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The Prevention upon the Congenital Anomalies Effect: A Comparative Study between Indonesia, the United Kingdom and the United States

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Abstract

Birth defects or congenital anomalies affect an estimated 1 in 33 infants, resulting in 3.2 million children with disabilities relating to birth defects every year. In addition, 11.3% of 2.68 million infant mortality caused by birth defects. South-East Asia region has the second-highest prevalence of birth defects in the world, 9% of under-five deaths and 12% of newborn deaths in South-East Asia Region were due to congenital anomalies in 2015. In response to this, some countries have established law to prevent children from congenital anomalies. In fact, genetic is not the single factor causing the congenital anomalies. In many cases, they were also the result of wrongful conduct of persons. The United Kingdom, for example, had passed a law to deal with the issue of congenital anomalies since 1976. Considering the above-mentioned statistic of birth defects in South-East Asia region, Indonesia have to take an action to prevent or reduce their occurrence. The paper aims to explore the possible ways to prevent the congenital anomalies in

Indonesia. It is found that the prevention of congenital anomalies can be made through legal instruments. Unfortunately, the existing law, including the Child Protection Act, does not cover such an issue. In this regards, the reform upon the law relating to it is urgent. For this purpose, learning from other countries such as the United States and the United Kingdom seems to be necessary.

Keywords: birth defects; child protection; congenital anomalies.

1. Introduction

Every year an estimated 7.9 million infant are suffering a defect (6 % of total births worldwide).¹ Then, birth defect with serious birth defect occurs more than 94 percent and 95 percent of these children are dying. South-East Asia Region has the second highest prevalence of birth defects in the world, 9% of under-five deaths and 12% of newborn deaths in South-East Asia Region were due to congenital anomalies in 2015. The birth defects/congenital anomalies become a global problem because the impact in middle- and low-income countries is severe. Congenital malformation is considered to be the most important genetic condition worldwide, because it can cause early mortality and significant health burden More than 90% neonates born with congenital malformation are from low-

¹ Chistianson, A., Hownson, C.P., and Modell B., Global Report on Birth Defects "The Hidden Toll of Dying and Disabled Children, White Plains, New York, 2006, p.2.

middle income country, which have limited source of health cost.²

2. Analysis and Results

2.1. Birth defects and Congenital Anomalies Effects

A birth defect is a health problem or abnormalities of structure or function, including metabolism, which is occur upon infant at birth.³ They include physical, intellectual, visual or hearing impairment or epilepsy as well as inherited diseases.⁴ Serious birth defects are life-threatening, in which case an infant may only live/survive for a few months. And those who live upon these conditions are at increased risk for long-term disabilities and other health problems.⁵ The most major causes of birth defects are unknown, only for some birth defect like fetal alcohol syndrome has been identified. Fetal alcohol syndrome cause is due to the woman who drinks alcohol.⁶ Even so, there is some allegation that the birth defects are caused by complex mix factors (internal and external) such as genes, behaviours, and environment.⁷ The term of

birth defect also known as the Congenital Anomalies.⁸

The global report on birth defects which published by March of Dimes (MODB) reported that more than seven thousand kinds of birth defects have been identified. Birth defect may occur before birth, at birth or any time after birth. The first 3 months of pregnancy is a crucial period that birth defect can occur because upon that period, the organs of the infant are forming.⁹ Birth defects are divided into structural birth defects and functional or developmental birth defects.¹⁰ The structural birth defects is concerned about the problem involve a structure of body part that is malformed/missing obviously upon birth.¹¹ While the functional or developmental birth defects is concerned about the problems with metabolism, or how body system/the organs work and may only be diagnosed later in life. Cleft lip or cleft palate is one of the structural birth defects which is obvious upon birth.¹² The bleeding disorder *hemophilia* is a functional birth defect which not clinically obvious until infancy or childhood.¹³ In 2001, MODB reported there were five common serious birth defects of genetic or partially genetic origin, namely:

1. congenital heart (1,040,835 births)
2. neural tube defects (323,904 births)

⁸ World Health Organization (2016). Congenital Anomalies. From <https://www.who.int/news-room/fact-sheets/detail/congenital-anomalies>, April 7, 2019

⁹ *Ibid.*

¹⁰ Anonym (2017). What are the types of birth defects?. From <https://www.nichd.nih.gov/health/topics/birth-defects/conditioninfo/types>, April 13, 2019

¹¹ Anonym (2001). What are the types of birth defects?. From <https://www.mass.gov/service-details/information-about-birth-defects>, April 20

¹² *Ibid.*

¹³ *Op Cit.* Chistianson A., Hownson C.P., Modell B. p.2.

² Ariani, Y., Soeharso, P., and Sjarif, D.R. 2017, Genetics and genomic medicine in Indonesia, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5370234/>, Published online 2017 Mar 29, accessed on 31 May 2019

³ Lannuncci, L. 2002. Birth Defects, Enslow Publisher, United States, 2002. P. 7

⁴ *Op Cit.* Chistianson A., Hownson C.P., Modell B. p.2.

