

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



Strategic Framework (2013–2017)



**World Health
Organization**

Regional Office for South-East Asia

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

Strategic Framework
(2013–2017)

Prevent birth defects – Improve newborn
survival – Ensure quality of life and dignity

Acknowledgement

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Foreword



Birth defects have been recognized as a global public health concern. WHO estimates that globally, about 7% of all neonatal deaths are caused by birth defects (more than 200 000 in 2011). 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 the SEA Region at present, it must be conceded 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 preconception period and pregnancy. Improving maternal 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 that contribute to neonatal mortality.

In response to the situation, the WHO Executive Board and World Health Assembly have deliberated on the problem of birth defects and adopted resolutions. WHO has been requested to support Member States in developing national plans and in increasing their capacity for implementation of effective interventions to prevent and manage birth defects.

In pursuance of this request, the WHO Regional Office for South-East Asia, in collaboration with Member States, has developed the “Strategic Framework for Prevention and Control of Birth Defects in South-East Asia

Region''. This Framework guides Member States to establish or strengthen national policies and programmes to prevent birth defects and develop national surveillance mechanisms. It promotes integration of birth defects prevention and control strategies into public health programmes like maternal and child health, nutrition, immunization and others. The important role of multisectoral partnerships and networks to support such programmes is duly emphasized.

It is acknowledged that countries in the Region have opportunities to integrate preventive programmes for birth defects in their existing public health and related programmes. However, due to the complexity of the problem, countries may like to prioritize selected birth defects and implement cost-effective strategies, adopting pragmatic and feasible approaches for their prevention in a phased manner. It is hoped that the Member States and partners would find this Strategic Framework useful while designing national plans for prevention and control of birth defects.



Dr Samlee Plianbangchang
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Abbreviations

CDC	The United States Centers for Disease Control and Prevention
CRS	Congenital rubella syndrome
DPR Korea	Democratic People's Republic of Korea
ICBD-SR	International Clearinghouse for Birth Defects Surveillance and Research
IUGR	Intra Uterine Growth Retardation
MDG	Millennium Development Goal
SEAR	South-East Asia Region
SEARO	South-East Asia Regional Office
WHA	World Health Assembly
WHO	World Health Organization

Executive summary

Birth defects are getting recognized as a significant cause of mortality and morbidity among children under five years of age and especially for foetal deaths (including stillbirth) and neonatal deaths. WHO has estimated that some 206 000 deaths (2011) worldwide - about 7% of all neonatal deaths, are caused by birth defects. However, in Member States of the South-East Asia Region, information on birth defects is noted to be inadequate at present.

The South-East Asia Regional Office of the World Health Organization (WHO-SEARO) collaborated with Member States to review available information on birth defects, including their prevalence, existing reporting and surveillance mechanisms, programmes for prevention and management, as well as prevention and control policies. The information was collated through circulation of a standard questionnaire, review of the published literature on birth defects, the SEAR Expert Group Meeting on Birth Defects, New Delhi, December 2011 and the SEAR Regional Programme Managers' Meeting on Birth Defects Prevention and Control, held in Bangkok in March 2012.

As a result of this process, Member States recognized the critical importance of preventing birth defects to contribute to reducing infant and child morbidity and mortality, and diminishing the social and economic burden as well as mitigating the emotional toll on affected families. This will contribute to accelerating progress towards achieving the United Nations Millennium Development Goal (MDG) 4 to reduce child mortality globally and at the country level. To accomplish this, SEARO has developed a South-East Asia Regional Strategic Framework, the goal of which is to reduce the prevalence of birth defects in the Region within five years (2012–2016). 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, i.e.:

- (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.

In addition, the Framework provides suggested steps for national implementation and monitoring indicators for the strategic directions.

Introduction

The decline in infant and childhood mortality rates in most countries in the 20th century is a public health achievement. Many Member States in the South-East Asia Region (SEAR) are undergoing a health transition, which has been marked initially by a decline in infant and under-five mortality from infectious diseases and malnutrition that predominated the early years of life (World Bank 1993). At the same time, mortality from birth defects^a has remained constant, which has resulted in their becoming a larger proportional cause of neonatal mortality.

In response to these developments, the WHO Regional Office for South-East Asia (SEARO)—in collaboration and consultation with Member States^b and partners^c—has developed a Strategic Framework for Prevention and Control of Birth Defects in the South-East Asia Region for a five-year period (2012–2016). The Framework provides guidance to Member States to evolve national surveillance systems, programmes and strategies for the prevention and control of birth defects to reduce morbidity and mortality among newborns, infants and children. The Framework also outlines the main areas of SEARO and partner support to Member States.

a Birth defects are defined as structural or functional abnormalities, including metabolic disorders present from birth. *The International statistical classification of diseases and related health problems, tenth revision* (ICD-10) includes as birth defects: congenital malformations, deformations, chromosomal abnormalities, inborn errors of metabolism and blood disorders of prenatal origin (<http://apps.who.int/classifications/icd10/browse/2010/en> - /XVII, accessed 3 October 2012).

b Bangladesh, Bhutan, Democratic People's Republic of Korea, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka, Thailand and Timor-Leste.

c Partners are considered to be multilateral, bilateral and nongovernmental organizations currently or potentially supporting the prevention of birth defects in the WHO South-East Asia Region.

Rationale

Child deaths are declining, but not quickly enough

The United Nations Millennium Development Goal (MDG) 4 commits world leaders to reduce the under-five mortality rate globally and at the country level by two-thirds between 1990 and 2015. Although substantial progress has been made, the rate of decline in child deaths is not enough to reach this goal.

The number of under-five deaths worldwide has declined from more than 12 million in 1990 to 6.9 million in 2011. This translates into 14 000 fewer children dying every day in 2011 than in 1990. Since 1990, the global under-five mortality rate has dropped 41% - from 87 deaths per 1000 live births in 1990 to 51 in 2010. Since 1990, the South-East Asia Region has reduced under-five mortality rate by more than 50%. In South-East Asia, the under-five mortality rate declined from 109 deaths per 1000 live births in 1990 to 55 deaths per 1000 live births in 2011¹.

Despite the fact that most child deaths are preventable, many Member States still have unacceptably high levels of child mortality and have made little or no progress in recent years. At the current pace of progress, the Region as a whole, is unlikely to achieve the MDG 4 target.

Birth defects are a major cause of death and disability among infants and children

Birth defects are a significant but under-recognized cause of mortality and morbidity among infants and children under five years of age and especially for foetal (including stillbirth) and neonatal deaths. With improvements in the management of infection and asphyxia—two major causes of neonatal death—birth defects are increasingly seen as a major cause of stillbirths and neonatal deaths. WHO estimated that some 260 000 deaths worldwide (about 7% of all neonatal deaths) were caused by birth defects in 2004.² However, there is considerable uncertainty about the prevalence of and mortality attributable to birth defects in Member States that lack adequate registration of births and deaths.

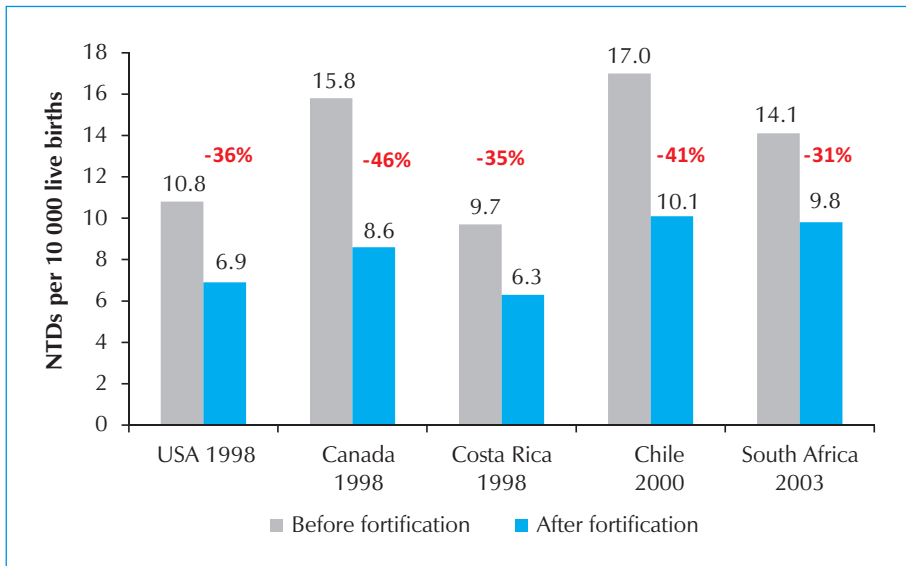
Birth defects cause a significant social and economic burden

Birth defects are not only life-threatening; they can also result in long-term disability, and negatively affect individuals, families, health-care systems and societies. Birth defects diminish productivity and quality of life, and cause significant social stigma, discrimination and economic burden. Birth defects can cause lifelong impairment and may need costly medical or surgical treatment that may not be available or affordable, and ultimately require long-term care by families, communities and health systems. The various costs of long-term care include drugs, 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 in middle- and low-resource countries where effective systems of care and social support are not yet adequately developed.

