of communication by Bangladesh, India, Indonesia and Nepal. Some countries mentioned civil societies as important communication platforms.</p>

## Annex 8

### Tips on community mobilization

*Use media for community mobilization:* adopt a media mix that best suits target audience cultural milieu, adjusts to community needs and is timely, informative, educative and entertaining. Use a combination of strategies – community meetings, group discussions, rallies, community walks, speaking to leaders and opinion-makers as well as interpersonal communication as well as mass media campaigns.

*Combine strategies and integrate with other ongoing programmes:* birth defects prevention messages may be integrated smoking and alcohol prevention campaigns; rubella immunisation, food fortification and supplementation and prevention of iron deficiency initiatives. RMNCAH programmes also offer spaces for integration of birth defects prevention messages, especially when individuals, groups and grassroots

**Figure A8.1:** Community worker checks infant's weight, Timor-Leste



©WHO/Timor-Leste

alliances are strengthened and motivated to act as agents of social change. Such groups are important when intervening in stigma, discrimination and negative practices that hamper birth defects prevention efforts and hinder access of communities to treatment and care. Forming partnerships with resource persons and local organisations, networks and community-based groups also help sustain prevention activities.

*Recognize contributions from groups and role models* (for instance a mother who brings her infant for treatment, a health worker who refers cases systematically and who keeps records of children with birth defects). Publicize good practices not only through the media, but also by discussing them with the community and encouraging more people to join the movement on birth defects prevention.

## Annex 9

### An example of communication campaign monitoring and evaluation

An article on achieving polio eradication, a review of health communication evidence and lessons learned in India and Pakistan,<sup>23</sup> covering the period between 2000 and 2007 showed how communication strategies guided by epidemiological, social and behavioural data have contributed to increased levels of polio immunity, particularly among underserved and hard-to-reach populations. It was found that in India, communities where social mobilization activities are conducted are consistently less likely to refuse oral polio vaccine (OPV), more likely to attend booths, more likely to report positive attitudes towards OPV and report a higher perception of polio risk, compared with families in communities without these activities, hence contributing to lower incidence. In four high-risk districts of Uttar Pradesh where social mobilization activities were conducted, the number of wild poliovirus cases dropped from 116 to 49 and there was a significant increase in booth coverage (between 50% and 57%, compared with 19% to 35% at district level). There were data to support the contribution of mass and folk media and advocacy for increased awareness and booth attendance. In India, large-scale mass media campaigns involving movie and cricket stars and political figures focused on dispelling rumours about OPV and encouraging caregivers to bring their children to vaccination booths. Entry and exit polls following exposure to messages in local media among 2552 randomly selected respondents showed a 60% increase in awareness of the next national immunization day's date and a 20% increased intention to get children immunized at the booth. Puppet/theatre shows, video vans and other folk media activities held in more than 3500 villages in Uttar Pradesh contributed to a 20% increase in booth attendance. Data from 2004 to 2005

23 Obregón A, Chitnis K, Morry C, Feek W, Bates J, Galway M, Ogden E. Achieving polio eradication: a review of health communication evidence and lessons learned in India and Pakistan. *Bulletin of the World Health Organization*. 2009;87:624-30.

showed that 68% of respondents exposed to polio radio and television spots reported taking their children to the booth for vaccination, compared with only 44% among those not exposed to the advertising.

Success factors for polio-related communication included:

- implementation of communication interventions based on routine monitoring of epidemiological, social and behavioural data on affected populations;
- intensive use of interpersonal communication and social mobilization at different levels to maximize reach, effectiveness and efficiency;
- mobilization of community leaders, communication and relationship-building, engaging families and caregivers who question repeated polio vaccination;
- involving religious leaders as spokespersons and using faith-based folk media (i.e. mosque announcements) to reach community members;
- working with trained communication outreach workers as part of a house-to-house strategy to reach children missed during national immunization days;
- advocacy with intensive grass-roots mobilization to reach and communicate with marginalized communities; and
- addressing social/gender norms to improve interpersonal communication, and increasing access to hard-to reach groups.

## Annex 10

### Checklist for strategic communication plans

This checklist<sup>a</sup> is a reminder of important steps in designing strategic health communication campaigns.

- ☒ Identification of health issue
- ☒ Analysis of the health situation at the national level
- ☒ Analysis of the health situation at the subnational level
- ☒ Segmenting potential audiences
- ☒ Setting SMART<sup>24</sup> objectives
- ☒ Developing strategic approaches
- ☒ Developing evidence-based messages with creative inputs
- ☒ Identifying appropriate channels and tools for communication with intended audience
- ☒ Planning monitoring and evaluation activities

<sup>a</sup>Adapted from: A field guide to designing a health communication strategy. Population Communication Services, Johns Hopkins Bloomberg School of Public Health/ Center for Communication Programs, 2003.

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24 SMART stands for:

Specific: the objective should say who or what is the focus of the effort and what type of change is intended.

Measurable: the objective should include a verifiable amount or proportion of change expected.

Appropriate: the objective should be sensitive to audience needs and preferences as well as to societal norms and expectations.

Realistic: the objective should include a degree of change that can reasonably be achieved under the given conditions.

Time-bound: the objective should clearly state the time period for achieving these behaviour changes.

## Annex 11

### Communication tools: Generic templates for the purpose of advocacy and awareness generation

This Annex includes a set of ready-to-use communication tools as generic templates that can be used for the purpose of advocacy and awareness generation. When using these in a country or in a province within the country, it will be required to insert country specific information, as indicated in the templates.

- (1) At-a-glance
- (2) Sample country profile fact sheet
- (3) Key messages
- (4) Frequently asked questions (FAQs)
- (5) Sample letter/Email
- (6) Sample newsletter/article
- (7) Sample press release
- (8) Sample web content
- (9) Social media posts
- (10) Executive Summary of Regional Strategic Framework for prevention and control of birth defects (2013–2017)

## Prevention and Control of Birth Defects

### At-a-glance

[TO BE CUSTOMIZED PRIOR TO DISTRIBUTION]

#### What are birth defects?

According to the Tenth Revision of the International Classification of Diseases (ICD10), birth defects—also known as congenital anomalies—include congenital malformations, deformations, and chromosomal abnormalities, but exclude inborn errors of metabolism. An expanded definition of birth defects, as stated by the March of Dimes, covers abnormalities of structure or function, including metabolism, which are present from birth.