⁵ Anonym (2018). World Birth Defects Day 2018 Raises Global Awareness of Birth Defects. From <https://blogs.cdc.gov/global/2018/03/03/world-birth-defects-day-2018-raises-global-awareness-of-birth-defects/>, April 4, 2019

⁶ Healthline Editorial Team (2017). What are the causes of fetal alcohol syndrome?. From <https://www.healthline.com/health/fetal-alcohol-syndrome#causes>, April 4, 2019

⁷ Anonym (2018). Causes of Birth Defect. From <https://www.cdc.gov/ncbddd/birthdefects/facts.html>, April 4, 2019

2.2. Prevention and Protection Upon the Birth defects and Congenital Anomalies Effects

In 2000, the United Nation Millennium Development Goals (UN's MDGs) for 2015, were launched, including reducing infant and child mortality.¹⁴ In the World Health Report 2005¹⁵ MDGs focused on the newborn as the effort to improve child health and survival. Even so, those reports failed to include birth defects as the major cause of child mortality and disability and also did not highlight care and prevention of birth defect as an essential part of woman, and child health program in all countries. The reports concluded the child mortality will be

International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR)¹⁷, a global birth defects surveillance affiliated with World Health Organization (WHO) that was established in 1974.¹⁸ Currently, the ICBDSR has 42 full members and 19 affiliate members worldwide.¹⁹ The majority of the member are from Asia (5 countries), Australia (2 countries), Europe (15 Countries), North America (3 countries), and South America (3 countries).²⁰

2.3. The Phenomenon of Birth Defects in the United State

Every 4 ½ minutes, a baby is born with birth defect, it nearly 120,000 babies are

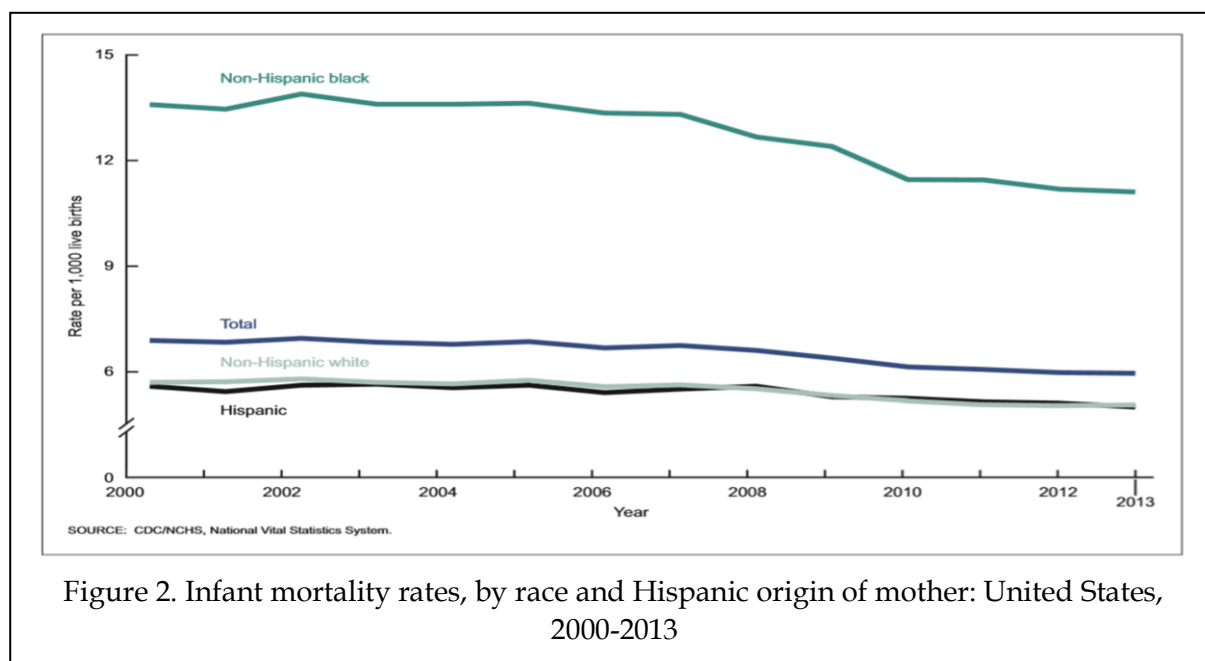


Figure 2. Infant mortality rates, by race and Hispanic origin of mother: United States, 2000-2013

reduced unless the international community did more to reduce neonatal mortality. In 193 countries over the world have about 9% of all neonatal mortality due to birth defects in 2010.¹⁶

¹⁴ Anonym (2010). 2010 UN Summit. From <https://www.un.org/en/mdg/summit2010/>, April 20, 2019

¹⁵ Make Every Mother and Child Count, and the first Lancet Neonatal Survival Series.

