The Development of a Best Practice Model to Support Young Children with Disabilities Affected by Environmental Risk Factors in West Timor, Indonesia

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Thesis submitted for the degree of Doctor of Philosophy

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August 2018

ABSTRACT

Developing countries such as Indonesia face a range of environmental risk factors in relation to childhood disability. These include poverty, stigma, inadequate interaction with parents, violence and neglect, and limited access to basic services, particularly for those living outside urban areas. As such, this thesis aims to develop a best practice model that can be adapted by stakeholders working with young children with disabilities affected by these risk factors in rural Indonesia. Achieving this aim could contribute to the prevention of complications arising from early childhood disabilities and ensure that children with disabilities are well placed to participate in the broader community when they become adults. This thesis focused on West Timor, a rural and underdeveloped area in Indonesia facing significant challenges to reduce environmental risks.

Study one (chapter three) comprised a scoping review of the literature, investigating interventions with an aim to support the development of young children with disabilities in Indonesia. This review identified eight studies, all of which were limited in terms of methodological quality. A key finding of this review was the use of interventions in many studies that utilized local resources while addressing broad aspects of child development. In order to broaden the knowledge about effective interventions for young children with disabilities, *study two* (chapter 4) comprised a systematic review of the literature to identify interventions addressing environmental risks faced by young children with disabilities in developing countries more broadly. A total of 48 studies met the inclusion criteria. A synthesis of these studies indicated that the impact of environmental risk factors on young children with disabilities might be addressed by providing disability screening services, community-based interventions, targeted services and inclusive basic services. In addition, some key barriers and facilitators were identified.

Study three (chapter five) involved the qualitative examination of community perceptions about disability, environmental risk factors and available services. Responses from 23 parents and 15 local leaders including a midwife, headmaster, priest, and staff from government and non-government organisations were collected via semi-structured interviews and photovoice. The study highlighted the importance of local culture and religion in influencing the perceptions of disability and environmental risk factors in West Timor.

Using an Implementation Science approach to enhance transferability of findings, results from these first three studies were then integrated into a holistic model in *study four* (chapter six) for addressing the needs of young children with disabilities affected by environmental risk factors in developing countries. Fifty-five local leaders, including kindergarten teachers, Sunday school teachers and community health centre workers, participated in focus groups, while 35 key participants were interviewed to collect additional data. Forty-one activities and programmes suggested by the literature reviews and community opinion formed the basis of a best practice model. These activities were also supplied with implementation strategies to help stakeholders in adapting the activities to ones which could be applied within specific organisations. In total, this thesis provides an evidence-based model which can be used by practitioners and policymakers in developing countries when working with young children with disabilities.

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DECLARATION

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma, in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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Published works:

Study one (chapter three):

Kiling, I. Y., Due, C., Li, D. E., & Turnbull, D. (2018b). Interventions supporting development of young children with disabilities at environmental risk in Indonesia: a scoping review. SAGE Open, 8 (1). doi: 10.1177/2158244018754935

Study two (chapter four):

Kiling, I. Y., Due, C., Gyss, C., Li, D. E., & Turnbull, D. (2018a). Intervention research addressing environmental risk threatening young children with disabilities in developing countries: a systematic review. Disability and Rehabilitation. doi: 10.1080/09638288.2018.1509142

Study three (chapter five):

Kiling, I. Y., Due, C., Li, D. E., & Turnbull, D. (2018c). Perceptions of disability, environmental risk factors and available services among local leaders and parents of young children with disabilities in West Timor, Indonesia. Disability and Rehabilitation. doi: 10.1080/09638288.2018.1466924

Indra Yohanes Kiling

Signed: Date: 1 August 2018

ACKNOWLEDGEMENTS

First and foremost I would like to thank my supervisors, Professor Deborah Turnbull, Dr Clemence Due and Dr Dominggus Elcid Li. You have fostered my skills and learning in many ways, while coping with my numerous limitations. The thesis reflects supportive guidance, detailed feedback and valuable ideas. Thank you for your efforts and time over the last four years. I am truly indebted to you, and hope we will work again in the near future.

I would also like to thank the Indonesia Endowment Fund for Education for providing me with a full scholarship to complete this research. The allowances have covered almost every need necessary to complete the degree, and the networking of the scholarship has given me countless study and career opportunities.

I acknowledge the contribution of Dr Diane Brown for copyediting this thesis, in accordance with the *Australian Standards for Editing Practice* (2013) and the national ACGR/IPED guidelines.