Reducing birth defects presents a major public health opportunity

There are significant opportunities to prevent many birth defects, reduce the consequences of those that occur, and to 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.

Figure 1: Food fortification with folic acid to reduce neural tube defects



For example, consumption of adequate amounts of folic acid and iron are important for general health and the prevention of neural tube defects and anaemia. Fortification of wheat and corn flour has proven to be an effective and cost-effective strategy in several countries for supplying folic acid and iron to the population. Consumption of adequate amounts of folic acid by women before and during early pregnancy decreases the risk of having a baby born with a neural tube defect. As reflected in Figure 1, increasing folic acid intake among women of reproductive age through fortification and other means could prevent 150 000–210 000 neural tube defects per year.³ This could prevent an estimated 13% of neonatal deaths currently attributed to observable congenital anomalies in low-income countries.⁴ In addition, folic acid fortification programmes have been shown to be cost-effective in countries with varying levels of economic development.

Adequate consumption of iron can eliminate iron deficiency, which is responsible for more than 850 000 deaths and billions of lost dollars per year in reduced mental and physical productivity.⁵ Similarly, impaired mental development due to iodine deficiency can also be prevented at a relatively low cost through the iodization of salt.

Member States have identified thalassaemia as another birth defect of public health importance among certain population subgroups. From the review of published studies from the countries, it is apparent that the prevalence of 'carrier' state of beta thalassaemia (heterozygous state – thalassaemia minor) varies from country to country: 7% in Bangladesh (11 million people being thalassaemia carriers); 3-4% in India with higher rates in certain communities; 6-16% in ethnic populations of Indonesia; 16% in Maldives (estimated 60-70 new cases of thalassaemia major every year); 4% in Nepal (estimated 327 new thalassaemia major cases every year); 1-5% in some areas of Sri Lanka (estimated 1600 new cases of thalassaemia major every year) and 1-9% in Thailand. Myanmar reports high prevalence of alpha thalassaemia in certain ethnic groups, as does Nepal in some population groups. Thalassaemia carriers have only minor clinical implications, whereas thalassaemia major (homozygous state) is associated with high lifelong financial and social costs for its management.

WHO Executive Board resolution EB 118.R1 urges Member States to design, implement and reinforce in a systematic, equitable and effective manner, comprehensive national, integrated programmes for prevention and management of thalassaemia and other haemoglobinopathies, including surveillance, dissemination of information, awareness-raising and screening, such programmes being tailored to specific socioeconomic and cultural contexts and aimed at reducing the incidence, morbidity and mortality associated with these diseases.

For prevention and management of thalassaemia, a specific strategy and infrastructure are required. A combination approach of carrier screening, counselling and prenatal diagnosis has been successful in reducing thalassaemia births, and even elimination in some countries.

Congenital rubella syndrome (CRS) is an important cause of a cluster of birth defects. When a woman is infected with the rubella virus early in pregnancy, she has a 90% chance of passing the virus on to her foetus. This can cause the death of the foetus, or CRS that is associated with several birth defects. Global estimates of the burden of rubella suggest that the number of infants born with CRS in 2008 exceeded 110 000 which makes rubella a leading cause of preventable congenital defects. The 2008 estimates indicated that the highest CRS burden is in the South-East Asia (approximately 48%) and African (approximately 38%) Regions.⁶ In 2010, only four SEAR Member States provided rubella vaccines at the national

level, covering only 4% of the Region's population. Among WHO Regions, only the South-East Asia and Africa Regions did not have rubella or CRS reduction goals at the regional level. CRS can be prevented through the immunization of children and women with rubella vaccine. The economic analysis evidence for rubella and CRS control similarly suggested significant net savings. A 2002 review of the literature of 10 studies demonstrated that incorporation of rubella containing vaccines into national childhood immunization schedules was both cost-beneficial and cost-effective.⁶

Congenital syphilis is also an important cause of birth defects, stillbirths, neonatal deaths, and clinical manifestations in newborns. More than 50% 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. In 2009, a regional strategy for the elimination of congenital syphilis was developed that committed to its elimination in the Region (i.e. to decrease the incidence of congenital syphilis to below 0.5 per 1000 live births in a country).⁷ This target has been reiterated in the Asia-Pacific elimination framework for 2011–2015.⁸

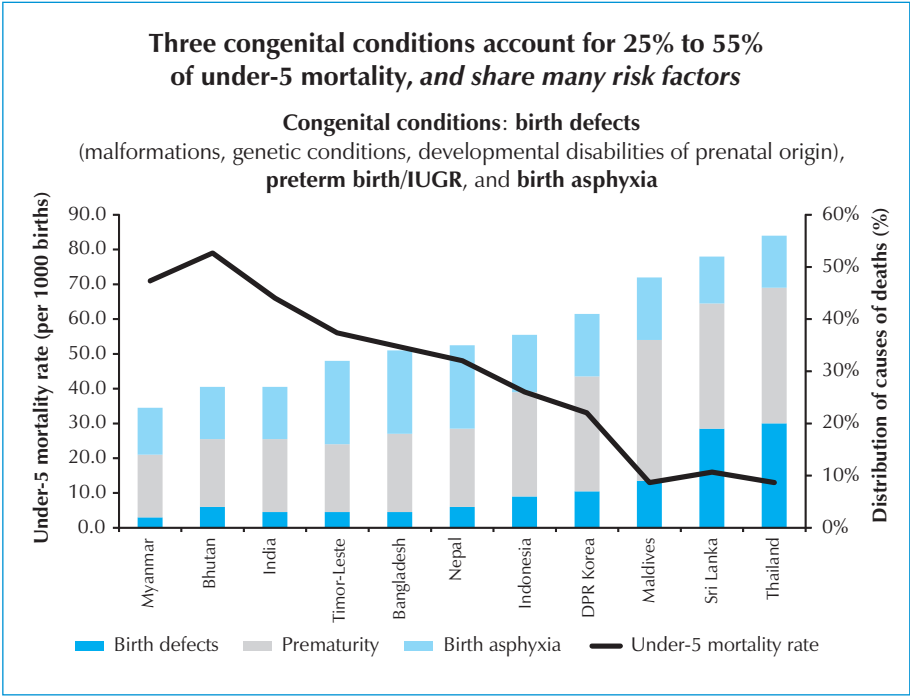
Public health education and preventive health-care services are critical components of birth defects prevention and control. Such services can provide screening, counselling and important information to women and families. This includes prevention of *in utero* effects of tobacco and alcohol use by encouraging abstinence and protection from second-hand smoke for women who are pregnant or planning a pregnancy. Pre-gestational and gestational diabetes mellitus shows a higher incidence of certain birth defects like congenital heart defects and oro-facial cleft⁹. Good management of diabetes and body weight, especially around conception and during early pregnancy, is important to prevent these.

The adolescent health programmes being scaled up in Member States is an opportunity to introduce pre-marital counselling and pre-conception care packages that promote healthy lifestyles and prevent health-risk behaviours such as tobacco and alcohol use, obesity, diabetes mellitus and provide immunization like rubella.

Globally, three congenital conditions—birth defects, preterm birth/intrauterine growth retardation, and birth asphyxia account for 35% of under-five mortality (e.g. Myanmar where infections cause a high proportion of

deaths) to 55% of under-five mortality (e.g. Sri Lanka and Thailand where infections are no longer the major cause of death). These three conditions share many risk factors that can be addressed by common interventions described above. Public health programmes that integrate such interventions would effectively contribute to progress towards achievement of MDG4.