#### Causes and types of birth defects

Of known causes of birth defects, approximately 25% are due to genetic factors and 4–10% are caused by environmental factors. The two most common genetic causes of congenital anomalies are single-gene defects and chromosomal abnormalities. Examples of identified environmental causes include:

- maternal nutritional status: e.g. Folic acid insufficiency is related to neural tube defects in the baby;
- maternal infections (e.g. rubella);
- chronic maternal diseases (e.g. diabetes);
- exposure to known teratogenic prescription medicines (e.g. retinoic acid, valproic acid);
- exposure to chemicals, and possibly illicit drugs during pregnancy; and
- physical factors, such as ionizing radiation and hyperthermia.

For more than 50% of birth defects, the causes are not unknown. Unknown causes are believed be environmental or multifactorial, meaning that multiple undefined gene variants interact with environmental factors to cause a specific anomaly.

**Major structural birth defects** are defined as structural changes that have significant medical, social or cosmetic consequences for the affected individual, and

typically require medical intervention. Examples include spina bifida and cleft lip. Major structural birth defects are the conditions that account for most of the deaths, morbidity and disability related to birth defects.

**Functional birth defects** are related to a problem in working of a body part or system. These often lead to developmental disabilities.

**Most common birth defects.** Globally, the most common serious birth defects of genetic or partially genetic origin are:

- congenital heart defects
- neural tube defects
- haemoglobin disorders, thalassemia and sickle-cell disease
- down syndrome
- G6PD deficiency.

Combined, these five conditions account for about 25% of all birth defects.

### Why are birth defects a public health concern?

As under-5 deaths have declined due to improved management of neonatal infections and birth asphyxia, the burden of birth defects has proportionally increased, resulting in birth defects being seen as an increasingly important cause of stillbirths and neonatal deaths. Preventing birth defects-related mortality would contribute to further reductions in child mortality in all countries. Many birth defects are preventable by interventions that can be delivered within existing reproductive, maternal and child health, immunization, nutrition and other related programmes.

### Birth defects are prevalent, severe, and costly.

**Birth Prevalence.** It is estimated that every year 6% of newborns worldwide are born with a serious birth defect/congenital disorder due to genetic or environmental causes. Based on 163 million annual global births, the estimate would be 9.78 million newborns. About 7% of all under-five deaths globally are caused by birth defects.

**Severe.** Many birth defects are severe. For example, newborns with anencephaly and serious congenital heart diseases do not survive, and many of those born with spina bifida will die or have varying degrees of lifelong disabilities.

**Costly.** Birth defects may result in long-term disability, which has significant impact on individuals, families, health-care systems and societies. For example, the lifetime direct cost of care for one child born with spina bifida in the United States is estimated to be US\$ 706 000. There also are great social and emotional costs for children with birth defects and their families.

## Prevention and control of birth defects

Some birth defects can be readily detected, prevented and controlled. Examples of primary detection, prevention, treatment and care of birth defects include:

- improving the diet of women throughout their reproductive years;
- ensuring an adequate dietary intake of vitamins and minerals and particularly folic acid and iodine;
- abstaining from or restricting intake of harmful substances, particularly the use of alcohol and tobacco;
- controlling pre-conceptional and gestational diabetes through counselling, weight management, diet, and the administration of insulin when needed;
- avoiding exposure to hazardous environmental substances (e.g. heavy metals, pesticides, some medications) during pregnancy;
- improving vaccination coverage, especially against the rubella virus, for children and women;
- using medical genetic screening and counseling, such as preconception screening, to identify persons at risk for specific disorders or at risk for passing a disorder on to their children;
- using prenatal and newborn screening for haematological, metabolic, and hormonal disorders to facilitate life-saving treatments and prevent the progression towards some physical, intellectual, visual or auditory disabilities; and
- in countries with well-established health services, correcting structural birth defects with paediatric surgery and administering early treatment to children with functional problems such as thalassaemia (inherited recessive blood disorders), sickle cell disorders and congenital hypothyroidism.

## Prevention and control of birth defects in the South-East Asian Region and [COUNTRY]

To address this situation, the Member States of the World Health Organization's South-East Asia Region (SEAR)<sup>1</sup> have developed a Regional Strategic Framework, the goal of which is to reduce the prevalence of birth defects in the Region within five years (2013–2017). Its four specific objectives in selected Member States are:

- (1) to reduce the prevalence of folic acid-preventable neural tube defects by 35%;
- (2) to reduce the number of thalassaemia births by 50%;
- (3) to reduce congenital rubella; and
- (4) to eliminate congenital syphilis.

Implementation of the Framework is guided by five strategic directions:

- (1) to establish or strengthen national policies and programmes for birth defects prevention and control;
- (2) to develop and strengthen national birth defects surveillance and evaluation mechanisms;
- (3) to integrate birth defects prevention strategies into public health, nutrition and other relevant programmes, as appropriate;
- (4) to expand and strengthen national capacity for implementation of birth defects prevention and control programmes; and
- (5) to develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes.

[COUNTRY SITUATION AND NATIONAL PLAN]

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1 South-East Asian Region Member States: Bangladesh, Bhutan, Democratic People's Republic of Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand and Timor-Leste

## Country Profile Fact Sheet on Birth Defects

[NAME OF THE COUNTRY]

[TO BE COMPLETED/CUSTOMIZED AT COUNTRY LEVEL PRIOR TO DISTRIBUTION]

(1) Contribution of birth defects to: [PROVIDE COUNTRY-SPECIFIC INFORMATION]

- (a) Neonatal mortality rate
- (b) Perinatal mortality rate
- (c) Stillbirths
- (d) Medical termination of pregnancy

(2) Most common birth defects: [PROVIDE COUNTRY-SPECIFIC INFORMATION]

- (a) ...
- (b) ...

(3) Health information system [PRESENT SITUATION]:

- (a) Proportion of births registered
- (b) Proportion of deaths registered
- (c) Proportion of stillbirths registered
- (d) Proportion of women older than 35 years at delivery
- (e) Proportion of population who marry consanguineously

(4) Source of data/information on birth defects in the country [PROVIDE COUNTRY-SPECIFIC INFORMATION]:

- (a) ...
- (b) ...