¹⁶ World Health Organization, "Congenital Anomalies", *Fact Sheet 370*, From

<https://www.who.int/en/news-room/fact-sheets/detail/congenital-anomalies>, May 8, 2019

¹⁷ Voluntary non-profit organization

¹⁸ ICBDSR (2014). International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR). From

<http://www.icbdsr.org/page.asp?n=AboutUs>, May 9, 2019

¹⁹ ICBDSR (2019). Member Directory. From <http://www.icbdsr.org/members-directory/>, May 13, 2019

²⁰ ICBDSR (2019). Programme Description. From <http://www.icbdsr.org/programme-description/>, May 13, 2019

affected by birth defects each year in United States.²¹ Based on the data, birth defects affect an estimated 1 in 33 infants (about 3% of all babies)²², a major contributor to infant mortality.²³ A birth defect is not only a problem for infant mortality but also it results in billions of dollars in the cost of care.²⁴ In 2004, the estimation of birth defects billed a cost for hospitalization for in the United State were almost 2.6 billion dollars.²⁵ Neural tube defects (NTDs) are one of the major birth defects of the brain and spine (anencephaly and spina bifida) occur early in pregnancy, which can lead to death.²⁶ The

birth defect account for approximately 20% of total infant deaths in the United States.²⁷

In 1998, as the mandate of United States Food and Drug Administration, all grain products labeled as 'enriched' was mand, such as breads and cereals, have folic acid²⁸ added to them to help reduce the risk of NTDs.²⁹ Nevertheless, the most major causes of birth defect are unknown, certain factors become a concern such as an increase in the prevalence of diabetes among women, might result in increased prevalence of birth defects over time.³⁰ Following the phenomenon, the United States government take an effort to prevent the big number of infant mortality through the enactment of the Birth Defect Prevention Act of 1998. The Birth Defects Prevention Act of 1998 stated that the exposure to environmental hazards, adverse health conditions during pregnancy, and or genetic mutations may become a birth defects causes.³¹ Meanwhile, the lack on data of the number and causes of birth defects become the factor that slows the prevention efforts.

In 1967 the first population-based birth defects surveillance program in United State was established by Center for Disease

²¹ Op Cit.

<https://www.cdc.gov/ncbddd/birthdefects/facts.html>, 10 May, 2019

²² CDC (2018). Data & Statistics on Birth Defects. From

<https://www.cdc.gov/ncbddd/birthdefects/data.html>, May 09, 2019

²³ Rynn, L., et al. January 2008, "Update on Overall Prevalence of Major Birth Defect-Atlanta, Georgia, 1978-2005", *Center for Disease Control and Prevention (CDC), Morbidity and Mortality Weekly Report*, Retrieved May 6, 2019, From

<https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5701a2.htm>

²⁴ Robbins, JM, et al. January 2007, "Hospital Stays, Hospital Charges, and In-Hospital Deaths Among Infants with Selected Birth Defects-United States, 2003", *Center for Disease Control and Prevention (CDC), Morbidity and Mortality Weekly Report*, Retrieved May 6, 2019, From

<https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5602a1.htm>

²⁵ Mburia-Mwalili, A., and Yang, W. October 2014, "Birth Defects Surveillance in the United States: Challenges and Implications of International

Classification of Diseases, Tenth Revision, Clinical Modification Implementation", *International Scholarly Research Notices*, Vol. 2014, From

<https://www.hindawi.com/journals/isrn/2014/212874/#B5>, May 7, 2019

²⁶ Williams, J, et al. January 2015, "Update Estimate of Neural Tube Defects Prevented by Mandatory Folic Acid Fortification-United States, 1995-2011". *Center for Disease Control and Prevention (CDC), Morbidity and Mortality Weekly Report*, Retrieved May 7, 2019, From

https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6401a2.htm?s_cid=mm6401a2_w

²⁷ Callaghan WM, MacDorman MF, Rasmussen SA, et al. The contribution of preterm birth to infant mortality rates in the United States. *Pediatrics* 2006;118:1566--73.

²⁸ Folic acid is the B vitamin that can help prevent neural tube defect (NTDs)

²⁹ CDC (2018). Birth Defects Preventions. Retrieved May 10, 2019, From

<https://www.cdc.gov/ncbddd/birthdefects/data.html>

³⁰ Yang J, et al. September 2006, "Fetal and Neonatal Outcomes of Diabetic Pregnancies", *Obstetrics & Gynecology. Volume 108, Issue 3*, https://journals.lww.com/greenjournal/Fulltext/2006/09000/Fetal_and_Neonatal_Outcomes_of_Diabetic.25.aspx, 10 May 2019.

³¹ Section 1 of Birth Defect Prevention Act of 1998

Control and Prevention (CDC).³² The program called as Metropolitan Atlanta Congenital Defects Program (MACDP), is a tracking system for birth defects using a population-based.³³ Population-based means getting a picture of what is happening within the population.³⁴ Starting from tracking the birth defect, then the information is used by public health officials, policymakers, and scientist for the following activities:³⁵

1. To understand if the number of birth defect is increasing or decreasing over time.
2. To investigate possible causes of and risk factors for birth defects.
3. To educate the public about birth defects and how to prevent them.
4. To plan and evaluate activities aimed at preventing birth defects.
5. To refer babies and families affected by birth defects to appropriate services.
6. To help policymakers allocate resources and services for affected babies and their families.