Thank you to Ethel, Clare, Amber, Christianna, Julia and Victoria as my office mates, the PPIA and GoLive Indonesia family in Adelaide for supporting me throughout the research, and to Sudarmadi, Wandono, Rinni, Dea, Berti, and the BUNGA research community for supporting my fieldwork.

I would like to thank my wife Beatriks and my son Giovanno. Writing this thesis was really difficult when you guys were not around, and when you were, it became so much fun. Thank you Beatriks for doing many things to help me cope with stress, including travelling overseas together, and letting me play video games. Your endless love brings harmony in our family, even though you have huge responsibilities in your career. Gio, thank you for all the kisses, hugs, and huge smiles you give your mom and me. You have given me and Beatriks the best four years of our lives, making the whole PhD programme an adventure, full of happy memories. Having you both in my life is living proof of how gracious God has been to me.

Thank you for my father Johny Kiling and mother Janny Rombot for being role models, and for your endless support and prayers. I would not be able to reach this highest academic degree if it was not for the constant education you provided since I was just a little person. The same gratitude goes to my parents-in-law, Hendrik Bunga and Mathelda Tallo for constant prayers given. Thank you also to my older brother, Erwin Kiling, for your constant support and for taking care of our parents all this time; I owe you a lot man.

I believe Jesus Christ has blessed me and my family, and I am grateful for that, and for many blessings to come.

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KEY TO ABBREVIATIONS

ASD	Autism Spectrum Disorder
CBR	Community-Based Rehabilitation
DPO	Disabled People's Organisation
ECED	Early Childhood Education and Development
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health for Children and Youth
JUG	Joined-Up Government
NGO	Non-Governmental Organisation
PND	Percentage of Non-overlapping Data
SEARO-WHO	South-East Asia Regional Office–World Health Organization
TEOAE	Transient Evoked Oto-acoustic Emissions
UN	United Nations
UNICEF	United Nations Children's Fund
WHO	World Health Organization

DEDICATION

For Beatriks and Giovanno

OVERVIEW

Thesis outline

The research presented in this thesis investigated issues related to young children with disabilities in West Timor, Indonesia and developed a best practice model in order to support them. The thesis presents a novel attempt to invent a holistic and consumer-driven model, using a rigorous methodological approach to build on a set of activities that can be implemented by practitioners and policymakers. Specifically, chapter one provides an introduction and literature review in the field of young children with disabilities, especially in the Indonesian context. Chapter two provides an exegesis, which aims to elaborate the research methodology and decisions made that influence the overall research. Chapters three to six present the four independent studies, which together provide a robust evidence base for both the current state of research concerning interventions for young children with disabilities in Indonesia and other developing countries, as well as the lived experiences of families and stakeholders working or living with this group of children, and finally a best practice model for practitioners and policy makers providing interventions in this area. Finally, chapter seven offers a critical discussion of the research findings, and their strengths and contributions for policymaking and service provision.

Candidature

This thesis was conducted to fulfil the requirements of the Doctor of Philosophy degree undertaken at The University of Adelaide, South Australia, Australia. The programme is expected to be completed in four years of full-time candidature. The four papers that form this work were completed within three years of full-time study. The PhD programme was fully funded by a scholarship from the Indonesia Endowment Fund for Education. Support funding of $1300 was provided by the School of Psychology to fund travel for two conferences. A total of $5016 was provided by the Indonesia Endowment Fund for Education to fund data collection in Indonesia.

CHAPTER ONE INTRODUCTION AND LITERATURE REVIEW

1.1 Preamble

This first chapter introduces the topic of young children with disabilities in developing countries, with a specific focus on West Timor, Indonesia. Disability is a global concern particularly considering the high rates of worldwide prevalence, at approximately 15% or about 1 billion people, with around 93 million or 5% of children aged 0 to 14 meeting criteria for having a disability (WHO, 2011). Developing countries such as Indonesia face a range of challenges relating to childhood disability, particularly in relation to environmental risk factors such as poverty, stigma and discrimination, inadequate interaction with parents or caregivers, violence, abuse and neglect, and limited access to basic services (WHO, 2012b), and this additional risk is illustrated by the fact that there are estimated to be more than 200 million children in developing countries who face challenges related to development (Grantham-McGregor et al., 2007). Given that environmental risk factors can be reduced with appropriate intervention, early intervention programmes are needed to reduce the probability of young children with disability experiencing developmental delays or other negative outcomes. Such programmes are particularly needed in rural areas due to the threat of various common environmental risks associated with remote locations, such as the challenge of service provision (Mishra & Gupta, 2006).