(5) Folic acid supplementation and fortification [PRESENT SITUATION]:

- (a) Adolescents: If yes, level of coverage
- (b) Pregnancy and lactation: If yes, level of coverage

- (c) Periconceptional: If yes, level of coverage
  - (d) Composition of tablets for above options a. b. and c.
  - (e) Food fortification:
    - (i) National or subnational: If yes, level of coverage
    - (ii) Mandatory by law or voluntary:
- (6) Pre-conception, pre-pregnancy and pregnancy care:  
[MENTION THE INTERVENTIONS OFFERED IN THE COUNTRY; EXAMPLES ARE PROVIDED BELOW]
- (a) Rubella vaccine
  - (b) Prevent and manage use of alcohol among women, before and during pregnancy
  - (c) Prevent and manage harmful use of tobacco and exposure before and during pregnancy
  - (d) Education and awareness programmes (reproductive and related health promotion)
  - (e) Avoid pregnancy after 35 years of age
  - (f) Avoid teratogens (medicines, radiation and environmental exposure) around conception and during pregnancy
  - (g) Detection and management of pre-existing Type 2 diabetes
  - (h) Detection and management of gestational diabetes
- (7) Screening for birth defects: [MENTION THE INTERVENTIONS OFFERED IN THE COUNTRY; EXAMPLES ARE PROVIDED BELOW]
- (a) Antenatal screening for risk factors
  - (b) Ultrasonography (prenatal) screening
  - (c) Newborn screening
  - (d) Population screening for thalassaemia, etc.
  - (e) Prenatal diagnosis

- (8) Services for care of children born with birth defects:  
[MENTION THE INTERVENTIONS OFFERED IN THE COUNTRY; EXAMPLES ARE PROVIDED BELOW]
- (a) Family support programmes
  - (b) Corrective surgery and /or rehabilitation programmes
  - (c) Community rehabilitation programmes
  - (d) Parent organizations
  - (e) Stakeholders
- (9) Genetic services:  
[MENTION THE EXTENT OF AVAILABILITY IN THE COUNTRY; EXAMPLES ARE PROVIDED BELOW]
- (a) Genetic screening
  - (b) Genetic counselling
  - (c) Genetic laboratories
  - (d) Genetic tests
- (10) National plan for birth defects prevention and control:  
[PROVIDE THE FOLLOWING COUNTRY-SPECIFIC HIGHLIGHTS]
- (a) Goal
    - (i) [e.g.] Significant reduction of preventable birth defects to contribute to achievement of MDG4 and beyond.
  - (b) Targets [e.g.]
    - (i) Reduce the prevalence of folic acid-preventable neural tube defects by 35%;
    - (ii) Reduce the number of thalassaemia births by 50%;
    - (iii) Reduce congenital rubella;
    - (iv) Eliminate congenital syphilis.
  - (c) Strategic directions
  - (d) Actions
  - (e) Indicators/expected outcomes



## Key Messages/Talking Points: Birth Defects Prevention in South-East Asia

[TO BE CUSTOMIZED PRIOR TO DISTRIBUTION]

In response to the World Health Resolution issued in 2010 to address birth defects, the Regional Office for South-East Asia of the World Health Organization (WHO) developed the *Strategic Framework for Prevention and Control of Birth Defects in South-East Asia Region (2013–2017)* (a.k.a., “the Framework”). The goal of the Framework is to promote the significant reduction of preventable birth defects in the South-East Asia Region and to accelerate the progress towards achievement of United Nations Millennium Development Goal (MDG) 4.

### Childhood deaths are declining, but not quickly enough.

MDG 4 commits world leaders to enable the resources to reduce the under-five mortality rate globally by two-thirds between 1990 and 2015.

- Although the South-East Asia Region has reduced the under-five mortality rate by more than 50% since 1990, high rates still exist among several individual Member States.
- At the current pace of progress, the Region as a whole is unlikely to achieve the MDG 4 target.

### Birth defects are now among the most common causes of death and disability in infants and children under five years of age in the South-East Asia Region.

- The South-East Asia Region has seen a decline in infant and childhood deaths due to the prevention of infectious diseases and malnutrition, but death resulting from birth defects has remained constant. This has resulted in birth defects assuming a greater proportionate burden of under-five deaths.
- WHO estimates that, globally, about 7% of all neonatal deaths are caused by birth defects.

### Birth defects are a severe and costly global public health challenge.

- The Framework targets four specific types of birth defects as priorities for prevention efforts: neural tube defects, thalassemia, congenital rubella syndrome and congenital syphilis.

- These are severe conditions that result in death and adverse health outcomes.
  - The most common types of neural tube defects include anencephaly and spina bifida. Babies born with anencephaly die within a few hours or days of birth. Babies born with spina bifida have varying degrees of lifelong disabilities.
  - Rubella in women during early pregnancy can lead to abortion or stillbirth later. In case the pregnancies is carried an affected baby is born with a cluster of serious birth defects including cataract (leading to blindness), hearing defects, heart defects, collectively called congenital rubella syndrome.
  - Syphilis in women during pregnancy can result in miscarriage, stillbirth or a baby born with congenital syphilis that has risk to life and immediate as well as long term morbidity.
  - Thalassemia major is associated with a lifelong need for repeated blood transfusions and iron chelation therapy that has enormous economic and social burden for the individual and family. Individuals affected with thalassemia major usually have a shorter life span.
- Additionally, birth defects have significant economic, social, and emotional impacts on individuals, families, communities and systems of care.
  - Birth defects cause a decreased quality of life, social stigma, and discrimination against affected individuals and their families.
  - Many, birth defects often result in long-term disability, causing decreased productivity and loss of potential income for the individual and their caretakers, and costly medical treatments (including surgery and medications).
  - Long-term disabilities also place a heavy burden on health systems that are already strained due to the challenges of operating in low-resource settings.

### **Many birth defects have significant opportunities for prevention**

- Each of the four birth defects targeted within the Framework has a unique and significant opportunity for public health intervention.