³² A. Correa-Villasenor, et al. 2003, "The Metropolitan Atlanta Congenital Defects Program: 35 years of birth defect surveillance at the centers for disease control and prevention", *Birth Defects Research Part A: Clinical and Molecular Teratology*, Vol. 67, No. 9, P. 617-624

³³ Mburia-Mwalili, A., and Yang, W. October 2014, "Birth Defects Surveillance in the United States: Challenges and Implications of International Classification of Diseases, Tenth Revision, Clinical Modification Implementation", *International Scholarly Research Notices*, Vol. 2014, Retrieved May 10, 2019, From

<https://www.hindawi.com/journals/isrn/2014/212874/#B5>

³⁴ CDC (2018). Metropolitan Atlanta Congenital Defects Program (MACDP). Retrieved May 11, 2019, From <https://www.cdc.gov/ncbddd/birthdefects/macdp.html>

³⁵ CDC (2018). State-Based Birth Defects Tracking Systems. Retrieved May 11, 2019, From <https://www.cdc.gov/ncbddd/birthdefects/stat es/index.html>

MACDP's purpose is to:³⁶

1. Track the occurrence of birth defects.
2. Maintain data for use in epidemiologic studies (studies that look at health effects within the population).
3. Understand other health outcomes, such as mortality or death rates, associated with birth defects.
4. Provide data for education and health policy decisions leading to the prevention of birth defects.
5. Serve as a model to help other programs to develop and implement new tracking methods.
6. Collaborate with state and international birth defects programs in tracking and prevention efforts.
7. Provide a training ground for public health scientists in tracking and epidemiologic methods.

The establishment of the birth defects surveillance program in some states was accelerated by the existence of The Birth Defects Prevention Act of 1998, even though there are a few states that have not implemented yet such a program.³⁷ Supporting that issue, a voluntary-based organization that works in collaboration with CDC was established in 1997. The organization name is National Birth Defects Prevention Network (NBDPN), is aimed to support a national network of state and the birth defects surveillance programs and also be a part in birth defects research and prevention. In 2004, the NBDPN successes to improve the uniformity of birth defects

³⁶ Op Cit.

³⁷ Mai, C.T., et al. 2013, "Selected Birth Defect Data from Population-Based Birth Defects Surveillance Program in the United States, 2006 to 2010: Featuring Trisomy Conditions", *Birth Defects Research (Part A): Clinical and Molecular Teratology*, Vol. 97, No. 11, May 12, 2019, From <https://onlinelibrary.wiley.com/doi/full/10.1002/bdra.23198>

surveillance in the USA through publishing the guidelines for performing the birth defects surveillance.³⁸ These birth defects surveillance programs are funded by the CDC's National Center on Birth Defects and Developmental Disabilities.³⁹

2.4. The Phenomenon of Birth Defects in the United Kingdom

Birth defects are fairly common in United Kingdom, affecting 15,966 infants in 2011.⁴⁰ Based on the data, birth defects affect an estimated 1 in 46 infants (about 2,2% of all babies).⁴¹ The term of birth defect also known as the Congenital Anomalies.⁴² Congenital Heart Defect was the most defects that affect at least 6 in 1,000 infants⁴³ in the UK and around six per cent of the infant with a heart defect will die before the age of one.⁴⁴ Recently, the number of birth defect case have a significant decreased and it is now estimated that 1 in 50 infants have a birth defect in the United Kingdom.⁴⁵ In response

to the issue, all pregnant mothers in the United Kingdom are welcomed to join the screening program to detect the early signs of certain types of birth defect.⁴⁶ The program is offered by the National Health Service (NHS) of the United Kingdom.⁴⁷ There are several screening programs that offered by NHS, as follow:⁴⁸

1. NHS Abdominal Aortic Aneurysm (AAA) Programme
2. NHS Bowel Cancer Screening Programme (BCSP)
3. NHS Breast Screening Programme (BSP)
4. NHS Cervical Screening Programme (CSP)
5. NHS Diabetic Eye Screening (DES) Programme
6. NHS Fetal Anomaly Screening Programme (FASP)
7. NHS Infectious Diseases in Pregnancy Screening (IDPS) Programme
8. NHS Newborn and Infant Physical Examination (NIPE) Screening Programme

³⁸ Server, L. E. 2004, *Guidelines for Conducting Birth Defect Surveillance*, National Birth Defects Prevention Network (NBDPN), Atlanta, USA, http://www.nbdpn.org/docs/NBDPN_Guidelines2012.pdf, May 12, 2019

³⁹ Op Cit. Mburia-Mwalili, A., Yang, W., May 13, 2019

⁴⁰ Express (2013). One in 46 Babies has Birth Defect. Retrieved May 13, 2019, Form <https://www.express.co.uk/news/uk/427230/One-in-46-babies-has-birth-defect>

⁴¹ Ibid

⁴² World Health Organization (2016). Congenital Anomalies. Retrieved April 7, 2019, From <https://www.who.int/news-room/fact-sheets/detail/congenital-anomalies>

⁴³ Op Cit. Express (2013), May 13, 2019

⁴⁴ Queen Mary University of London (2011). Report Find One In 50 Babies Has Birth Defect and Highlights Worrying Gaps In Regional Monitoring. Retrieved May 13, 2019, Form <https://www.qmul.ac.uk/media/news/2011/smd/report-finds-one-in-50-babies-has-birth-defect-and-highlights-worrying-gaps-in-regional-monitoring.html>

⁴⁵ The Telegraph (2019). One in 50 Babies Has a Birth Defect: Research. Retrieved May 13, 2019,

From

<https://www.telegraph.co.uk/news/health/news/8953930/One-in-50-babies-has-a-birth-defect-research.html>