Figure 2: Under-five mortality because of congenital conditions: birth defects, preterm birth/IUGR, and birth asphyxia



Source: World Health Statistics 2011 <http://www.who.int/whosis/whostat/2011/en/index.html>

Although treatment and management of children with birth defects depend on the level of health care available, significant improvements can be made, even with limited resources. Affordable medications, surgical treatments, and community-based rehabilitation and palliative care can help improve the health and quality of life for these children and their families. This care can be made accessible through existing primary health services, which can make referrals to, and receive support from, secondary and tertiary care facilities.

Reduction of birth defects is a WHO and global priority

In recognition of this public health priority, WHO included birth defects as an agenda item in its Executive Board decisions. Following recommendations to the World Health Assembly (WHA), several resolutions have been adopted (WHA63.17, 2010,¹⁰ WHA65.6, May 2012¹¹). These reaffirm the call for global action for surveillance, prevention and treatment of birth defects and implementation of the comprehensive maternal, infant and young child nutrition plans, which include food fortification and iron and folic acid supplementation activities.¹²

The World Health Assembly specifically recommended several country-level actions that can support the development of services for the prevention of birth defects and care of children with birth defects. It also stated that prevention “requires basic public health approaches to be integrated into health systems including maternal and child health services” and that “many of the services and interventions proposed are already within the reach of low- and middle-income countries, while others can be added as needs and resources determine.”

WHO has emphasized that a “portfolio of prevention approaches is needed” because of the wide range of causes of birth defects. Most birth defects of environmental origin can be addressed by prevention approaches, and legislation controlling management of toxic chemicals (e.g. environmental and occupational exposure to certain agricultural and industrial chemicals). Other measures include vaccination of girls and women against rubella, avoidance of alcohol, tobacco and cocaine, an adequate general diet (e.g. with sufficient protein, calories, iron) before and during pregnancy and supplementation and fortification of basic foods with micronutrients like iodine-fortified salt to prevent iodine deficiency disorder, staple foods fortified with folic acid to prevent neural tube defects and other malformations, and food fortification with iron for prevention of iron deficiency anaemia.

Global partners such as the United States Centers for Disease Control and Prevention (CDC) and the International Clearinghouse for Birth Defects Surveillance and Research (ICBD-SR) have committed to supporting birth defects prevention and surveillance, and there is a need to mobilize more partners and resources to intensify such efforts.

Present situation, challenges and needs of countries in the South-East Asia Region

There has been a significant decline in infant and childhood mortality in the Member States in the last two decades. However, in the South-East Asian Region neonatal mortality has declined at a slower rate and presently contributes to 60–70% of infant mortality. Within countries, child mortality is higher in rural areas and among poorer and less educated families.

The South-East Asia Region as a whole is not on track to achieve MDG4, i.e. to reduce the child mortality by two thirds by 2015. At present, Bangladesh, Maldives, Thailand and Timor-Leste have achieved the target, while Bhutan, Indonesia, Nepal and Sri Lanka are on track to attain the target. The progress is slow in Democratic People's Republic of Korea, India, and Myanmar. The under-five mortality rate varies from a low of 11 per 1000 live births in Maldives to a high of 61 and 62 per 1000 live births in India and Myanmar, respectively.¹

The March of Dimes Birth Defects Foundation has provided estimates of the number and prevalence of birth defects in the South-East Asia Region, as shown in Table 1 below. These are broad estimates based on epidemiological modelling and may not allow for precise comparisons of birth defects prevalence between countries. Valid comparisons require the collection of additional empirical data on birth prevalence, underlying risk factors and prevention and management services available in the countries. This lack of information emphasizes the need for Member States to strengthen birth defects surveillance systems.

Table 1: Birth defects prevalence estimates in the South-East Asia Region, 2006

Country	Children born with birth defects annually	Prevalence per 1000 live births				
		Total	Neural tube defects	Birth defects of cardio-vascular system	Pathological haemoglobin disorders	Down syndrome
Bangladesh	251 221	58.6	4.7	7.9	0.7	1.6
Bhutan	4 378	58.4	4.7	7.9	0.0	2.1
DPR Korea	20 295	54.1	4.7	7.9	0.0	0.8
India	1 613 502	64.3	4.7	7.9	1.2	1.6
Indonesia	263 154	59.3	0.7	7.9	0.8	1.4
Maldives	670	60.8	2.0	7.9	6.4	1.7
Myanmar	68 587	58.5	0.7	7.9	4.0	1.7
Nepal	49 180	59.9	4.7	7.9	0.2	2.1
Sri Lanka	20 652	62.2	2.0	7.9	0.6	1.9
Thailand	70 045	59.9	0.7	7.9	5.6	1.5
Timor-Leste	140	60.3	0.7	7.9	1.0	2.1

Source: March of Dimes Birth Defects Foundation 2006

At the Expert Group Meeting on Birth Defects held in New Delhi in December 2011¹³, and the Regional Programme Managers' Meeting on Birth Defects Prevention and Control held in Bangkok in March 2012¹⁴, Member States presented and discussed their current situation and opportunities related to birth defects surveillance, prevention and control policies and programmes. The following is a summary of the Member States' situation reports^d detailed tables are provided in Annex 1.

Birth defects surveillance activities in Member States

Birth registration

There is clear evidence of the need to strengthen birth defects surveillance systems, starting with birth registration systems that track stillbirths,

^d Member States participating in the meetings were Bangladesh, Bhutan, India, Indonesia, Maldives, Myanmar, Nepal, Sri Lanka and Thailand.

Thailand national birth registry and birth defects prevention programme

In 2008, Thailand established a working group called the “Thailand Task Force on Birth Defect Registry” which led, in 2011, to the “Thailand National Plan for Prevention and Care of Birth Defects and Disabilities”, supported by the Thai Health Promotion Agency. Its objectives are: (1) to build a holistic approach and set up the system for provision of diagnosis, treatment and rehabilitation; (2) to improve the referral system of primary health care to tertiary care level; and (3) to prevent birth defects by folic acid supplementation/fortification. The programme focuses on five priority birth defects: Down syndrome, neural tube defects, cleft lip/palate, limb anomalies and Duchenne muscular dystrophy with the goal of covering one third of the population in three years (2011–2014). At present, the birth defects registry involves only 20 hospitals under the Ministry of Public Health and is linked to national health-care payment systems since 2012.

and demographic risk factors for birth defects like the age of mother at delivery and consanguineous marriages. Most Member States reported that a significant proportion of births are registered. Death registration at significant levels is reported by India, Maldives, Sri Lanka and Thailand only. The percentage of women aged 35 and older at the age of delivery ranges from a high of 15.5% in Sri Lanka to “negligible” in India. Consanguineous marriages are uncommon in most Member States except for Bangladesh (10%) and India, where it is common in some populations like Muslims (22%), South Indians (20%).

Contribution of birth defects to mortalities

Most Member States reported data (mainly from published hospital-based studies) on the contribution of birth defects to neonatal mortality rates. Birth defects contribute to 21% of neonatal deaths in Thailand, and 19% in Indonesia. In India, birth defects cause 19.5% of perinatal mortality. Other Member States reported that birth defects contribute to about 10% of neonatal deaths. Only a few Member States track perinatal deaths related to birth defects.

Country reports point to the critical need for surveillance and monitoring of the prevalence of birth defects and their contribution to perinatal mortality, stillbirths, and medical termination of pregnancies.

Most common birth defects

The most common birth defects reported by SEAR Member States are congenital heart defects followed by neural tube defects. Thalassaemia is common in Bangladesh, India, Indonesia, Maldives, Myanmar and Thailand; Down syndrome is reported in six Member States; and Bangladesh, Maldives and Myanmar reported the common occurrence of glucose-6-phosphate dehydrogenase deficiency. Bhutan, Myanmar, Nepal and Thailand reported that cleft lip and cleft palate are common birth defects. Limb defects are common birth defects in Thailand, whereas Nepal reported congenital rubella syndrome as a common birth defect.