- The majority of neural tube defects can be prevented by increasing intake of folic acid among women of reproductive age.
  - A supplement of 400 micrograms (mcg) of folic acid daily to women before conception and during early pregnancy is effective prevention of occurrence of neural tube defects.
  - Fortification of food staples with folic acid is a proven cost-effective public health intervention to ensure more babies are born without neural tube defects.
  - Mandatory folic acid fortification of enriched cereal-grain products in the United States has contributed to a 36% reduction of neural tube defects from 1996 to 2006, and resulted in a savings of more than US\$ 4 billion over 10 years. Other countries, including Canada, Costa Rica, Chile and South Africa, also have had similar successes with folic acid fortification.
- For prevention and management of thalassemia, a combination approach of carrier screening, counselling and prenatal diagnosis has been successful in reducing thalassemia births, and even elimination in some countries.
- Congenital rubella syndrome can be prevented through the immunization of children and women with rubella vaccine, which has been shown to be both cost-effective and cost-beneficial.
- More than half of newborn deaths and stillbirths related to syphilis could be prevented with simple, low-cost interventions to increase the coverage of screening and treatment of syphilis during pregnancy.

These interventions can be integrated into current national programmes, such as reproductive, maternal, newborn, child and adolescent health, nutrition, immunization, noncommunicable diseases, and tobacco and alcohol control programmes.

**The WHO Regional Office convened representatives from Member States to discuss challenges and needs related to implementing these public health interventions. The Framework resulting from these consultations outlines five strategic directions to guide effective implementation of birth defects prevention and control activities in Member States.**

- establish or strengthen national policies and programmes for birth defects prevention and control;

- develop and strengthen national birth defects surveillance, monitoring and evaluation mechanisms;
- integrate birth defects prevention and control strategies into public health, maternal and child health, nutrition and other relevant programmes;
- expand and strengthen national capacity for implementation of birth defects prevention and control programmes; and
- develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes.

**The WHO Regional Office and partners would assist Member States to implement activities to reduce the prevalence of birth defects in the Region within five years**

Technical assistance can include (but is not limited to) support for the following activities:

- advocating at high-level for birth defects prevention programmes at regional and national levels;
- developing and/or strengthening national birth defects surveillance systems, including dissemination of the information collected through these systems;
- integrating public health interventions into existing programmes;
- developing and/or strengthening diagnostic laboratory capacity;
- promotion of partnerships with various global and national agencies; and
- monitoring of implementation of strategic directions within the Framework to help Member States assess their progress.

**Our goal is to prevent birth defects, improve newborn survival, and ensure quality of life and dignity. Together, we can accelerate progress towards achieving MDG 4 to reduce child mortality globally.**

**Media-ready quote:** Birth defects are a prevalent, severe, and costly global public health challenge. We know that many birth defects are preventable with the use of readily available, cost-effective public health interventions. With the help of the WHO Regional Office for South-East Asia and partners, Member States in South-East Asia are now faced with an exciting opportunity to expand birth defects prevention to help improve the health of women and babies across the Region.

## Frequently Asked Questions (FAQs)

### Prevention and Control of Birth Defects

[TO BE CUSTOMIZED PRIOR TO DISTRIBUTION]

#### What are birth defects?

Birth defects can be defined as structural or functional anomalies, including metabolic disorders, which are present at the time of birth. Birth defects are also known as congenital anomalies, congenital disorders or congenital malformations.

#### What are the most common birth defects?

Globally, the most common serious birth defects are heart defects, neural tube defects and Down syndrome. Thalassaemia, Glucose-6-phosphate dehydrogenase deficiency, cleft lip and cleft palate, limb defects, and congenital rubella syndrome are also common in the region.

Exact information on prevalence of birth defects is not available, however, in the South-East Asia Region the most common birth defects are congenital heart defects followed by neural tube defects. Thalassaemia is common in some populations in Bangladesh, India, Indonesia, Maldives, Myanmar and Thailand. Down syndrome is common in six Member States. Glucose-6-phosphate dehydrogenase deficiency is reported from Bangladesh, Maldives, and Myanmar. Cleft lip and cleft palate are reported in Bhutan, Myanmar, Nepal, and Thailand. Congenital rubella syndrome is also reported in several countries of the Region.

#### What is the global public health impact of birth defects?

Globally, birth defects affect an estimated 1 in 33 infants and result in approximately 3.2 million birth defect-related disabilities every year. An estimated 270 000 newborns die during the first 28 days of life every year from birth defects.

Severe birth defects are not only life-threatening; they can also result in long-term disability, and greatly impact individuals, families, health-care systems and societies. Birth defects can affect an individual's productivity and quality of life, and cause significant

social stigma, discrimination, and economic burden. Babies born with birth defects may face lifelong impairment, may need costly medical or surgical treatment that may not be available or affordable, and can ultimately require long-term care by families, communities, and health systems.

The various costs of long-term care include medication, diagnosis and treatment, transport to and from medical facilities, and the potential loss of earnings of caregivers. These costs of long-term care may be insurmountable to families and communities, particularly in middle- and low-resource countries where effective systems of care and social support might not yet be adequately developed.

Reducing birth defects presents a major public health opportunity. There are significant opportunities to prevent many birth defects, reduce the negative impacts of those that occur, and do so at reasonable cost. For this, several interventions have been shown to be effective and viable in a variety of social and economic settings.

### **What is the public health impact of birth defects in [COUNTRY]?**

In [COUNTRY] it is estimated that [NUMBER/PERCENTAGE] newborns die during the first 28 days of life from birth defects.

[Other data on public health impact]

### **What are the causes and risk factors of birth defects?**

Birth defects may have a genetic, infectious, or environmental origin, although for approximately half of the cases it is difficult to identify the cause. However, some causes or risk factors have been associated with birth defects. These include:

#### ***Socioeconomic factors***

Although it may be an indirect determinant, birth defects are more frequent among resource constrained families and countries. It is estimated that about 94% of serious birth defects occur in middle- and low-resource countries, where mothers are more susceptible to macronutrient and micronutrient malnutrition and may have increased exposure to an agent or factor that induces or increases the incidence of abnormal prenatal development, particularly infection and alcohol.

### ***Genetic factors***

Consanguinity (relationship by blood) increases the prevalence of rare genetic birth defects and nearly doubles the risk for neonatal and childhood death, intellectual disability, and serious birth defects in first cousin unions. Some ethnic communities, such as Ashkenazi Jews or Finns, have comparatively high prevalence of rare genetic mutations, leading to a higher risk of birth defects.

### ***Infections***

Maternal infections such as syphilis and rubella are a significant cause of birth defects in low- and middle-resource countries.

### ***Maternal nutritional status***

Iodine deficiency, folate insufficiency, overweight, or conditions like diabetes mellitus are linked to some birth defects. For example, folate insufficiency increases the risk of having a baby with a neural tube defect.