Until now, information about best practice regarding child health in Indonesia has been limited to health programmes related to malaria, avian influenza, nutrition, and child mortality (UNICEF Indonesia, 2010), with some attention also being paid to childhood education (International Labour Organisation & World Bank, 2012; Wahab, 2005). In addition, while the National Plan of Action for People with Disabilities 2004–13 was developed in 2004 to address eight priority areas for people with disabilities in Indonesia (including early detection, early intervention and education), this plan has been considered poor in achieving better outcomes for people with disabilities (Adioetomo, Mont & Irwanto, 2014). Moreover, there is currently no specific focus on appropriate interventions, models or support for young children living with disabilities in Indonesia.

As such, research concerning the development of a best practice model to support the development of young children with disabilities needs to be a priority in Indonesia, particularly for those living in rural areas. In this context, supporting young children with disabilities means addressing their needs in a holistic fashion, including their overall level of functioning, development, and wellbeing (WHO, 2011). Therefore, a model aimed at supporting the needs of young children with disabilities in developing countries should be similarly holistic, covering health, education, and social areas, while also being consumer driven so as to be used and adapted by practitioners and stakeholders. The model should also include both best practice- and community-defined evidence to improve effectiveness. Community-defined evidence means interventions that are considered effective and socially accepted in a community (Johnson, Walters & Armstrong, 2015).

To identify and build evidence for such a best practice model, this thesis used an approach influenced by participatory action research principles involving community members in West Timor to improve ownership and future sustainability of the model, with the goal of building a model that could then be applied to other rural areas in Indonesia, or to other countries that deal with similar issues. More generally, the research outlined in this thesis follows calls for a greater evidence base for interventions for young children with disabilities from both the World Health Organization (WHO) and The United Nations Children's Fund (UNICEF) (WHO, 2012b).

This chapter begins by outlining four contributing studies to the thesis followed by key concepts. A review of the recent literature includes disability in Indonesia and the West Timor context and rationale for the research, followed by a review of environmental risk factors related to disability. Current early intervention programmes in developing countries and Indonesia are reviewed subsequently. These theoretical and conceptual frameworks are presented to establish a foundation for the research. Lastly, a review of the current gaps in the literature and resulting aims of the thesis are presented.

1.2 Key concepts

1.2.1 Disability

As a complex concept, the definition of disability has shifted from a "medical model" to a "social model". Previously understood as an individual medical condition, the social model of disability emphasizes systemic barriers, stigma and discrimination as the main contributory factors to the overall wellbeing of disabled people (WHO, 2011). In need of a more balanced approach, The International Classification of Functioning, Disability and Health (ICF) of the World Health Organization (WHO) developed a "bio-psycho-social" model of disability, defining it as an umbrella term for impairments, activity limitations and restrictions on community participation. As such, disability can be seen as the interaction between an individual's health condition, and other personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social support) (WHO, 2013). The ICF highlights environmental factors in creating disability, and notes that disability can occur at three levels (WHO, 2012b):

(1) Impairments are problems in physical function (e.g. blindness or deafness).

(2) Activity limitations are difficulties in carrying out activities (e.g. walking or taking a bath).

(3) Participation restrictions are problems with involvement in any area of life (e.g. facing discrimination in school or employment).

Accordingly, the United Nations (UN) Convention on the Rights of Persons with Disabilities states "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006). These definitions have become the foundation for many regulations and research in many countries worldwide, including Indonesia (Ministry of Social Affairs and Ministry of Health, 2009; WHO, 2011).

Despite present holistic approaches to understanding disability, it is worth highlighting that in the past, disability in Indonesia has not been clearly defined, with previous surveys and census materials defining disability in several different ways. For example, The National Socioeconomic Survey conducted in 1995 exclusively defined disability as impairments, while the National Socioeconomic Survey conducted in 1998 defined disability as both impairments and activity limitations (Irwanto, Kasim, Fransiska, Lusi & Okta, 2010). Moreover, different ministries also have different views on definitions of disability. The Ministry of Health, for example, defines disability as "the loss or abnormality of function or structure of the anatomy, psychology and physiology". However, the Ministry of Social Affairs, according to Law No. 4 of 1997 views disabled people as "individuals who have physical and/or mental abnormalities that can interfere or hinder him properly to perform activities" (Trisnowati, Sunusi, & Handayani, 2013). These differences in collecting and presenting data between the Ministry of Health and the Ministry of Social Affairs can be problematic in defining disability in the Indonesia context. The Ministry of Social Affairs, for instance, often associates disability with poverty while the Ministry of Health emphasizes physical conditions. A more comprehensive and collaborative approach between related stakeholders is needed. More recently, the ICF's classification was used by both relevant ministries in 2007 and 2009 (Isfandari, 2009; Kementerian Sosial RI, 2009), and Law No. 19 of 2011 (Presiden Republik Indonesia, 2011) for the first time legalizes the UN Convention on the Rights of Persons with Disabilities and became the main reference until 2016 when Law No. 8 of 2016 which regulates people with disabilities was enacted (Presiden Republik Indonesia, 2016).