Source of information on birth defects in Member States

Hospital-based surveys are the most common sources of information on birth defects in the Member States. Only Thailand has recently initiated pilots for a national registry for birth defects that is proposed to be put in place in 3–5 years. India has sub-national level registries for birth defects. Sri Lanka collects birth defects in the national health information system. Four Member States reported that they had conducted disability surveys—India, Indonesia, Myanmar, Sri Lanka and Thailand.

Existing national programmes and policies that contribute to birth defects prevention

Folic acid supplementation and fortification

All Member States report that they provide folic acid supplementation to pregnant and lactating women, while only Thailand provides periconceptional supplementation nationally. The composition of supplementation tablets varies from a low of 60 mg iron and 0.25 mg folic acid in Indonesia to highs of 200 mg iron in Myanmar and 1 mg folic acid in Sri Lanka. Triferdine tablets (ferrous fumarate, 60 mg elemental iron, 0.4 mg folic acid and 0.15 mg iodine) are provided in Thai public health hospitals, although the coverage level is not known. Most Member States provide, or will start providing iron and folic acid supplementation to adolescents, some using a weekly supplementation strategy.

Food fortification programmes also vary widely. Only India, Indonesia and Nepal reported folic acid fortification in some provinces. Bhutan, India,

Flour Fortification Initiative (FFI)

FFI is a network of partners working together to make flour fortification a standard milling practice. FFI builds alliances between governments and international agencies, wheat and flour industries, and consumer and civic organizations. FFI's goal is for 80% of the world's roller miller flour to be fortified with at least iron or folic acid by 2015. Currently 74 countries, including Indonesia and Nepal, have legislation that requires fortification of at least one type of wheat flour with at least iron and/or folic acid.

FFI's focus is shifting to cereal grains, including wheat and maize flours and whole grain rice. Where wheat is not the main cereal consumed, such as several countries in Asia and Africa, maize and rice must also be considered for mass fortification to reach the population in a cost-effective and efficient manner.

Six states of USA, Costa Rica, Malaysia, Nicaragua, Papua New Guinea and the Philippines already have mandatory rice fortification. Brazil, Colombia, Dominican Republic and India have voluntary rice fortification.

Indonesia, Myanmar, Nepal and Thailand reported that iodine fortification programmes are being implemented at the national level.

Pre-conception care

All Member States reported some type of pre-conception care including provision of rubella vaccines, education on the use of alcohol and tobacco (and exposure) among women – pregnant or not – as part of related health programmes. Also, most Member States reported providing education and awareness programmes on avoiding pregnancy for women 35 years and older, avoiding teratogens and detection of Type 2 diabetes.

Screening for birth defects

Countries reported a variety of efforts to screen for birth defects. Bhutan, India, Maldives, Sri Lanka and Thailand reported antenatal screening at the national or sub-national level, mostly for anaemia (as part of their antenatal care package) or haemoglobinopathies. Ultrasonography, though available in

Sri Lanka's pre-pregnancy care programme

Sri Lanka has a comprehensive pre-pregnancy care programme that addresses many factors related to birth defects prevention. The programme provides counselling and follow-up on avoidance of pregnancy after 35 years of age, avoidance of medications, X-rays, environmental hazards, alcohol and tobacco exposure during pregnancy, as well as detection and treatment of diabetes in women before and during pregnancy. The pre-pregnancy care programme is coupled with a national universal salt iodization programme and a supplementation programme for pregnant and lactating women providing 60 mg iron and 1 mg folic acid daily for the second and third trimesters which continues for six months after delivery. Coverage is over 98% of women of reproductive age. Rubella vaccinations have also been provided since 1994, ensuring that 98% of women are protected at the time of conception.

most Member States, is used only to confirm and monitor pregnancies and localize placenta and not for antenatal screening of birth defects. Bhutan reported that ultrasound examination was used for antenatal screening, including for detection of anomalies, but only at the national referral hospital. In Bangladesh, Maldives, Myanmar, Sri Lanka and Thailand too, ultrasonography screening is available only at major hospitals. In India, ultrasonography is used during antenatal care in 44% of cases in urban areas and 16% in rural areas. The expertise for prenatal diagnosis of birth defects is, however, limited.

Newborn screening for hypothyroidism is conducted in Bangladesh, India and Indonesia in selected hospitals, and for hypothyroidism and phenylketonuria in Sri Lanka and Thailand. Thailand's national newborn screening programme – established in 2001 following a five-year pilot project – has a coverage rate of 90–95%.

Population-based screening and prenatal diagnosis for thalassaemia is available in limited areas of India, Maldives, Sri Lanka and Thailand.

Services for care of people with birth defects

Almost all Member States reported that services were available for the care of people with birth defects, including family support programmes, corrective

Thalassaemia screening in South-East Asia

Thailand has had a programme for prevention and control of thalassaemia since 1994. The programme consists of four strategies: education, carrier screening, genetic counselling and prenatal diagnosis. In the Maldives, a national thalassaemia programme provides free population screening and day-care treatment services in the capital, Male. India provides limited thalassaemia screening through some medical universities and organizations such as the Indian Council of Medical Research. Sri Lanka maintains a national thalassaemia registry and provides prenatal and antenatal screening. In all countries, thalassaemia screening and other services are supported by networks of parent, patient and advocacy groups.

surgery and/or community rehabilitation programmes. However, these are available at a limited number of places and are not adequate. Countries also reported that parent organizations related to selected birth defects provide social support and act as pressure groups. Countries also identified existing or potential partners to support birth defects-related activities.

Genetic services

Only a few Member States reported having either the capacity or programmes for birth defects genetic services. Genetic screening and counselling are available at selected centres in India, Indonesia, Maldives (for thalassaemia), Sri Lanka and Thailand. India, Sri Lanka and Thailand reported that they had a few genetic laboratories that offer a range of genetic tests.

Challenges and needs

In the Regional Programme Managers' Meeting, Member States expressed several common challenges and needs related to advancing national birth defects prevention and control programmes at the national level. The following needs were conveyed:

- Model implementation guidelines for the prevention and management of birth defects;
- Integration of information related to birth defects into existing national health information systems (including vital registration

system, health management information systems and population-based health surveys) or other platforms;

- Strengthened capacity for establishing and running birth defects surveillance;
- Initiation and/or expansion of folic acid supplementation and food fortification programmes;
- Technology transfer of food fortification;
- Laboratory support for birth defects diagnostics;
- Improving capacity for stillbirth post-mortem examination;
- Strengthened programmes for care of children with birth defects;
- Technical, financial and capacity-building support for birth defects preventive intervention programmes;
- Piloting and modelling birth defects surveillance programmes before scaling up to national systems;
- Sustained advocacy of birth defects prevention and control policy.

Guiding principles

The Regional Strategic Framework in the South-East Asia Region to reduce the prevalence of birth defects is guided by several principles:

- (1) The prevention of fetal, neonatal and infant deaths related to birth defects is a public health priority in the South-East Asian Region;
- (2) Information on birth defects in the Region needs to be strengthened to improve national birth defects prevention and control policies and programmes;
- (3) There are unique and significant opportunities to prevent selected birth defects, like neural tube defects, congenital rubella, congenital syphilis and thalassaemia (in selected countries) in the Region;
- (4) Precedence should be given to effective interventions for prevention and control of selected priority birth defects. Such interventions need to be integrated into current national programmes, like reproductive, maternal, newborn, child and adolescent health, nutrition, immunization, noncommunicable diseases, and tobacco and alcohol control programmes;
- (5) Partnerships and networks, multisectoral engagement and sustained advocacy are required to support prevention and management of birth defects in the Region; and
- (6) Ethical issues related to birth defects prevention and control, including equity, human rights and the rights of children with disabilities should be addressed within the local sociocultural contexts.

Goal and targets

Guided by these principles, the goal of the Regional Strategic Framework is the significant reduction of preventable birth defects in the South-East Asia Region to contribute to the achievement of MDG4 and beyond.

Targets

- (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.

Strategic directions

To achieve the aforementioned goal, the Regional Strategic Framework focuses on the effective implementation of the following five strategic directions. These will guide Member States' implementation of birth defects prevention and control activities, and SEARO and Partners' support.

- (1) Establish or strengthen national policies and programmes for birth defects prevention and control;
- (2) Develop and strengthen national birth defects surveillance, monitoring and evaluation mechanisms;
- (3) Integrate birth defects prevention and control strategies into public health, maternal and child health, nutrition and other relevant programmes;
- (4) Expand and strengthen national capacity for implementation of birth defects prevention and control programmes;
- (5) Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes.

