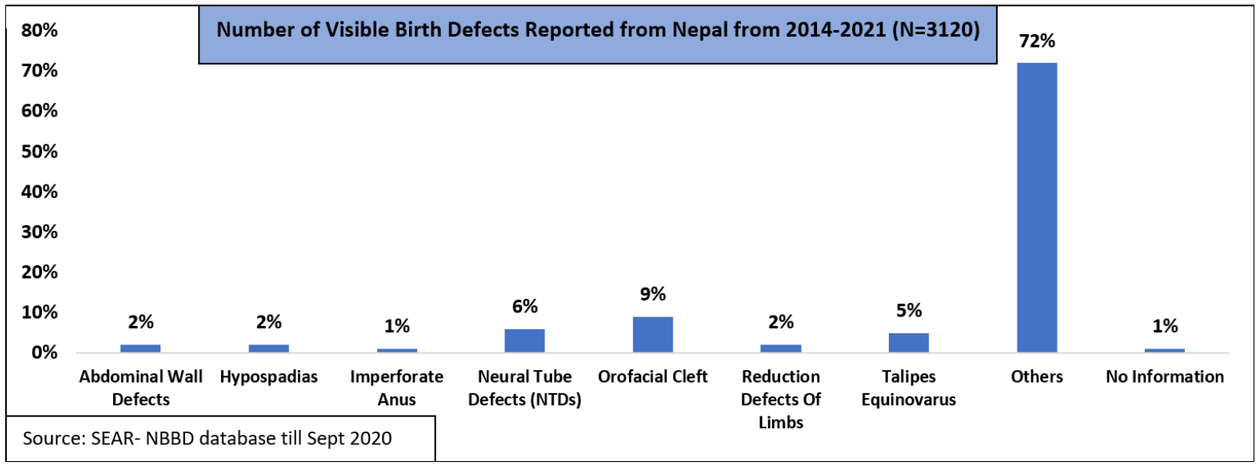
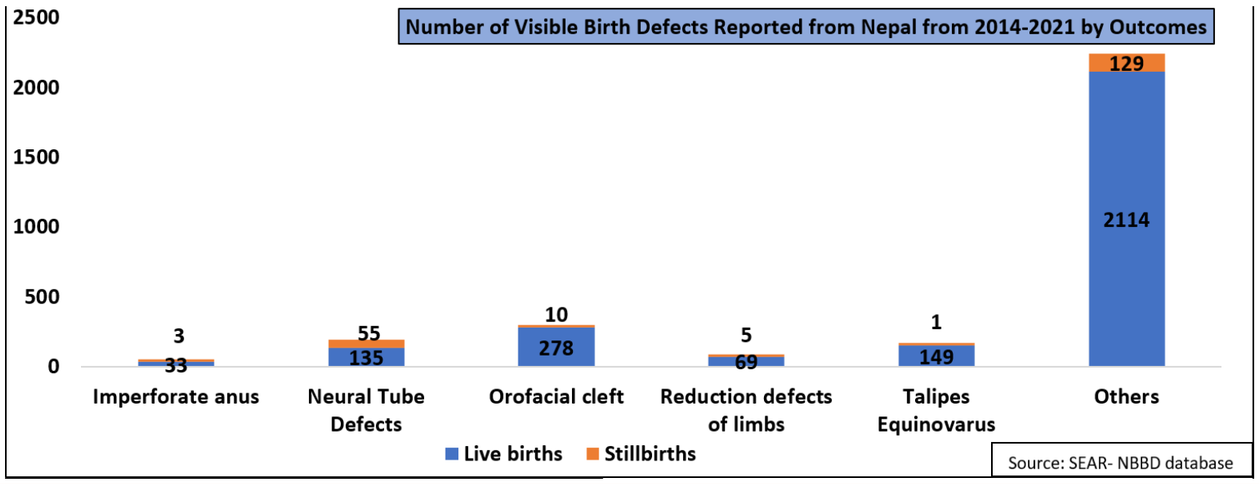




ISSUES AND CHALLENGES

- Absence of National Coordinator / Nodal Hospital leading to gap in first level verification of birth defect data
- Gap in recording, reporting and timeliness and completeness of data and overall regular functioning of the program due to rapidly changing human resource, inadequate or absence of trained human resource resulting in gap in regular identification of BD cases, timeliness and completeness of data recording as well as reporting
- Non utilization of allocated budget due to lack of knowledge on budget availability / division and utilization
- Internet issue in hospitals leading to delay in entry of filled abstraction forms in the NBBD site.
- Medical recorders not actively involved in BD recording and reporting due to work overload / lack of training