1.2.2 Young children and early childhood

Internationally, early childhood is considered to span the pre-natal period to eight years of age (WHO, 2012b). This definition is used in this thesis to categorize young children. In Indonesia, however, young children are categorized from zero to six years of age (Presiden Republik Indonesia, 2003). It is worth noting that this difference in age range could lead to practical problems, since primary school students in Indonesia start at seven years of age, meaning students in first and second grade will not be able to access early childhood care services. These students are still in need of early childhood care because in rural parts of Indonesia like West Timor, primary school teachers focus more on the sixth grade with less attention paid to first and second grades.

Beside early childhood care, quality, nutrition, protection and attachment at home also play a significant role in shaping young children’s development (UNICEF Indonesia, 2010; Zevalkink, Riksen-Walraven & Bradley, 2008). Nurturing the development process of young children will form the basis for life-long participation and learning, while simultaneously averting developmental delay and disabilities (WHO, 2012a). Simply put, early childhood is the period of greatest risk and greatest opportunity. These children are vulnerable to environmental risk and can benefit from supportive intervention (World Bank, 2009).

1.2.3 Early childhood development

Early childhood development refers to a child’s cognitive, social, physical and emotional development (WHO, 2012b). It is a dynamic process ranging from dependency on parents or caregivers in early childhood to independence in adulthood (WHO, 2007a). In order to develop their capacity to become independent, young children need developmental stimulation (e.g. cognitive, social, physical and emotional). Young children who experience little to no stimulation caused by environmental factors (e.g. familial circumstances, malnutrition) may experience developmental delays (WHO, 2012b). If not addressed properly this could lead to disability, thus highlighting the importance of addressing the needs of young children’s development during critical developmental periods.

1.3 Context and rationale for research

1.3.1 Indonesia and West Timor

The Republic of Indonesia (usually known as Indonesia) is a country in South-East Asia located between the Asian and Australian continents (see Figure 1.1). Consisting of 17.508 islands, this country's population in 2006 was 222 million (Kementerian Sekretariat Negara Republik Indonesia, 2010).

Figure 1.1: Location of Indonesia (Wikimedia Commons, 2011)

Indonesia consists of various ethnic, linguistic, traditional and religious diversities. Javanese is the most dominant ethnicity, relating to the fact that the island of Java is the most developed region in Indonesia (Kementerian Sekretariat Negara Republik Indonesia, 2010). Development in other parts of Indonesia, especially Eastern Indonesia has been slow from independence in 1945 until the 2000s (Rikang, 2014; Soekirman, 1991). The newly elected President in 2014, Joko Widodo, declared that Eastern Indonesia would become his priority in development policies (Rikang, 2014). Various foreign aid agencies, such as the New Zealand Aid Programme (NZAID), United States Agency for International Development (USAID), and Australian Agency for International Development (AUSAID), have also consistently made Eastern Indonesia a primary target for their international aid policies, emphasizing the importance of this region in relation to trade (Ministry of Foreign Affairs and Trade, 2011; Tapp, 2011; USAID, 2013) as well as humanitarian concerns.

The Indonesian Government uses the term ‘Eastern Indonesia’ to cover all those islands outside Java, Sumatra, Bali and Madura, more specifically provinces in Kalimantan, Sulawesi, East Nusa Tenggara, West Nusa Tenggara, Maluku and Papua (Asian Development Bank, 1993). East Nusa Tenggara province had the third worst human development index ranking compared to other provinces from 2011 to 2016 (Badan Pusat Statistik, 2017).