Commitment to achieving MDG4 to reduce child mortality in the Region, and the contribution of birth defects prevention and control, is acknowledged. Hence Member States need to identify birth defects prevention as a national priority and ensure sustained political and managerial support along with adequate financing.

In developing or strengthening their birth defects prevention and control activities, Member States should first carry out a national-level review of current efforts and prioritization and consider the possibility of integrating birth defects activities within existing public health programmes.

The Regional Strategic Framework recognizes that Member States are at different stages of health development and have different capacities and systems for planning and implementing a national birth defects prevention and control programme. It is also recognized that all required activities may not be able to be undertaken at the same time. Member States need to develop plans and activities that can be implemented in a phased manner in accordance with the needs and conditions of evolving health systems.

The success of efforts to prevent birth defects in the Region depends on the effective planning and implementation of policies, programmes, surveillance, monitoring and evaluation activities, as well as engagement in partnerships, development of networks, and mobilization of resources and advocacy.

With these considerations, the following sections provide a generic framework to guide the implementation of the five strategic directions by all countries in the Region.

Strategic direction 1 – Establish or strengthen national policies and programmes for birth defects prevention and control

Member States' national policies and programmes to reduce infant and child mortality have so far focused on the control of infectious diseases and malnutrition. The next steps to reduce infant mortality should involve low-cost strategies for birth defects prevention, some of which would reduce other adverse pregnancy outcomes like preterm births and IUGR, in addition to mitigating the impact of severe, lifelong disability caused by birth defects.

The Regional Office review process indicated that most Member States had neither a national programme, nor a national focal point for birth defects prevention and control supported by appropriate working and steering groups. Similarly, very few national strategic plans exist on the prevention and control of birth defects. There is, therefore, an urgent need to develop

national policies, strategic and implementation plans on this issue using a public health approach.

It is observed that despite the significance of birth defects as a cause of fetal, neonatal and infant mortality, prevention of birth defects is not currently a public health priority in the Region. Advocacy should be put in place at all levels in support of birth defects prevention and control programmes. Available evidence should be used to inform and influence action by policy-makers, partners and the public. The advocacy should emphasize the public health, social and economic benefits of birth defects prevention, such as reduced fetal and neonatal deaths and improved health of women of reproductive age through interventions like folic acid and iron fortification and/or supplementation, along with the cost-effectiveness of such interventions.

At the same time, social mobilization is crucial to create demand to improve population coverage and ensure compliance of prevention recommendations. Birth defects prevention advocates at all levels and the media could be mobilized through the involvement of advisory and working groups in national planning and programme implementation. A regional advocacy campaign would ensure partners' involvement and support to Member States, facilitate resource mobilization, ensure political commitment for policy formulation and programme development and implementation in the countries.

Accordingly, it is recommended that Member States consider the following activities to develop/strengthen national policy and plans to prevent and control birth defects:

- 1.1 identification and appointment of a national focal point for birth defects prevention supported by appropriate multidisciplinary working and/or steering groups;
- 1.2 a national review of policies, programmes, guidelines, interventions and availability of resources related to prevention and management of birth defects in the country and development/strengthening a supportive policy for birth defects prevention and control, if required;
- 1.3 consideration of the relevant ethical, legal, religious and cultural issues appropriate for the local population while formulating birth defects surveillance and prevention services.

- 1.4 Development of a national strategic plan as well as implementation plans for prevention and control of birth defects. Implementation will require prioritization and consideration of phased plans depending on the availability of resources and system's capacity. The national plan should include one or more of the following interventions:
- mandatory, legislated national folic acid fortification and supplementation programmes that include other priority micronutrients like iodine, iron and others;
 - premarital, preconception, and prenatal screening for birth defects;
 - newborn screening for birth defects;
 - screening for thalassaemia trait, services for prenatal diagnosis and termination of pregnancy if legal and opted for;
 - screening and management of congenital syphilis;
 - rubella immunization for children and women of childbearing age;
 - health education campaigns and counselling of women of reproductive age and their families to promote healthy habits that focus on avoidance of evidence-informed risk factors;
 - treatment and care as well as rehabilitation of children born with birth defects.
- 1.5 Development and implementation of a communication strategy to promote birth defects prevention for advocacy, social mobilization and behaviour change to increase demand and uptake of the services.

Strategic direction 2 – Develop and strengthen national birth defects surveillance, monitoring and evaluation mechanisms

There is a critical need in the Region to develop birth defects surveillance systems (including registries) that provide standardized and comparable data within and across countries. Existing data and information should be reviewed to develop more accurate estimates of the prevalence of birth

defects and assess the availability of preventive and management services and their uptake by beneficiaries.

Integration of information on birth defects into existing information systems like vital registration, health management information, and demographic health surveys, must be considered in line with the recommendations of the Commission on Information and Accountability of the Global Strategy for Women's and Children's Health, initiated by the United Nations Secretary-General.

In addition, information on causative factors of birth defects, such as folic acid insufficiency and iodine deficiency among women of reproductive age is important. To collect this information, laboratory capacity must be strengthened for possible biomarker surveys. Depending on the availability of resources, countries could consider surveillance of exposure to teratogens that sometimes present as acute occurrences.

A monitoring and evaluation framework should be developed to guide birth defects prevention and control programmes in the Region. This could include monitoring and evaluation of the effectiveness and quality of birth defects prevention and control activities, including compliance by the beneficiaries.

Therefore, it is recommended that Member States conduct the following activities as appropriate:

2.1 Establishment and strengthening of national birth defects surveillance including the following components:

- Development and promotion of adoption of the regional surveillance standards that provide standardized, valid and comparable data on birth defects;
- Integration of information on birth defects, including surveillance and dedicated registries, into existing national health information systems like vital registries, health management information systems, and demographic health surveys or other platforms;
- Development of a national birth defects surveillance system and registries; and
- Collection of information on folate and iron levels through biomarker surveys.

2.2 Monitor, evaluate and report on the effectiveness of birth defects prevention activities. The activities would include:

- Availability of birth defects prevention policy, training, health education/communication efforts, and access to services;
- Cost-effectiveness/benefits analysis of programmes for prevention of birth defects;
- Effectiveness of, and barriers to fortification and/or supplementation programmes and other preventive interventions;
- Assessment of coverage and quality of birth defect prevention programmes;
- Evaluation of fortification and/or supplementation programmes through assessment of specific and measureable outcomes and biomarkers; and
- Reporting through regular public reports and published scientific articles.

Strategic direction 3 – Integrate birth defects prevention and control strategies into public health, maternal and child health, nutrition and other relevant programmes

The interventions for prevention and control of birth defects should be integrated into existing reproductive, maternal, newborn, child and adolescent health programmes, and other related programmes such as nutrition, immunization, and noncommunicable diseases. Efforts being implemented in Member States to decrease the exposure of women of reproductive age to alcohol and tobacco or their use may also be expanded. Progress in prevention and control of birth defects will contribute to the continuum of care, especially during the preconception, prenatal, and perinatal periods in addressing risk factors that are common to birth defects, preterm and IUGR births and birth asphyxia that are responsible for 35-55% of neonatal deaths.

There are several elements of effective, evidence-informed national birth defects programmes. For example, screening conducted of women of reproductive age for risk factors of birth defects at different stages—premarital,

preconception, during pregnancy—and of newborns are examples of prevention programmes. Addressing risk factors prior to marriage and conception, and conducting prenatal screening, can help women reduce risks of adverse pregnancy outcomes including birth defects, preterm and IUGR births and birth asphyxia. Antenatal care can detect specific risk factors and identify babies who may have a birth defect. Another example of prevention activities are the development and implementation of immunization programmes such as national rubella immunization for children and women of childbearing age, and integrating this into existing measles immunization programmes. This would reduce fetal morbidity and mortality associated with the contraction of rubella during pregnancy.