WAY FORWARD

- Identify National Coordinator and Nodal Hospital for first level verification
- Strengthen the NBBD program in implementing hospitals / medical colleges through regular monitoring follow-up and orientation
- Sensitize all involved in Newborn Birth Defect recording and reporting in hospitals
- Expansion of Birth Defect program in hospitals / medical colleges
- Biannual / Annual National Review and Orientation
- Strengthen capacity for genetics diagnosis and counselling
- Strengthen the care and management services for Birth Defects in Newborn linking with Child Health and Non- Communicable Diseases programs
- Update the program implementation guideline for Federal hospitals
- Update the National Birth Defect Prevention

Newborn Birth Defect (NBBD) Surveillance in Nepal

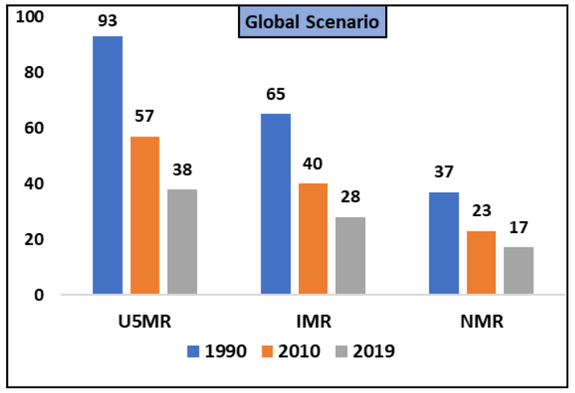
World Health Organization
Nepal

Government of Nepal
Ministry of Health and Population
Department of Health Services
Family Welfare Division

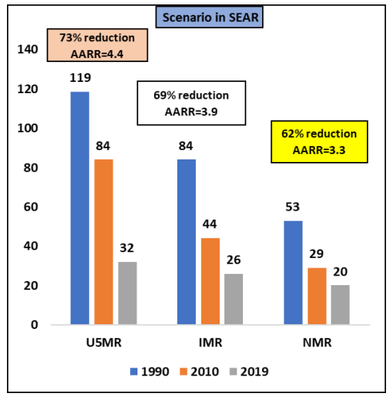
WHAT IS BIRTH DEFECT ?

Birth defects, also called congenital anomalies, or rare diseases (when the defect is very rare), are structural or functional anomalies, that occur during pregnancy. They can be identified before birth, at birth, or later in infancy. Birth defects are a leading cause of child death in the first year of life and those who survive may be severely disabled for life.

Access to appropriate treatment or care can prevent disabilities in these children and even save their lives.



*1990 and 2019 data from UNIGME Report 2020 and 2010 data from UNIGME Report 2011

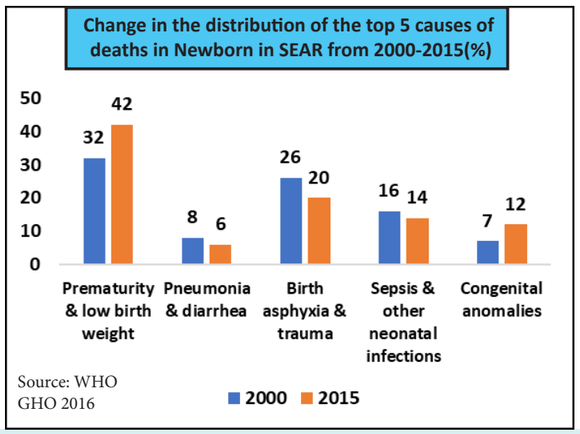


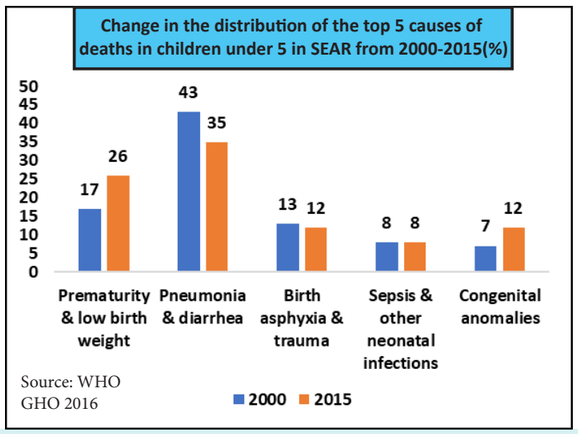
*1990 and 2019 data from UNIGME Report 2020 and 2010 data from UNIGME Report 2011