East Nusa Tenggara has many islands; some of the bigger islands are Sumba, Timor, Flores, Alor, Rote and Savu. The island of Timor is divided into two regions: East Timor which has gained independence from Indonesia and become Timor Leste, and West Timor which belongs to East Nusa Tenggara Province (see Figure 1.2) (Jones, Nagib, Sumono & Handayani, 1998). Composed of five regencies and one municipality, West Timor has 1.8 million people that contribute more than one-third of the total population of East Nusa Tenggara (Badan Pusat Statistik – Statistics of East Nusa Tenggara Province, 2017).

Figure 1.2: Map of West Timor, which borders Timor Leste (Source: Google Maps)

The majority of West Timor’s population belongs to a group known as the *Atoni* or the *Atoni Pah Meto* (native land people/people who stay on dry land). They were also known as *Dawan* (Highlander) by fellow indigenous West Timorese, the Belunese. They are mostly located in the western and central parts of West Timor (Ormeling, 1956). The second largest group is the *Belu*, known also as the *Tetun*. They live mainly in the eastern part of West Timor and on the other side of the border in East Timor as the majority. The last group considered to be indigenous to West Timor is the *Helon*. They were living in the Kupang city area, before they were driven back during the war between the Dutch and tribes from the highland. The *Helon* now live mainly on Semau Island (Ormeling, 1956). Nowadays, significant numbers of immigrant populations are also established in West Timor, especially in Kupang City, mainly ethnic Chinese and people from the neighbouring islands of Roti, Savu, Flores and Sumba (McWilliam, 2002).

1.3.2 Disability in Indonesia

In 2009, the number of people with disabilities in Indonesia was over 3 million (Ministry of Social Affairs and Ministry of Health, 2009), and the demand for social and health services is rapidly increasing (Dowd & Manton, 1992). Based on data from Central Data and Information on Social Welfare, Ministry of Social Affairs in 2007, there were 295,763 children with disability in Indonesia, around 66,425 children with disability had access to special education, and 10,341 had access to inclusive education. That leaves over 200,000 children with the possibility of little or no education access (Ministry of Social Affairs and Ministry of Health, 2009). This is also true according to WHO survey results; the gap in primary school attendance rates between children with disability and children without disability is 60% in Indonesia; these gaps are considered among the worst across 51 countries that participated in the survey (WHO, 2011). Importantly, however, these figures are likely an underestimation since many parents may not report that they have a child with a disability due to reasons related primarily to stigma and shame (Trisnowati et al., 2013). As a result, many children with disabilities may not be identified in these figures, or receive much needed services (WHO, 2011).

Despite the potential for under-reporting, disability in Indonesia has a significantly higher prevalence when compared to other countries in South-East Asia, which have similar economic backgrounds (see Table 1.1).

Table 1.1 Estimates of disability from available survey data or country census for different years (SEARO-WHO, 2013)

Country	%	Year
Bangladesh	5.6	2005
Bhutan	3.4	2005
Democratic People's Republic of Korea	3.4	2007
India	2.1	2001
Indonesia	21.3	2006
Maldives	4.7	2010
Myanmar	2.4	2009
Nepal	1.6	2001
Sri Lanka	2.0	2001
Thailand	2.9	2007
Timor-Leste	1.5	2006

Two more recent data sources provide estimates of the prevalence of disability: the 2007 Riskesdas (basic health research) household survey and the 2010 national census (Adioetomo et al., 2014). The overall rate of disability according to the 2007 Riskesdas data is approximately 11.05%, while 2010 Census concluded that only around 4.3% of the population have a disability. Differences in defining disability and survey questions and response categories could be the reason for these variations in estimates (Adioetomo et al., 2014). When comparing the set of questions used in both research projects, it was found that similar questions were used, as recommended by the UN, with the exception that the 2010 Census had less detail, due to combined questions and fewer response categories, while 2007 Riskesdas used more extensive questions, especially in investigating various types of physical functionality such as seeing, hearing, mobility and self-care. Findings from 2007 Riskesdas confirmed that the prevalence of disability in Indonesia is similar to the average of most countries (15%); more importantly, it also highlighted dramatic differences across provinces. The data showed that people in Jakarta pose a lower risk of having a disability compared to those in rural provinces such as Gorontalo, Central Sulawesi, and East Nusa Tenggara Indonesia (Adioetomo et al., 2014).

Mobility is the most common disability in Indonesia, while intellectual disability is the least prevalent, behind speech and hearing, and visual impairment (SEARO-WHO, 2013). This is also consistent with data from Statistic Centre Bureau of Indonesia (INFODATIN, 2014; Irwanto et al., 2010). This could be due to the fact that mobility disability can be easily detected while intellectual disability is harder to identify, remains stigmatised, and tends to be hidden from the community.