National programmes should also provide preconception health education and counselling to women of reproductive age and their families to promote healthy habits. Such efforts should focus on improving access to good quality antenatal care and fostering good habits that reduce specific risk factors for pregnancy outcomes, and include:

- Promotion of folic acid consumption and appropriate diet;
- Testing for rubella seronegativity and provision of vaccination;
- Encouragement of preconception glycaemic control in women with, or at risk of diabetes;
- Prevention and reduction of obesity;
- Management of the use of certain medications and teratogens that can cause birth defects;
- Prevention or treatment of STI and HIV/AIDS;
- Elimination of tobacco smoking and exposure to second-hand smoke;
- Prevention or treatment of alcohol use during pregnancy and when planning a pregnancy;
- Discouragement of the use of illicit drugs (primarily cocaine);
- Prevention and treatment of sexually transmitted diseases and hepatitis B;
- Assessment of women over 35 years of age (advanced maternal age);
- Carrier screening for thalassaemia in areas where there is high prevalence.

It is recommended that Member States conduct the following activities as appropriate:

- 3.1 prioritization of specific birth defects based on local epidemiology and public health importance, amenability to prevention and availability of cost-effective preventive interventions;
- 3.2 integration of food fortification and supplementation in the national nutrition programmes for micronutrients like:
 - Folic acid
 - B vitamins
 - Iodine
 - Iron.
- 3.3 inclusion of birth defects prevention and control interventions in maternal-newborn-child-adolescent health programmes:
 - **Adolescent and school health programmes:** including rubella immunization, counselling for prevention of consanguineous marriage and screening for thalassaemia;
 - **Pre-conception programmes:** including health promotion, screening for familial diseases, thalassaemia, diabetes and referral for care and counselling, supplementation programmes with folic acid and iron should also be considered;
 - **Pregnancy and childbirth care programmes:** including screening for anaemia, syphilis, rhesus blood group, individual risk by family history and Down syndrome;
 - **Family planning** to limit family size and prevent unwanted pregnancies;
 - **Newborn screening programmes:** including examination for birth defects and congenital hypothyroidism;
 - **Immunization programmes:** including rubella vaccine in the national immunization programme.
- 3.4 inclusion of birth defects prevention in noncommunicable disease programmes, such as:
 - avoidance of tobacco use and exposure to second-hand smoke during pregnancy;
 - avoidance of alcohol during pregnancy, or while trying to conceive;

- detection and control of diabetes mellitus before and after conception.
- 3.5 strengthening referral services for treatment, surgery and rehabilitation of children with birth defects.

Pre-conception care package could include the following:

- prevention of adolescent pregnancy and promotion of birth spacing;
- balanced diet and folic acid and iron supplementation;
- rubella vaccination;
- promotion of healthy life styles;
- prevent noncommunicable diseases;
- prevention and management of obesity, hypothyroidism and diabetes mellitus;
- prevention of alcohol use;
- prevention of tobacco use and exposure;
- prevention of exposure to medications and illegal drugs like cocaine and optimize use of medicines during pregnancy like anti-epileptics;
- prevention of exposure to environmental teratogens;
- Genetic counselling and screening depending on epidemiology and availability of resources.

Strategic direction 4 – Expand and strengthen national capacity for implementation of birth defects prevention and control programmes

Most Member States may not have adequate policy and programme, infrastructure or technical capacity to conduct national birth defects prevention and control activities. There is a need to train national staff on planning and managing birth defects programmes. In addition, there is a need for training to engage multiple sectors and conducting advocacy for birth defects prevention and control.

Expertise in Member States needs to be strengthened to develop birth defects surveillance systems; surveillance methodology such as data

collection, coding and validation methods; and use of data for monitoring, evaluation and reporting for programme implementation and improvement. The existing capacity-building mechanisms, such as epidemiology and laboratory training programmes in the country, should be used to integrate birth defects elements.

Health-care providers should be trained and laboratory services developed, where feasible, for effective delivery of national birth defects interventions. Accordingly, it is recommended that Member States conduct the following activities as appropriate:

- 4.1 Improvement of capacity for birth defects policies and programmes at national, and where feasible, subnational levels. Capacity building should include:
 - capacity for strategy development, multisectoral national planning, programme management and implementation;
 - develop and manage health education campaigns and counselling;
 - premarital, preconception, prenatal, and newborn screening;
 - development and implementation of mandatory, legislated national folic acid fortification and supplementation programmes for the prevention of neural tube defects as well as fortification with other micronutrients and iron (for prevention of anaemia).
- 4.2 Improvement of national capacity for birth defects surveillance, monitoring, evaluation and laboratories and, where feasible, at subnational levels including components such as workshops, trainings and communications on:
 - development and establishment of birth defects surveillance systems;
 - national birth defects data collection;
 - national vital registries;
 - data management;
 - monitoring, evaluation and reporting;
 - increasing national diagnostic laboratory capacity, ultrasonology capacity and develop accreditation guidelines.

Strategic direction 5 – Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

The SEARO review found that there were few effective, sustained partnerships or networks for prevention and control of birth defects in the Region at any level. Effective coordination and collaboration between all birth defects prevention partners in the South-East Asia Region could accelerate progress and maximize opportunities and resources. Multifactorial etiology of birth defects necessitates a multisectoral approach to prevention and control. Collaboration and coordination are needed at all levels and between key sectors, including bilateral and multilateral organizations and other nongovernmental organizations, government partners (ministries of health and family welfare, departments of nutrition/agriculture, secondary education, women's development, and rural and urban development), and industries like health care, food and agriculture.

There is also a demonstrated need to establish networks to facilitate cooperation, exchange of information and resources that support birth defects policies and programme implementation, surveillance, monitoring, evaluation and research in the Region. These networks can include Member States' national and sub-national programmes and stakeholders, including United Nations agencies and other international organizations, civil societies, academic institutions and professional organizations. Such networks can serve as platforms for meetings, training workshops and/or conference calls at regional and national levels.

In addition, there is a need to mobilize resources to facilitate development and sustainable scaling up of birth defects prevention, surveillance, monitoring and evaluation in the Region.

It is recommended that Member States conduct the following activities as appropriate:

- 5.1 increase the number of partners that could be, or are actively involved in supporting national birth defects prevention and control by conducting targeted outreach to new partners.

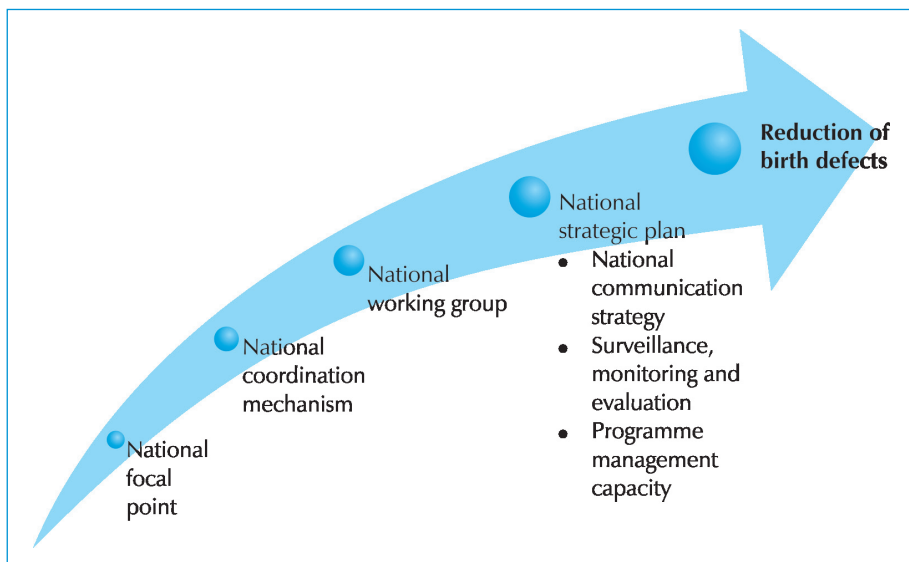
- 5.2 increase in networking and collaboration/coordination opportunities for all national partners supporting birth defects prevention and control;
- 5.3 establishment of sustainable mechanisms for informal, active and frequent exchange of information, including social media mechanisms;
- 5.4 facilitation of development and mobilization of resources to support national birth defects prevention and control initiatives.
- 5.5 establishment of networks of institutions at national and regional levels to support activities like advocacy, research, and capacity-building.