⁴⁶ London Health (2019). Birth Defects: London Health. Retrieved May 13, 2019, From <http://www.londonhealth.co.uk/children-health/newborn/birth-defects.html>

⁴⁷ Public Health England (2018). Research and analysis National Congenital Anomaly and Rare Disease Registration Service Statistics 2016 Summary Report. Retrieved May 13, 2019, Form <https://www.gov.uk/government/publications/ncardrs-congenital-anomaly-annual-data/national-congenital-anomaly-and-rare-disease-registration-service-statistics-2016-summary-report#contents>

⁴⁸ Anonym (2016). Population Screening Program. Retrieved May 13, 2019, From <https://www.gov.uk/topic/population-screening-programmes>,

9. NHS Newborn Blood Spot (NBS) Screening Programme
10. NHS Newborn Hearing Screening Programme (NHSP)
11. NHS Sickle Cell and Thalassaemia (SCT) Screening Programme
12. Population Screening: Data and Intelligence

NCARDRS goals is to improve data collection over the service to be able to report various indicators to increase knowledge on possible risk factors which influence the congenital anomalies and rare diseases.⁵⁰ The NCARDRS is consist of 10 reporting regions (Figure 3).

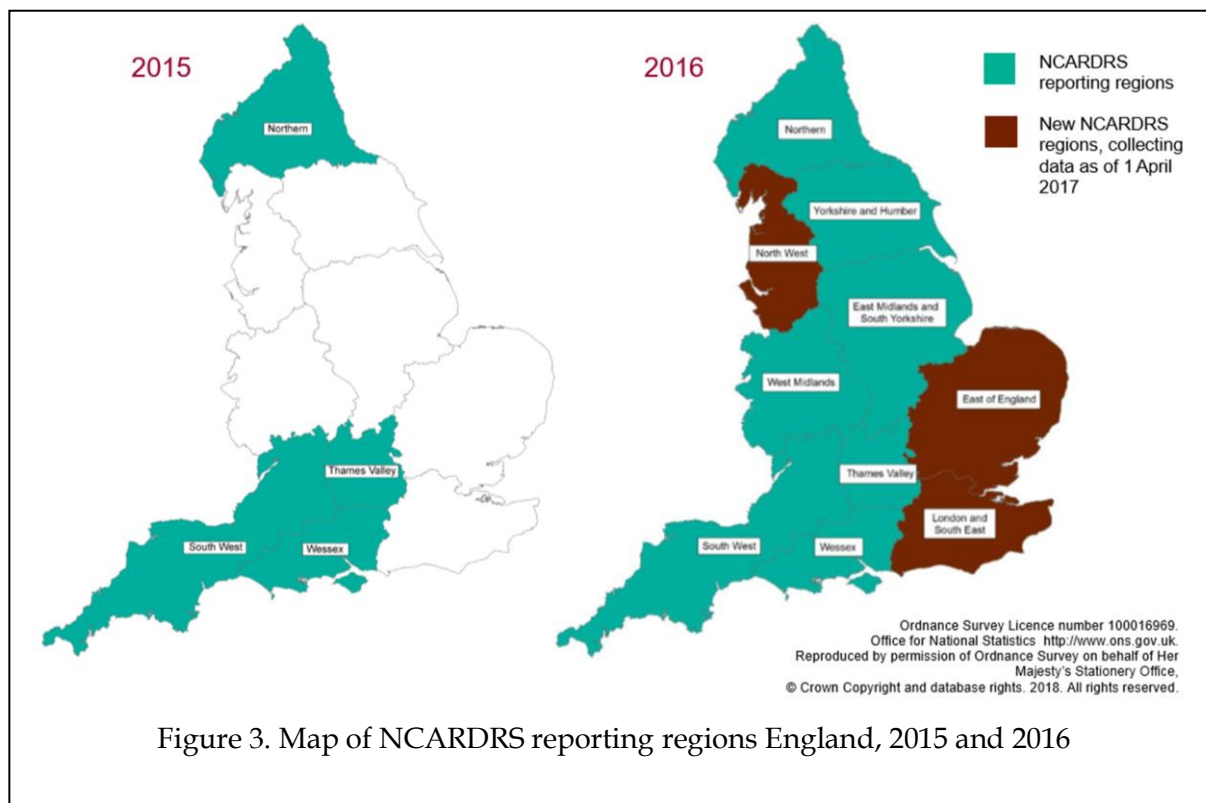


Figure 3. Map of NCARDRS reporting regions England, 2015 and 2016

13. Population Screening: Evidence and Guidance
14. Population Screening: Quality Assurance

Supporting the effort to prevent the birth defects, the Public Health England launched National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) on 1 April 2015.⁴⁹ The

The data collections are helpful to people to understand the congenital anomalies and rare diseases to help ensure that people have these conditions receive the best treatment.⁵¹ “It is essential we know how many babies are being born with anomalies and how good their survival is across the whole country, so we can identify ways to reduce the occurrence and plan for the care of

⁴⁹ NCARDRS (2018). National Congenital Anomaly and Rare Disease Registration Service: Congenital Anomaly Statistic 2016. Retrieved May 13, 2019, From https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/751553/Congenital_anomaly_statistics_2016.pdf