BIRTH DEFECT SCENARIO

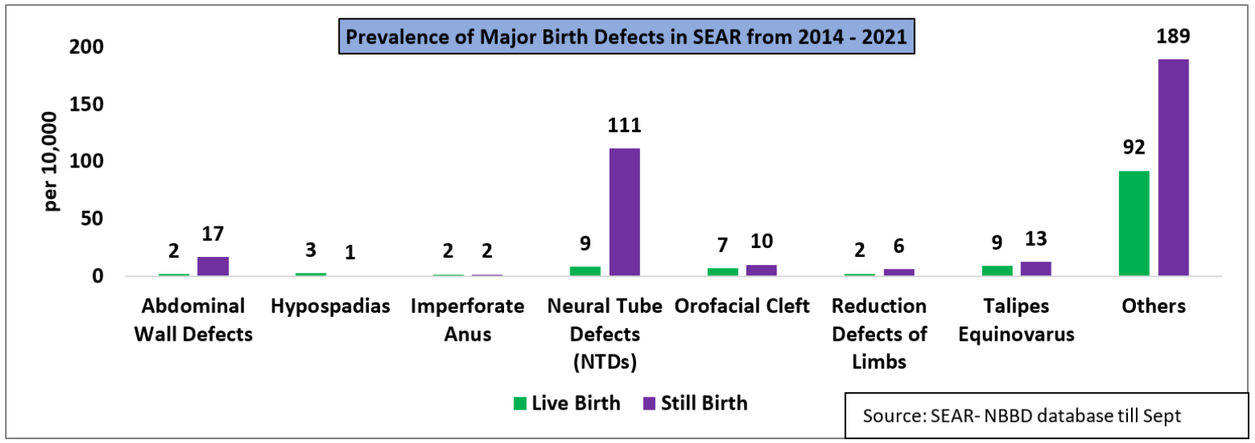
- Six countries in the South East Asia Region (SEAR) report birth defect in the SEAR-NBBD database.
- Since 2014, more than 3.28 million babies have been reported, with more than 39000 birth defects[1]
- In 2020, at birth prevalence of birth defect was 116 per 10,000 births[1]
- Some birth defects can be prevented and their early identification followed by appropriate interventions can prevent deaths in newborn and also prevent life-long disability
- Some birth defects can be identified in utero and some become more apparent in infancy

[1] SEAR- NBBD database



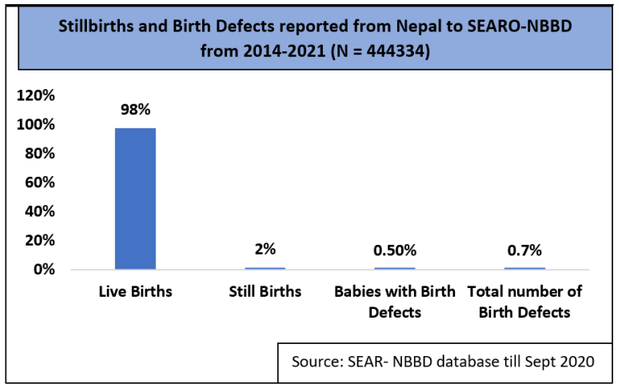


The causes of deaths in newborns and under-5 child shows a changing trend from 2000 to 2015. There has been a rise in the cause of death due to prematurity & low birth weight and congenital anomalies. Hence, there is a need to focus on these causes.



NATIONAL INITIATIVES

- Universal Salt Iodization (USI) since 1998.
- The National Anemia Control Strategy and Iron Intensification Program since 2003.
- Flour fortification initiated in 2008.
- Birth Defect Surveillance, Prevention and Control Implementation Plan 2015-2019.
- Birth Defect prevention program initiated at community level in two districts (Ilam and Dang) with Folic acid distribution to newly married couple, expanded to 6 more districts in 2022.
- Maternal and Perinatal Death Surveillance and Response (MPDSR) program in hospitals provide information on fatal birth defects.
- Sick Newborn Care Unit / Neonatal Intensive Care Unit (SNCU/NICU), delivery registers and Information Management System (HIMS) have space to record birth defects.
- Folic acid distribution to mothers in their first ANC visit initiated in 77 districts from the year 2022/23.



Surveillance in Nepal:

- Hospital based NBBD surveillance was initiated from Paropakar Maternity and Women's Hospital in 2013.
- The database is based in SEAR – NBBD and WHO-SEARO has been supporting this program.
- In 2016, Government of Nepal took ownership of NBBD Surveillance program. As of 2022, 17 Referral hospitals are involved in NBBD surveillance.

MAJOR TIMELINE

2014
- NBBD Initiated in 10 hospitals
- PMWH as nodal hospital & National coordinator
- NBBD Database with support from WHO-SEARO

2015
- Birth Defect Surveillance Prevention & Control Implementation guideline and plan

2016
- GoN ownership
- Expanded to 16 hospitals

2019
- Expanded to 17 hospitals