Implementation steps

These strategic directions guide Member States to develop a national strategy and an implementation plan to reduce the prevalence of birth defects (Figure 3). Member States should consider the following essential actions while designing the national birth defects prevention programme:

- (1) designate a national focal point in the ministry of health;
- (2) establish a national coordination mechanism;
- (3) establish a national technical working group or task force;
- (4) develop national strategic plan and a phased implementation;
- (5) develop and implement a national communication strategy and public education plans;
- (6) plan and conduct surveillance, monitoring and evaluation, including operation research;
- (7) strengthen programme management capacity.

Figure 3: Strategic implementation steps towards a national reduction in birth defects



Role of WHO South-East Asia Regional Office and partners

SEARO will work with Member States and partners to prevent birth defects and achieve MDG4 in the Region, focusing on the following priority activities across the strategic directions:

Strategic direction 1 – Establish or strengthen national policies and programmes for birth defects prevention and control

- 1.1 support high-level advocacy for birth defects programmes at regional and national levels;
- 1.2 provision of necessary evidence-informed information to Member States to facilitate political commitment, policy formulation and programme development;
- 1.3 engage with partners and donors for their active and increased support;
- 1.4 assistance in development of a communication strategy for prevention and control of birth defects, and materials for advocacy and education campaigns that can be adapted at national and local levels;
- 1.5 provision of support and guidance for developing national plans among priority Member States and sharing policy and programme norms and standards to facilitate and support Member States in the national adaptation;

- 1.6 respond to country-specific needs by developing additional tools and guidelines in collaboration with WHO Headquarters, expert institutions and WHO collaborating centres.

Strategic direction 2 – Develop and strengthen national birth defects surveillance, monitoring, and evaluation mechanisms

- 2.1 provision of technical support to develop and/or strengthening of national birth defects surveillance systems among priority Member States.
- 2.2 development of guidelines and recommendations for birth defects surveillance covering all the important elements of efficient surveillance systems.
- 2.3 provision of support to Member States for effective dissemination of information from birth defects surveillance, monitoring, research and programme evaluation to improve policies and practices.
- 2.4 tracking progress in the implementation of the Regional Strategic Framework and country-specific plans.

Strategic direction 3 – Integrate birth defects prevention and control strategies into public health, maternal and child health, nutrition and other relevant programmes

- 3.1 provision of required support to Member States to identify priority birth defects.
- 3.2 provision of guidance and support for integration of prevention interventions:
 - food fortification programmes (folic acid, B vitamins, iron and iodine);
 - supplementation programmes (folic acid and iron);

- birth defects prevention and control interventions in pre-conception care, newborn-screening, child health, adolescent-health, immunization, noncommunicable disease programmes etc.
- 3.3 provision of technical assistance in developing services for treatment and rehabilitation of children with birth defects

Strategic direction 4 – Expand and strengthen national capacity for implementation of birth defects prevention and control programmes

- 4.1 development of generic training programmes that can be adapted and conducted at national level; Training support may be required for:
- communication and advocacy, social mobilization and behaviour change communication
 - national planning
 - programme management
 - surveillance, monitoring and evaluation
 - diagnostic and laboratory capacity.
- 4.2 provision of technical support for national adaptation of regional/global packages, guidelines and conduct training of trainers;
- 4.3 provision of support to develop and enhance diagnostic and laboratory capacity in priority Member States for birth defects prevention.

Strategic direction 5 – Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

- 5.1 promotion of partnerships with various global and national initiatives, United Nations partners, other development partners, and donor agencies;

- 5.2 consideration of establishment of an Inter-Country Working Group to support national level efforts on birth defects.
- 5.3 Creation of opportunities for exchange of information and updates on birth defects programme and surveillance activities as well as progress on the Regional Strategic Framework implementation;
- 5.4 support to organization of periodic regional and national-level meetings;
- 5.5 support to development of regional-national networks of institutions and experts for birth defects programmes.
- 5.6 support to resource mobilization activities for birth defects programmes at regional and national levels.

Monitoring progress

Goal and targets

In order to accelerate progress towards achieving MDG4, SEARO has developed a South-East Asia Regional Strategic Framework, the goal of which is to reduce the prevalence of birth defects in the Region within five years (2012–2016). Its four specific targets in selected Member States are:

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

Indicators

Strategic direction 1 – Establish or strengthen national policies and programmes for birth defects prevention

- (1) national programme with a national focal point and dedicated budget;

- (2) national advocacy/education campaigns to mobilize political and public support for birth defects prevention;
- (3) national communication strategy/education campaign framework and materials for birth defects prevention.

Strategic direction 2 – Develop or strengthen birth defects surveillance, monitoring and evaluation capacity

- (1) birth defects information integrated in existing health information systems;
- (2) national birth defects surveillance mechanism that collects standardized, comparable data.

Strategic direction 3 – Integrate birth defects prevention strategies into public health, maternal and child health, nutrition and other relevant programmes

- (1) reports on integration of birth defects strategies in selected Member States;
- (2) regional/national guidelines on:
 - (a) food fortification and supplementation programmes;
 - (b) birth defects prevention interventions in pre-conception, prenatal and newborn screening, child health, adolescent health and other programmes;
 - (c) birth defects prevention in noncommunicable disease programmes.

Strategic direction 4 – Expand and strengthen national capacity for implementation of birth defects prevention and control programmes

- (1) regional capacity building packages on:
 - (a) birth defects prevention and control policies, planning or programmes;
 - (b) birth defects surveillance, monitoring and evaluation.
- (2) SEARO generic packages adapted and implemented in priority Member States for:
 - (a) national planning and advocacy
 - (b) programme management
 - (c) surveillance, monitoring and evaluation.

Strategic direction 5 – Develop and expand national, regional and international multisectoral partnerships and networks to support birth defects prevention and control programmes

- (1) regional birth defects partnerships and networks;
- (2) intercountry Working Group to support national level efforts on birth defects;
- (3) national partnerships and networks to support birth defects prevention.

Prevent birth defects – Improve newborn survival – Ensure quality of life and dignity

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Annex 1

Selected birth defects related activities in Member States: Existing situation

(As reported by the countries in the regional programme managers' meeting. DPR Korea and Timor-Leste could not participate)

Birth registration					
	Births registered	Deaths registered	Stillbirths registered	Women older than 35 years at delivery	Population who marry consanguineously
Bangladesh	Project in progress	Data NA	Data NA	Data NA	1 district: 10%
Bhutan	99.9%	Data NA	Data NA	4.5% (single facility)	Exists, Data NA
India	National: 68% 7 states: 100%	63%	Data NA	Negligible	South Indian: 20% Muslims: 22%
Indonesia	Data NA	Data NA	Data NA	Data NA	Data NA
Maldives	99%	Yes	Yes	11%	Uncommon
Myanmar	65%	Data NA	Data NA	Yes	Data NA
Nepal	Urban: 42% Rural: 34%	Data NA	3831 cases/year	7.8%	7%
Sri Lanka	97.2%	94%	Limited	15.5%	Uncommon
Thailand	98.4%	98.4%	4000 cases/year	12.8%	Data NA

NA: not available.

Contribution of birth defects to select mortalities				
	Neonatal mortality rate	Perinatal mortality rate	Stillbirths	Medical termination of pregnancy
Bangladesh	NA	NA	NA	NA
Bhutan	Single hospital: 10%	NA	NA	NA
India	9.6%	19.5%	9.9%	NA
Indonesia	19%	NA	NA	NA
Maldives	NA	NA	NA	NA
Myanmar	National: 3% Hospital-based: 0.6%	NA	NA	NA
Nepal	7.9%	9.7%	11%	NA
Sri Lanka	10.8%	NA	NA	NA
Thailand	21%	21%	NA	NA

NA: not available.