### ***Environmental factors***

Maternal exposure to pesticides, medicinal and recreational drugs, alcohol, tobacco, certain chemicals, high doses of vitamin A during early pregnancy, and high doses of radiation increase the risk of having a baby with a birth defect. Working or living near or in waste sites, smelters, or mines may also be a risk factor.

### **Can birth defects be prevented?**

Many birth defects can be prevented and treated. Adequate intake of folic acid and iodine, maternal vaccination, and adequate antenatal care are key. For example, about 110 000 cases of babies born with congenital rubella syndrome can be prevented through timely vaccination of the mothers during childhood and the reproductive years.

### ***Prevention***

Preventive public health measures administered through pre- and peri-conception and use of prenatal health care services decrease the frequency of certain birth defects. Primary prevention of birth defects involves:

- *Nutrition*
  - Improving the diet of women throughout their reproductive years, ensuring an adequate dietary intake of vitamins and minerals such as folic acid and iodine, and restricting harmful substances, particularly the abuse of alcohol
  - Controlling pre-conceptional and gestational diabetes through counselling, weight management, diet and the administration of insulin when needed
- *Environmental health*
  - Avoiding exposure to hazardous environmental substances (e.g. heavy metals, pesticides, some medicinal drugs) during pregnancy
- *Vaccination*
  - Improving vaccination coverage, especially with rubella virus, for children and women; through childhood vaccination or at least 1 month prior to pregnancy to women who are not already immune
- *Education*
  - Increasing and strengthening education to health staff and others interested in promoting birth defects prevention

## ***Detection***

Pre- and peri-conceptional care includes basic reproductive health practices as well as medical genetic screening. Screening can be conducted during the following three periods:

- *Preconception screening*
  - used to identify persons at risk for specific disorders or at risk for passing one on to their children, through the use of family histories and carrier screening;
  - particularly valuable in countries where consanguineous marriage is common.

- *Antenatal screening*
  - includes screening for advanced maternal age, Rhesus blood group incompatibility, and carrier screening;
  - ultrasound can be used to detect Down syndrome during the first trimester and serious foetal anomalies during the second trimester; maternal serum screening can also be used for detection of Down syndrome and neural tube defects during the first and second trimesters.
- *Newborn screening*
  - includes clinical examination and screening for haematological, metabolic, and hormonal disorders
  - screening for deafness and heart defects as well as early detection of birth defects can facilitate life-saving treatments and prevent the progression towards some physical, intellectual, visual or auditory disabilities.

### ***Treatment and care***

In countries with well-established health services, structural birth defects can be corrected with paediatric surgery and early treatment can be administered to children with functional problems such as thalassaemia, sickle cell disorders and congenital hypothyroidism.

### **Why fortifying food with folic acid is emphasized in birth defects prevention efforts?**

Folic acid is a B vitamin. If a woman has enough folic acid in her body at least one month before getting pregnant and during pregnancy, it can help prevent neural tube defects, which are major birth defects of the baby's brain and spine (like anencephaly and spina bifida). Women can get folic acid from fortified foods or supplements, or a combination of the two, in addition to a varied diet rich in folate.

### **How much folic acid should women get?**

It is recommended that women consume 400 micrograms (mcg) of folic acid every day, starting at least one month before getting pregnant, to help prevent major birth defects of the baby's brain and spine.

## How a woman can get enough folic acid?

There are two easy ways to be sure to get enough folic acid each day.

- Take a vitamin that has 400 mcg folic acid in it every day.
- Eat fortified food every day.
- In addition to getting 400 mcg of folic acid from supplements and fortified foods, women can eat a diet rich in folate. Foods containing folate include beans, peas and lentils, oranges and orange juice, asparagus and broccoli, and dark leafy green vegetables such as spinach, and mustard greens.

### *Country response*

[DETAIL COUNTRY PLANS]

## What is being done to prevent birth defects?

### *Global response*

In 2010, the Sixty-third World Health Assembly issued a report on birth defects. The report describes the basic components for creating a national programme for the prevention and care of birth defects before and after birth. It also recommends priorities for the international community to assist in establishing and strengthening these national programmes.

The Health Assembly also adopted a resolution no. WHA63.17 in 2010 calling all Member States to promote primary prevention and the health of children with birth defects by:

- developing and strengthening registration and surveillance systems;
- developing expertise and building capacity;
- strengthening research and studies on aetiology, diagnosis, and prevention; and
- promoting international cooperation.

The Global Strategy for Women's and Children's Health, launched in 2010 by the UN in collaboration with leaders from governments and other organizations like WHO and UNICEF, has been crucial in implementing high-impact and cost-effective interventions to improve neonatal and child health.

WHO is also working with the US Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities and other partners to advance neural tube defects prevention programs such as fortification and supplementation at the country level, provide needed technical expertise for the surveillance of neural tube defects, monitor neural tube defect prevention efforts, and improve laboratory capacity for biomarker surveillance and analysis.

The International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) is a voluntary, non-profit international organisation in official relations with WHO. This organization brings together birth defect surveillance and research programmes from around the world. Along with the WHO departments of Reproductive Health and Research and Nutrition for Health and Development and CDC's National Center on Birth Defects and Developmental Disabilities, ICBDSR convenes annual workshops on the surveillance and prevention of birth defects and preterm births.

The GAVI Alliance (formerly the "Global Alliance for Vaccines and Immunization"), of which WHO is a partner, is assisting developing countries in improving control and elimination of rubella and congenital rubella syndrome through immunization.

WHO develops normative tools, including guidelines and a global plan of action, to strengthen medical care and rehabilitation services to support the implementation of the Convention on the Rights of Persons with Disabilities. Similarly, WHO supports countries to integrate medical care and rehabilitation services into overall primary health care, supports the development of community-based rehabilitation programmes and facilitates the strengthening of specialized rehabilitation centres and their links with community-based rehabilitation.

#### Sources:

- (1) WHO. Born too soon. The global action report on preterm birth. Geneva, World Health Organization, 2012 [http://www.who.int/pmnch/media/news/2012/201204\\_borntoosoon-report.pdf](http://www.who.int/pmnch/media/news/2012/201204_borntoosoon-report.pdf)
- (2) WHO Media Centre <http://www.who.int/mediacentre/factsheets/fs370/en/>
- (3) CDC Facts About Folic Acid <http://www.cdc.gov/ncbddd/folicacid/about.html>
- (4) Regional Strategic Framework for prevention and control of birth defects, visit the WHO-SEARO website [LINK: [http://www.searo.who.int/entity/child\\_adolescent/documents/sea\\_cah\\_12/en/](http://www.searo.who.int/entity/child_adolescent/documents/sea_cah_12/en/)].