⁵⁰ Ibid

⁵¹ Public Health England (2019). The National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). Retrieved May 13, 2019, From https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/778951/NCARDRS_2019_leaflet.pdf,

these babies,” commented Joan Morris, Professor of Medical Statistics at Queen Mary, University of London in the report on birth defects published by Queen Mary, University of London.⁵² Preventing and treating birth defects/anomalies identified as genetic contagious, medical occupational, harmful and multifactorial are significant public health issues, not only because of the high incidence of particular demographic groups, but also because of physical, emotional and social consequences for families and societies.⁵³ Moreover, environmental and occupational exposures, as well as problems related to exposure dose, time, and other factors are also potential causes of birth defects.⁵⁴

The government effort is not only focused on the prevention through NCARDS but also protect the civil liability of the infant who born with defects. The protection was strengthened by the existence of Congenital Anomalies (Civil Liability) Act 1976. The Congenital Anomalies Act came out from the case of children born in consequence of some person’s fault as mention in the beginning of this act and also to extend the Nuclear Installations Act 1965.

2.5. Birth Defects and Congenital Anomalies Effect in Indonesian

Based on the National Health Basic Research conducted in 2010, 2013 and 2018,

⁵² Mary, Q. University of London (2011). Report Finds One in 50 Babies Has Birth Defect and Highlights Worrying Gaps in Regional Monitoring. Retrieved May 13, 2019, Form <https://www.qmul.ac.uk/media/news/2011/smd/report-finds-one-in-50-babies-has-birth-defect-and-highlights-worrying-gaps-in-regional-monitoring.html>

⁵³ Tulchinsky, T.H., 2018, *Robert Guthrie and Nicholas Wald, Case Studies in Public Health*, p. 476

⁵⁴ Yu, X., Nassar, N., Mastroiacovo, P., Canfield, M., Groisman, B., Bermojo-Sanchez, E., et al., Hypospadias Prevalence and Trends in International Birth Defect Surveillance System, 1980-2010, *European Urology*, 2019, p. 488

the case of down syndrome for a child age 24 until 59 months in Indonesia is continuously increased. In 2010, the result of the research showed that the number of down syndromes is 0.12%, 2013 in the number of 0.13% while on 2018 the percentage was increasing rapidly into 0.21%.⁵⁵

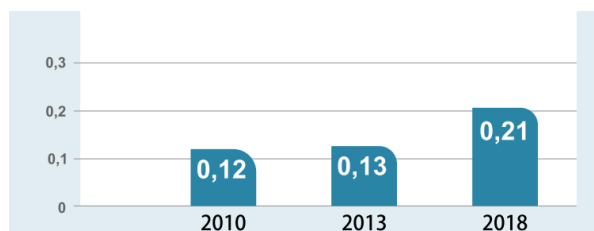


Figure 4. Down syndrome for a child

According to Global Report on Birth Defects, released by Dimes Birth Defects Foundation on 2006, The prevalence of babies with birth defects in Indonesia is 59.3 per 1,000 live births. Compared to other countries in Southeast Asia, Indonesia is still one of the countries with a high prevalence of babies with anomaly.



Sumber: Global Report on Birth Defects, March of Dimes Birth Defects Foundation, 2006

Figure 5. Prevalence of infants with congenital abnormalities

In order to decrease the number of birth defects in Indonesia, The Ministry of Health Republic of Indonesia was started to conducting sentinel surveillance on September 2014 together with 28 selected private and public Hospitals.⁵⁶ In developing

⁵⁵ Kementerian Kesehatan RI, 2019, Antara Fakta dan Harapan: Sindrom Down, Retrieved Jun 24, 2020, from <https://pusdatin.kemkes.go.id/resources/download/pusdatin/infodatin/infodatin-down-syndrom-2019-1.pdf>

⁵⁶ Kementerian Kesehatan RI, 2018, Kelainan Bawaan, Retrieved Jun 24, 2020, from

this surveillance, they choose 16 priority cases. The process of selecting the cases was based on the consideration of easy to recognize when the baby born so it can be easily diagnosed visually without any special supporting tools.

From the data that was collected since September 2014 until the end of August 2015, there were 231 babies born with birth defects with different condition and characteristic. 87% or Most of the baby were born with 1 type of defect and another 13% born with more than 1 defects.⁵⁷ Those babies from 13 hospitals was reported born with weigh < 2500 gram: baby born weight < 1500 gram (19.5%) dan born with weight between 1500-2499 gram (37.7%).⁵⁸ From the anomaly faced by the baby, the most are from musculoskeletal system (talipes equinovarus) around 22,3%, nervous system (anencephaly, spina bifida dan meningocele) around 22%, Chippy around 18,5% and omphalocele around 12,5%.⁵⁹

Aside of the report from Indonesian Ministry of Health above, another case of birth defect also occurred in some places in

<https://www.kemkes.go.id/download.php?file=download/pusdatin/infodatin/infodatin%20kelainan%20bawaan.pdf>

⁵⁷ Biro Komunikasi dan Pelayanan Masyarakat, Kementerian Kesehatan RI. (2016). 3 Maret: Hari Kelainan Bawaan Sedunia Cegah Bayi Lahir Cacat dengan Pola Hidup Sehat. Retrieved May 13, 2019, from