Most common birth defects									
Rank	Bangladesh	Bhutan	India	Indonesia	Maldives	Myanmar	Nepal	Sri Lanka	Thailand
1	CHD	CHD	NTD	-	CHD	Thal	Cleft	CHD	CHD
2	NTD	NTD	Down	-	NTD	CHD	CHD	Chrom	Ank
3	Thal	Cleft	MD	-	Thal	Cleft	NTD	NTD	Limb defects
4	Down	Chrom	Thal	-	Down	CGI	CRS		Cleft
5	G6PD		CH	-	G6PD	Down			Down
6			DMD	-		G6PD			NTD

Ank: Ankyloglossia (As per the insurance payment records)

CGI: Congenital gastrointestinal conditions

Chrom: Chromosomal abnormalities, includes Down syndrome

Cleft: Cleft lip, cleft palate

CH: Congenital hypothyroidism

CHD: Congenital heart defects, includes cardiovascular system defects

CRS: Congenital rubella syndrome

DMD: Duchene muscular dystrophy

Down: Down syndrome

G6PD: Glucose-6-phosphate dehydrogenase deficiency

MD: Metabolic disorders

NA: Not available

NTD: Neural tube defects, including spina bifida

Thal: Thalassemia and pathological haemoglobin disorders

Source of data/information on birth defects in the country					
	Registry: national or sub-national	Hospital- based health information survey	Population- based health information survey	Special surveys	Other Surveillance systems
Bangladesh	No	No	No	No	No
Bhutan	No	Yes	No	Pilot survey on mental disorders	No: CD Yes: cancer registry
India	Sub- national	Yes	No	Disability survey	No
Indonesia	No	Yes	No	Disability survey	No
Maldives	No	Yes	No	No	CD (STI, HIV, VPD)
Myanmar	Some hospitals have registries	Some	No	Disability survey (2009)	CD
Nepal	No	Yes	No	No	No
Sri Lanka	Pilot	Yes	Yes	No	Perinatal death reviews, CD
Thailand	Yes	Yes	No	Yes	Yes

CD: Communicable diseases

STI: Sexually transmitted diseases

HIV: Human immunodeficiency virus

VPD: Vaccine-preventable diseases

Folic acid supplementation and fortification					
	Adolescents	Pregnancy and lactation	Peri-conceptional	Composition of tablets	Food fortification: National/sub-national
Bangladesh	Yes	Yes	No	NA	Yes: Iodized salt
Bhutan	Yes, school children (WIFS)	Yes: same dose daily	First 3 months of pregnancy	Iron: 60 mg Folic acid: 0.5 mg	Yes: Only iodized salt coverage (100%)
India	Yes (WIFS)	60% coverage	No	Iron: 100 mg Folic acid: 0.5 mg	Flour fortification in some states (IFA); iodized salt
Indonesia	No	Yes	No	Iron: 60 mg Folic acid: 0.25 mg	Yes: Biscuits with folic acid, iron (89 districts); Iodized salt
Maldives	No	Yes	No	Iron: 60 mg Folic acid: 0.4 mg	No
Myanmar	Yes: twice a day, partial coverage	Yes: daily	No	Iron: 200 mg Folic acid: 0.4 mg	Yes: Iodine
Nepal	Yes	Yes	Private clinics	NA	Iodized salt; Flour fortification with iron, folic acid, Vit A
Sri Lanka	Starting in 2013	Yes	No	Iron: 60 mg Folic acid: 1 mg	Iodized salt
Thailand	No	Yes	Yes	Triferdine: Iron (60mg), folic acid (0.4 mg) & iodine (0.15 mg)	Yes: Iodine No: Iron and folic acid

WIFS: Weekly iron folic acid supplementation

Pre-conception and pregnancy care						
	Rubella vaccine	Use of alcohol among women	Harmful use of tobacco and exposure during pregnancy	Education and awareness programmes		
				Avoid pregnancy > 35 years	Avoid teratogens	Detection Type 2 diabetes
Bangladesh	Yes: 2012	Banned	General	Sporadic	Yes	Urine test
Bhutan	Yes: Since 2006 (women & children)	No programmes but awareness programmes, high taxation	Strict legislation against tobacco	Maternal & child health handbook, posters	Yes	Yes
India	Yes: Some states	No: national ban in one state	Yes	No	No	Yes: secondary & tertiary care
Indonesia	Yes	Yes: ANC	Yes: ANC	Yes: ANC	Yes: ANC	Yes: ANC
Maldives	Yes: Since 2007	General national campaign	General national campaign	Yes	Yes	Yes
Myanmar	Private sector	Health education	Health education	No	Yes	Yes: for DM during ANC
Nepal	Yes: 2012	Yes	Yes	No	Yes	Yes
Sri Lanka	Yes: Since 1994	General national campaign	General national campaign	Yes	Yes	Yes
Thailand	Yes	Yes	Yes	Yes	Yes	Yes

ANC: Ante natal care

DM: Diabetes Mellitus

Screening for birth defects						
	Antenatal screening	Ultrasonography screening	Newborn screening	Population screening for thalassaemia, etc.	Prenatal diagnosis	Medical termination of pregnancy
Bangladesh	In high risk group	Yes	Hypo-thyroidism	No	Sporadic	Yes
Bhutan	National Hospital: NTD and other major defects All levels: anaemia, STIs	Only for confirming pregnancies	No	No	No	Yes 20 weeks
India	Yes (Some states for Hbpathies)	Yes	Yes in some states	Yes	Yes	Yes
Indonesia	Anemia infections	No	Yes in some provinces	No	No	No
Maldives	Yes	Yes	Selectively	Yes	Abroad	120 days
Myanmar	Anaemia, infectious diseases	Yes: Tertiary care & private	No	No	No	No
Nepal	No	No	No	No	No	28 weeks
Sri Lanka	Yes	Yes	Yes	Yes	Yes	Not legal
Thailand	Yes (Hbpathies, Down, anaemia and infectious diseases)	Yes	Yes: PKU, Hypo-thyroidism	Yes	Yes, at tertiary hospitals	Yes: Up to 12 weeks

Hbpathies: haemoglobinopathies; NTD: neural tube defects; PKU: phenylketonuria; STI: sexually transmitted infections.

Services for care of people with birth defects					
	Family support programmes	Corrective surgery and /or rehabilitation programmes	Community rehabilitation programmes	Parent organizations	List of stakeholders
Bangladesh	Yes	Yes	No	Yes	Yes
Bhutan	None	Yes: "Camps" for cleft lip and palate 2/year	Yes	Disabled persons association for visually impaired	NA
India	Some	Medical colleges and tertiary care	NGOs/Civil Society	Yes	Multiple
Indonesia	Yes	Yes	Yes	Yes	Yes
Maldives	Yes	Yes	Yes	Yes	Yes
Myanmar	Yes	Yes	Yes	Yes: autism, cleft lip and cancer	Multiple
Nepal	Yes	Yes	Yes	Yes	Yes
Sri Lanka	Yes	Yes	Yes	Yes	Yes
Thailand	Yes	Yes	Yes	Yes	Multiple

Genetic services				
	Genetic screening	Genetic counselling	Genetic laboratories	List of available genetic tests
Bangladesh	No	No	Few	No
Bhutan	No	No	No	No
India	Yes: Support from Indian Council of Medical Research	Yes: 45 ICMR facilities	26 biochemical and 28 molecular laboratories	Yes
Indonesia	No	No	Few	No
Maldives	Yes: for thalassaemia	Yes: for thalassaemia	Yes: for thalassaemia	No
Myanmar	No	No	No	No
Nepal	No	Yes	No	No
Sri Lanka	Yes: for thalassaemia	Yes	Yes	Yes
Thailand	Yes	Yes	Yes	Yes

Annex 2

Resources

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Member States in the South-East Asia Region have observed declining child mortality over the past two decades. This decline has been possible because of improved health services and a reduction in child mortality from causes such as birth asphyxia, infectious diseases and malnutrition. However, mortality from birth defects has remained constant, which has resulted in it becoming a larger proportional cause of infant mortality. Birth defects are not only life-threatening but can also result in long-term disability, and negatively affect individuals, families, health-care systems and societies. Several interventions have been shown to be effective for prevention of birth defects in a variety of social and economic settings.

In recognition of this public health priority, World Health Assembly resolutions have been adopted that call for global action for surveillance, prevention and treatment of birth defects within the comprehensive maternal, newborn, child health, and infant and young child nutrition plans. In response, the WHO Regional Office for South East-Asia has, in collaboration with Member States, developed a Strategic Framework for prevention and control of birth defects in the Region in the next five years. In the context of the existing situation in the Region, this Framework provides strategic directions to guide Member States in developing and strengthening birth defect surveillance and prevention programmes with consideration to integrate these within existing public health programmes. The Framework also outlines the roles and responsibilities of Member States, the WHO and partners.



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