## Sample Letter / E-mail for Policymaker / Funder / Partners

[TO BE CUSTOMIZED PRIOR TO DISTRIBUTION]

Dear \_\_\_\_\_

I am writing about our shared concern about prevention of birth defects to reduce newborn and child mortality and prevent long term disability associated with birth defects.

As you may know, birth defects have been recognized as a global public health concern. WHO estimates that, globally, about 7% of all neonatal deaths—more than 200,000 in 2011—are caused by birth defects.

However, the overall burden of birth defects is disproportionately higher in developing countries owing to large population and poor maternal health and other risk factors like poverty. Although there is insufficient information on birth defects in [COUNTRY] at present, we do know that the burden of birth defects is large.

While we are making progress towards achievement of MDG 4 by achieving a decline in newborn and child mortality caused by infections and birth asphyxia, birth defects continue to contribute to a significant proportion of child mortality.

A large majority of birth defects is attributed to the poor health status of women during the preconception period and pregnancy. Improving maternal nutritional status by increasing iron, folic acid, and iodine intake, and enhancing awareness of the impact of exposure to teratogens during pregnancy will significantly help in reducing the number of birth defects. Such interventions are also likely to contribute to reduction in the birth of preterm and low birth weight babies, thereby further reducing neonatal mortality.

In [COUNTRY] we are confronting this public health challenge with a significant collaborative [global effort/effort, with partnerships with the World Health Organization (WHO), WHO South-East Asia Regional Office, technical assistance from the US Centers for Disease Control and Prevention and organizations such as the Food Fortification Initiative, Micronutrient Initiative, Global Alliance for Improved Nutrition, and [local partners]

We have developed a national plan for birth defects prevention and control with the support of WHO. This includes guidelines to promote the establishment [or strengthening] of national policies and programmes to prevent birth defects as well as national surveillance mechanisms. It promotes integration of birth defects prevention and control strategies into public health programmes like maternal and child health, nutrition, and immunization.

We need your help. We have an ambitious goal of significantly reducing preventable birth defects in [COUNTRY by YEAR] to contribute to the achievement of MDG4, with specific targets of:

- reducing the prevalence of folic acid-preventable neural tube defects by 35%;
- reducing the number of thalassaemia births by 50%;
- eliminating congenital rubella; and
- reducing congenital syphilis.

In [COUNTRY], multisectoral partnerships and networks are critical to our success in implementing cost-effective strategies for birth defects prevention, and for adopting pragmatic and feasible approaches for their prevention in a phased manner. [Discuss specific proposal to partner: funding for specific project, technical assistance, advocacy role, etc.]. We can achieve this important public health goal with your support.

We would be pleased to [meet with you/contact you to discuss further/discuss our proposal/invite you to meeting/etc.]

Sincerely,

[TO BE CUSTOMIZED PRIOR TO DISTRIBUTION]

### Preventing Birth Defects in South-East Asia: Folic Acid Can Help Prevent Neural Tube Defects

[NAME OF THE CHILD] is an 18-month-old girl who was born with spina bifida, a serious birth defect of the spine. Like most children with spina bifida, [NAME] has paralysis and no bowel or bladder control. She lives with her family in a village in [COUNTRY] where primary health center is not able to help her. As a result, [NAME] could not have surgery to close the opening on her back until she was nine months old. During this time, her spinal cord was exposed and without protection. The first surgery for a baby born with spina bifida should happen within the first 24 hours of life to avoid complications or death. But [NAME] had no choice but to wait.

[NAME] will face lifelong medical challenges associated with spina bifida, and the financial and emotional impacts her family will endure are overwhelming. With the appropriate care, it is possible for children born with spina bifida to live long and productive lives, even though they face many challenges. But without the proper treatment and management, the future for children like [NAME] is not as positive.

Worldwide, more than 300 000 babies are born every year with a neural tube defect, which include spina bifida and anencephaly, a birth defect of the brain. Neural tube defects are a significant cause of infant death and lifelong disability. Research has shown that the majority of neural tube defects can be prevented if a woman consumes 400 micrograms (mcg) of folic acid, a B vitamin, daily before conception and during early pregnancy.

Fortification of food staples with folic acid is a cost-effective public health intervention to help women of reproductive age get enough folic acid every day and help ensure more babies are born without a neural tube defect. Mandatory folic acid fortification in the United States contributed to a 36 percent reduction of neural tube defects from 1996 to 2006, and resulted in a savings of more than US\$ 4 billion over 10 years. Other countries including Canada, Costa Rica, Chile and South Africa have had similar successes with folic acid fortification. In addition, expanding folic acid fortification can lead to the prevention of 150 000–210 000 neural tube defects worldwide each year.

Despite documented successes with folic acid fortification in several countries, rates of neural tube defects remain very high throughout the South-East Asia region. Additionally, many other birth defects remain prevalent in South-East Asia even though affordable public health interventions are available for their prevention and management. For this reason, public health professionals in [COUNTRY] have joined forces with the Regional Office for South-East Asia of the World Health Organization (WHO) to implement strategies from the Strategic Framework for Prevention and Control of Birth Defects in the South-East Asia Region (2012–2016). The goal of the Framework is to contribute to the achievement of the United Nations Millennium Development Goal (MDG) 4 by significantly reducing preventable birth defects in the South-East Asia region. Thus we can help reduce the challenges faced by children like [NAME].

For more information:

Please access the Regional Strategic Framework for prevention and control of birth defects, visit the WHO-SEARO website [LINK: [http://www.searo.who.int/entity/child\\_adolescent/documents/sea\\_cah\\_12/en/](http://www.searo.who.int/entity/child_adolescent/documents/sea_cah_12/en/)].