<http://www.depkes.go.id/article/view/16030300001/march-3-the-world-congenital-abnormalities-day-to-prevent-birth-defects-in-infant-by-healthy-lifesty.html>,

⁵⁸ Biro Komunikasi dan Pelayanan Masyarakat, Kementerian Kesehatan RI. (2016). Inilah Hasil Surveilans Kelainan Bawaan. Retrieved May 13, 2019, from

<http://www.depkes.go.id/article/view/16030300002/congenital-defect-surveillance.html>,

⁵⁹ *Ibid*: Biro Komunikasi dan Pelayanan Masyarakat, Kementerian Kesehatan RI, 2016, 3 Maret: Hari Kelainan Bawaan Sedunia Cegah Bayi Lahir Cacat dengan Pola Hidup Sehat

Indonesia and those cases are mostly caused by the environment or an external factor. The report which is delivered by the Indonesian Ministry of Health is based on the data of baby which were born in the hospital which means that it does not cover the baby with birth defects or congenital anomalies who born outside the hospital.

The case of Ipan from Sekotong is one of the examples of birth defect which is clearly caused by the external factor. Ipan currently is 16 months old and suffering his third seizure of the morning. His head is too large for his body, and his legs are as thin as sticks. He arches his back, and his limbs stiffen. He cries out in pain. Regarding the current condition of Ipan, Doctors say that the real culprit is more down-to-earth: mercury poisoning. His parents are small-scale miners who used the heavy metal to process gold for years before Ipan was born, including while Fatimah was pregnant.⁶⁰ Similarly with Ipan, In Mandailing Natal Regency of North Sumatra, Indonesia, there was a baby born with the missing an eye and a nose due to affected by the mercury. We may conclude that the baby was affected by the mercury because the baby's father was often exposed to the harmful material as he works as an artisanal gold miner. Mercury is a heavy metal that is toxic to adults. Its effects on unborn babies are thoroughly researched, often pinpointing it to be the source of birth defects and irregularities in the nervous system. The harmful material is widely used to extract gold within ore in gold mining processing sites. A United Nations Development Programme (UNDP) report

⁶⁰ National Geographic. (2016). Indonesia's Gold Mines are Causing Birth Defects. Retrieved May 21, 2019, from

<https://www.nationalgeographic.com.au/people/indonesias-gold-mines-are-causing-birth-defects.aspx>

states that Indonesia hosts among the largest number of artisanal mines globally.⁶¹

According to the Stephan Bose-O'Reilly, a children's health expert who volunteers at the Indonesian environmental group BaliFokus Foundation, Indonesia an archipelago of 17,500 islands with the world's fourth-largest population, has one of the worst mercury problems. There were 46 suspected victims of mercury poisoning identified by doctors in impoverished southwestern Lombok, and another 131 people with mercury poisoning also found on the islands of Java, Lombok, and Sulawesi.⁶²

2.6. The role of the Government in preventing and eradicating birth defects and congenital anomalies effect in Indonesia

In order to protect the health of the pregnant mother, the Indonesian government through the Ministry of Health has issued the Ministry Regulation No. 79 on the Pregnant Health Services. The law regulates the services that should be done by the doctor or nurse to the pregnant mother starting from before the pregnancy, in the pregnant period until the mother gave birth.

Aside of the protection of the mother, Indonesian government also have enacted several regulations in order to provide well protection for the child. Among those laws, are: Law No. 23 year 2002 junto Law No. 35 year 2014 on Children Protection Act, Law No. 4 year 1997 on People with Disabilities Act and others. Those kinds of laws have their own purpose. Through Children protection Act, the Government try to give more protection the child since the children

play an important role for the future as the successor of the current generation.⁶³

In the Children Protection Act has been discussed several things, but from those things we would like to concern in some issues, they are: the issue of Rights and obligation of the children which is discussed in the chapter III of this law, the issue of obligation among the children as discussed in the chapter IV in the Law and the most important one is the issue of health of the children and special protection of the children which were discussed in the part II and V of chapter the IX in this Law.

From those issue above which were specifically discussed in the Children Protection Act cannot cover the phenomenon of birth defects and congenital anomalies. The closest article which is protect the children from the condition of birth defect and congenital anomalies are in the article 46 of this law which is clearly stated that "The state, the government, families and parents are obliged to make efforts that born children are free from diseases which are life-threatening or may inflict disabilities."⁶⁴ But in fact this article has no power, since there is no penalties or such kind of obligation to those parties mentioned in the article if there is a baby born with diseases or specifically birth with defect or congenital anomaly.

The bad environment condition which were occurred in some places in Indonesia which may affected the pregnant mothers also being one of the issues which is needed to be discussed in the law. Related to the article 46, the law does not provide any preventive action upon the bad environmental condition which may cause the baby born with defects. The law only provides special protection to the children

⁶¹ The Asian Parent. Newborn with mercury poisoning lives for just seven hours after birth. Singapore: Kevin Wijaya Oey. Retrieved May 17, 2019, from <https://sg.theasianparent.com/birth-defects-caused-by-mercury-baby/amp>

⁶² *Ibid*: National Geographic, Indonesia's Gold Mines are Causing Birth Defects

⁶³ Consideration C. Indonesian Children Protection Act 2014

⁶⁴ Art 46 of Law No. 23 year 2002 junto Law No. 35 year 2014 on Children Protection Act

with disabilities as mentioned in Article 70 Paragraph 1 in the law.