[INSERT INFORMATION ON HOW TO ACCESS RELEVANT RESOURCES – WEB, TELEPHONE, EMAIL, ETC. IN THE COUNTRY]

## Sample Press Release for Prevention and Control of Birth Defects

[TO BE CUSTOMIZED PRIOR TO DISTRIBUTION]

[COUNTRY] Public Health Professionals Join Forces with the World Health Organization to Prevent Birth Defects in South-East Asia

[COUNTRY], [DATE]

In an effort to achieve the United Nations Millennium Development Goal (MDG) 4 (to reduce under-five mortality globally and at the country level by two-thirds by 2015), public health professionals in [COUNTRY] have joined forces with the Regional Office for South-East Asia of the World Health Organization (WHO) to implement strategies to prevent and control birth defects throughout the region. The strategies are outlined in the Strategic Framework for Prevention and Control of Birth Defects in South-East Asia Region (2012–2016), that has been developed by WHO-SEARO in consultation and collaboration with Member States.

Despite the availability of affordable, effective public health interventions, many birth defects remain prevalent in South-East Asia. In fact, birth defects are now among the most common causes of death and disability in infants and children under five years of age in the region.

“Birth defects are a prevalent, severe, and costly global public health challenge. However, we know that many are preventable with the use of readily available, cost-effective public health interventions. Member States in South-East Asia are now faced with an exciting opportunity to expand birth defects prevention to help improve the health of babies across the region,” said [INSERT NAME OF SPOKESPERSON].

We have developed national plan to successfully implement the strategic directions provided by the Regional Strategic Framework to prevent birth defects. The national action plan aims to significantly reduce preventable birth defects in [COUNTRY] to improve newborn survival and contribute to the achievement of the United Nations Millennium Development Goal 4 as well as ensure quality of life and dignity.

For more information on the Regional Strategic Framework for prevention and control of birth defects, visit the WHO-SEARO website [LINK: [http://www.searo.who.int/entity/child\\_adolescent/documents/sea\\_cah\\_12/en/](http://www.searo.who.int/entity/child_adolescent/documents/sea_cah_12/en/)].

[PROVIDE LINK TO COUNTRY-SPECIFIC RESOURCES]

Contact:

NAME

ORGANIZATION

PHONE

EMAIL

## Sample Web Content

### Prevention and control of birth defects in [COUNTRY]

[TO BE CUSTOMIZED PRIOR TO DISTRIBUTION]

Despite the availability of affordable, effective public health interventions, many birth defects remain prevalent in South-East Asia. In fact, birth defects are now among the most common causes of death and disability in infants and children under five years of age in several countries of the South-East Asia Region. In [COUNTRY] birth defects contribute to XX% of neonatal and XX% of child mortality.

In an effort to reduce under-five mortality to achieve the United Nations Millennium Development Goal (MDG) 4 and improve quality of life and ensure dignity public health professionals in [COUNTRY] have committed to prevention and management of birth defects. National action plan for prevention of birth defects has been prepared in consonance with the Regional Strategic Framework for Prevention and Control of Birth Defects in South-East Asia Region, 2013–2017 developed by the South-East Asia Regional Office (SEARO) of the World Health Organization (WHO).

Its aim is to significantly reduce preventable birth defects in [COUNTRY] to contribute to the achievement of MDG 4. The Framework outlines four specific targets:

[PLEASE MODIFY AS PER THE NATIONAL PLAN]

- (1) reduce the prevalence of folic acid-preventable neural tube defects by 35%
- (2) reduce the number of thalassaemia births by 50%
- (3) reduce congenital rubella
- (4) eliminate congenital syphilis.

Services for prevention and management of birth defects will be made available as an integral part of existing reproductive-maternal-newborn-child-adolescent health programmes, immunization, nutrition and related programmes.



## Social Media Posts

### Prevention and control of birth defects

[TO BE CUSTOMIZED FOR COUNTRY LEVEL USE PRIOR TO DISTRIBUTION]

#### Facebook

- (1) The WHO Regional Office for South-East Asia has developed a Regional Strategic Framework for Prevention and Control of Birth Defects in the South-East Asia Region (2013–2017). Learn more: [http://www.searo.who.int/entity/child\\_adolescent/documents/sea\\_cah\\_12/en/](http://www.searo.who.int/entity/child_adolescent/documents/sea_cah_12/en/)
- (2) The Strategic Framework for Prevention and Control of Birth Defects in the South-East Asia Region (2012–2016) targets neural tube defects, thalassemia, congenital rubella syndrome and congenital syphilis. Learn more: [http://www.searo.who.int/entity/child\\_adolescent/documents/sea\\_cah\\_12/en/](http://www.searo.who.int/entity/child_adolescent/documents/sea_cah_12/en/)
- (3) The Strategic Framework for Prevention and Control of Birth Defects in the South-East Asia Region (2012–2016) outlines five strategic directions to guide Member States' effective implementation of birth defects prevention and control activities. Learn more: [http://www.searo.who.int/entity/child\\_adolescent/documents/sea\\_cah\\_12/en/](http://www.searo.who.int/entity/child_adolescent/documents/sea_cah_12/en/)
- (4) With the help of WHO-SEARO and partners, Member States in South-East Asia now have an exciting opportunity to expand birth defects prevention to help improve the health of babies across the region. Learn more: [http://www.searo.who.int/entity/child\\_adolescent/documents/sea\\_cah\\_12/en/](http://www.searo.who.int/entity/child_adolescent/documents/sea_cah_12/en/)
- (5) The WHO Regional Office and partners are ready to help Member States implement activities to reduce the prevalence of birth defects in the region within five years. Learn more: [http://www.searo.who.int/entity/child\\_adolescent/documents/sea\\_cah\\_12/en/](http://www.searo.who.int/entity/child_adolescent/documents/sea_cah_12/en/)
- (6) [COUNTRY] has seen a decline in infant and childhood deaths from infectious diseases and malnutrition, but deaths resulting from birth defects have remained constant. Learn more: [link to: XYZ]
- (7) [COUNTRY] has developed national plan for prevention and control of birth defects. Learn more: [link to: XYZ]
- (8) A combination approach of carrier screening, counselling, and prenatal diagnosis has been successful for prevention and management of thalassemia. Learn more: [link to: XYZ]
- (9) Congenital rubella syndrome can be prevented through the immunization of children, adolescents and women with rubella vaccine. Learn more: [link to: XYZ]
- (10) More than half of newborn deaths and stillbirths related to syphilis could be prevented with simple, low-cost interventions to increase the coverage of screening and treatment of syphilis during pregnancy. Learn more: [link to: XYZ]

- (11) Mandatory folic acid fortification in the U.S. has led to a 36% reduction in neural tube defects and a savings of more than \$4 billion over 10 years. Learn more: [link to: XYZ]
- (12) Countries such as the U.S., Canada, Costa Rica, Chile and South Africa have had success with folic acid fortification. Learn more: [link to: XYZ]

## Twitter

- (1) WHO estimates that globally about 7% of all neonatal deaths are caused by birth defects #BIRTHDEFECTS
- (2) The most common types of neural tube defects are anencephaly and spina bifida. #NEURALTUBEDEFECTS
- (3) The majority of neural tube defects can be prevented if a woman gets 400 micrograms of folic acid daily before and during early pregnancy #FOLICACID
- (4) Fortification of food staples with folic acid is a cost-effective public health intervention #FORTIFICATION
- (5) Countries such as the U.S., Canada, Costa Rica, Chile and South Africa have had success with folic acid fortification. #FAFORTIFICATION
- (6) Prevent birth defects, improve newborn survival, and ensure quality of life and dignity. #PREVENTBD
- (7) Take action to prevent birth defects and accelerate progress towards achieving MDG 4 to reduce child mortality globally and at the country level. #MDG4
- (8) Birth defects result in adverse health outcomes and impact individuals, families, communities, and systems of care. #BDIMPACT
- (9) Birth defects are among the most common causes of death and disability in infants and children under five in South-East Asia. #BDSEA
- (10) Newborn, infant, and childhood deaths due to birth defects in South-East Asia are declining, but not quickly enough. #PREVENTBD
- (11) Birth defects are a severe and costly global public health challenge. #PHCHALLENGE
- (12) Many birth defects have significant opportunities for prevention. #PREVENTBD

# Prevention and Control of Birth Defects in South-East Asia Region

## Strategic Framework (2013–2017)

### Executive Summary

Birth defects are recognized as a global public health concern. The World Health Organization (WHO) estimates that, globally, about 7% of all neonatal deaths are caused by birth defects (about 206 000 in 2011). A large majority of birth defects is attributed to the poor health status of women during the preconception period and pregnancy. Improving maternal nutritional status by increasing iron, folic acid, and iodine intake, and enhancing awareness of the impact of exposure to teratogens during pregnancy will significantly help reduce the number of birth defects. Other contributors to neonatal mortality, including preterm and low birth weight births, are likely to be reduced by such interventions.

The overall burden of birth defects is disproportionately higher in low- and middle-resource countries. The burden of birth defects is large in the South-East Asia Region<sup>1</sup>, although there is insufficient country-level data at present to determine precise estimates. In addition, while the South-East Asia Region is making progress towards achievement of the United Nations Millennium Development Goal 4<sup>2</sup> by achieving a decline in newborn and child mortality because of improved health services and a reduction in causes such as birth asphyxia, infectious diseases and malnutrition, birth defects continue to contribute to a significant proportion of child mortality.

WHO has been asked by the World Health Assembly to support Member States in developing national birth defects prevention plans and in increasing their capacity for implementation of effective interventions to prevent and manage birth defects. In response, the WHO Regional Office for South-East Asia, in collaboration with its

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1 South-East Asian Region Member States: Bangladesh, Bhutan, Democratic People's Republic of Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand and Timor-Leste

2 United Nations Millennium Development Goal 4 to reduce child mortality, specifically seeks to reduce by two thirds, between 1990 and 2015, the under-five mortality rate.

Member States, has developed the *Strategic Framework for Prevention and Control of Birth Defects in South-East Asia Region*. The overall goal of the Framework is to reduce the prevalence of birth defects in the Region within five years (2013–2017). Its four specific targets in selected Member States are:

- (1) to reduce the prevalence of folic acid-preventable neural tube defects by 35%;
- (2) to reduce the number of thalassaemia births by 50%;
- (3) to reduce congenital rubella; and
- (4) to eliminate congenital syphilis.

Implementation of the Framework is guided by five strategic directions:

- (a) to establish or strengthen national policies and programmes for birth defects prevention and control;
- (b) to develop and strengthen national birth defects surveillance and evaluation mechanisms;
- (c) to integrate birth defects prevention strategies into public health, nutrition and other relevant programmes, as appropriate;
- (d) to expand and strengthen national capacity for implementation of birth defects prevention and control programmes; and
- (e) to develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes.

Please access the Regional Strategic Framework for prevention and control of birth defects, visit the WHO-SEARO website [LINK: [http://www.searo.who.int/entity/child\\_adolescent/documents/sea\\_cah\\_12/en/](http://www.searo.who.int/entity/child_adolescent/documents/sea_cah_12/en/)].



For the prevention and management of birth defects, an enabling and supportive environment is crucial to encourage individuals, families and communities to adopt and sustain new behaviours. This is achieved through a range of health communication activities including community mobilization and media campaigns. Public campaigns need to focus on alleviating the stigma related to birth defects and sensitively address cultural and religious issues such as consanguinity, myths and misconceptions around birth defects.

Strategically planned communication helps influence policy-makers and opinion leaders to bring about changes in policies, as well as encouraging structural changes within the community to support healthy behaviours. Hence, it is equally important to conduct advocacy with policy- and decision-makers to position birth defects among existing priorities in the national health agenda of countries.

The World Health Organization (WHO) Regional Office for South-East Asia developed a regional strategic framework for the prevention and control of birth defects (2013–2017), to guide Member States in developing national plans to address birth defects. The strategic framework recommends that a well-designed communication strategy is an important element for the prevention and control of birth defects.

This regional communication strategy for the prevention and control of birth defects has, therefore, been prepared, in consultation with Member States, to guide the development of strategic communication plans to facilitate implementation of national plans for the prevention and control of birth defects. Considering that health communication is an important component of ongoing reproductive, maternal, newborn, child and adolescent health and related programmes in Member States, the regional communication strategy recommends the integration of communication activities for birth defects into existing public health programmes, as far as possible, for synergistic effect.

A set of communication tools is also provided in the form of ready-to-use templates that could be used for advocacy, awareness generation etc. in different media channels for prevention of birth defects within the country.



**World Health  
Organization**

Regional Office for South-East Asia  
World Health House  
Indraprastha Estate,  
Mahatma Gandhi Marg,  
New Delhi-110002, India  
[www.searo.who.int](http://www.searo.who.int)

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