Special protection for disabled children as meant in Article 59 is conducted through acts of:

- a. treating the children humanely in line with their dignity and rights.
- b. fulfilling basic needs; and
- c. getting equal treatment as other children do in order to acquire social⁶⁵

Besides the establishment of such legislation and regulation, Indonesian government also tries to held some program to counter the spread of the congenital anomalies and birth defects. One of the programs as the prevention efforts from the Indonesian government is National Measles-Rubella Immunization Campaign. From 2017, the Indonesian Government had planned to launch the National Measles-Rubella Immunization Campaign. This campaign surely to encourage the society to have a Measles and Rubella (MR) immunization. The MR immunization will be administered to protect Indonesian children from hearing, vision and heart problems, intellectual disability and other birth defects caused by Rubella infection during pregnancy.⁶⁶

The National Measles-Rubella Immunization Campaign currently has been effectively run in java Ireland, but outside of java, there still a lot of society who are not covered by this program because the program is not well spread to another place. Another obstacle in spreading this program

⁶⁵ Art 70 paragraph 1 of Law No. 23 year 2002 junto Law No. 35 year 2014 on Children Protection Act

⁶⁶ Bureau of Communication and Public Service, Indonesian Ministry of Health. (2017). Government launches National Measles-Rubella Immunization Campaign, Retrieved April 27, 2019, from https://www.unicef.org/indonesia/media_27296.html

is, the rejection from the society due to the halal status of the vaccine. Last year, the spreading of this Immunization has been more than 95% in java Ireland, but outside of java, it is still in the number 62,7%.⁶⁷

Another program establishes by the government in order to prevent the congenital anomalies and birth defects is "program Indonesia sehat". This program aimed to increase the quality of life of the Indonesian society. As we knew that the lack of nutrition is one of the causal factors of the birth defects and congenital anomalies.⁶⁸ In order to prevent the society especially pregnant mothers from nutritional deficiencies which may affect the baby, then the government provides such kind of this program which may give equal treatment of health to the society.

Regarding on the lack of nutrition, Program Indonesia Sehat is not the only program provided by the government. There is also program which is called as "Program Keluarga Harapan" (PKH) where through this program, the government will distribute social assistance in the form of money to the impoverished family who meet the criteria.⁶⁹ Moreover, Government will provide special arrangement for family who has pregnant mother and or baby in order to fulfill the need of the pregnant mother and the babies.⁷⁰

⁶⁷ AntaraNews.com. (2018). 600 ribu bayi kemungkinan terlahir cacat bila masyarakat masih tolak imunisasi MR. Indonesia: Aditya Ramadhan, Revealed 22 May, 2019, from <https://www.antaranews.com/berita/760823/600-ribu-bayi-kemungkinan-terlahir-cacat-bila-masyarakat-masih-tolak-imunisasi-mr>

⁶⁸ World Health Organization-Regional Office for South-East Asia. (2013). Birth Defects in South-East Asia: A public health challenge. Pg. 3.

⁶⁹ Program Keluarga Harapan. Apa itu Program Keluarga Harapan. Kementrian Sosial Republik Indonesia. Revealed May 13, 2019, from <https://pkh.kemsos.go.id/?pg=tentangpkh-1>

⁷⁰ CNN Indonesia. (2019). Kemensos Kaji Bantuan Program Keluarga Harapan Cair Bulanan. Revealed May 30, 2019, from

This is one of the solutions from the government to prevent and eradicate the birth defects and congenital anomalies.

3. Conclusion

3.1. Conclusion

Indonesia already has several efforts to reduce the big number of infants born with defect either through enacting an act or establishing a program. Even so, Indonesia still has the big number of birth defect and death due to the birth defect which showed in the Global Report on Birth Defects which published by March of Dimes (MODB) compared to the United States and the United Kingdom. The data shows birth defect occurred 59,3 per 1000 birth in Indonesia, 47,8 per 1000 birth in the United States, and 43,8 per 1000 birth in the United Kingdom.

3.2. Recommendation

To begin with, in order to reduce the big number of infants born with a defect, Indonesia needs to establish a surveillance program. Clearly, the surveillance program has the significant role in reducing the big number of birth defect issue as happened in the United States and the United Kingdom. The United States has population-based birth defects surveillance program established by the Center for Disease Control and Prevention (CDC) that tracking birth defects using population-based. Then, the United Kingdom has National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) with aims to improve data collection over the service to be able to report various indicators to increase knowledge on possible risk factors which influence the congenital anomalies and rare diseases. The surveillance program is very helpful in order to reduce the big number of babies born with defects. Moreover, it is essential to know how

many babies are being born with anomalies and how good their survival is across the whole country, so the state can identify ways to reduce the occurrence and plan for the care of these babies.

Moving forward, Indonesia also needs to rule the protection upon the infant born with a defect in consequence of some person's fault or external factors. The aim is to make a provision as to civil liability in the case of an infant born disabled in consequence of some person's fault. The United Kingdom has Congenital Anomalies Act 1976, it's the example of the protection upon the infant born with a defect in consequence of some person's fault or external factors.

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