Some current important laws and regulations concerning a person with a disability in Indonesia are as follows (Kusumastuti, Pradanasari & Ratnawati, 2014):

(1) Law No. 4 of 1997 concerning people with disabilities. This law emphasizes that equality and non-discrimination are important to improve services and access for people with disabilities. It prescribes their rights in health, education, employment, equality in development and access to results of development, rehabilitation and social welfare.

(2) Law No. 23 of 2002 concerning child protection. This law regulates issues for children with disabilities. It covers their rights to regular and special education, special protection, social welfare, to be treated the same as other children, and to achieve individual development and social inclusion.

(3) Law No. 11 of 2009 concerning social welfare. This law considers people with disabilities as those with problems and social dysfunction. The term ‘social dysfunction’ is controversial, since it could disable people with disabilities and exclude them from the community.

(4) Law No. 8 of 2016 concerning people with disabilities. This is the most recent law that regulates comprehensive issues on people with disabilities in several areas including health, education, etc.

There are several ministries with activities relevant to disability issues. These include: the Ministry of Health; the Ministry of Social Affairs; the Ministry of Education and Culture; the Ministry of Law and Human Rights; the Ministry of Manpower; the Ministry of Public Works and Public Housing; the Ministry of Female Empowerment and Child Protection; the Ministry of Village, Disadvantaged Regions and Transmigration; the Ministry of Transport; and the Ministry of Youth and Sports Affairs. Even though there are many related ministries, the Ministry of Social Affairs has been entrusted through Law No. 8 of 2016 as the focal point in handling issues concerning people with disabilities (Presiden Republik Indonesia, 2016). The ministry's main objective is to provide rehabilitation and social services in order to help people with disabilities to function in social life. The challenge arises from the fact that most programmes are developed to eradicate poverty, with less concern for health and education matters. Organisations concerned with disability issues also state that the Ministry of Social Affairs should not be dealing with multifaceted issues of disabilities in isolation (Adioetomo et al., 2014). A reassessment of people with disabilities and their needs would ensure that health and education issues are also addressed in future.

1.3.3 Disability in West Timor

In terms of disability in West Timor specifically (the focus of this thesis), there were 30,400 people with disabilities in East Nusa Tenggara in 2017, while in West Timor there were 9,353 persons. Furthermore, there are 5,775 children with disabilities in East Nusa Tenggara, and there are as many as 1,236 children with disabilities in West Timor (Badan Pusat Statistik – Statistics of East Nusa Tenggara Province, 2017). Again, it is predicted that the actual numbers are higher due to under-reporting for the same reasons as those outlined above. Data from 2007 Riskesdas showed that the disability rate of females in rural areas of East Nusa

Tenggara is about 34.5%, slightly higher than males in rural areas, which is 29.7% (Adioetomo et al., 2014). The data reflect a high prevalence of disability in rural areas of East Nusa Tenggara.

Moreover, children in developing areas such West Timor are exposed to multiple risks, including poverty, malnutrition, and poor education which can harm motor, cognitive, and social–emotional development (Durkin, 2002; Grantham-McGregor et al., 2007). As a result, children in West Timor are prone to health conditions because of the low level of modern sanitation access (Li et al., 2013). For example, malaria is prevalent in West Timor, and urgent intervention is needed (Walker et al., 2007). Poor ventilation and indoor smoke pollution from internal fires used for cooking in *Ume kbubu* (traditional houses), is believed to play a significant role in poor respiratory health. However, the house is essential to the Dawan's ethnic (an indigenous ethnic in West Timor) identity and sense of psychological wellbeing (Windi & Whittaker, 2012). Indigenous children in West Timor are also vulnerable to the practices of modern-slavery and human trafficking. Driven by their motivation to escape these poor and unsafe conditions, many children are sold or encouraged by their parents to work in Kupang city, or outside of Timor. This is because children are prone to violence and sexual abuse in their workplace (Li et al., 2014).

1.3.4 Rationale for the current research

Given the above, it is clear that there are multiple risk factors facing children in West Timor, and the prevalence of disability is high. Given this, the rationale for this research is based mainly on the global agenda for disability outlined by both WHO and UNICEF in 2012 (WHO, 2012b), which state that there is an urgent need for evidence-based best practice in supporting early childhood development for children with disabilities, especially in developing countries which generally have more environmental risk factors.

1.4 Environmental risk factors and disability

1.4.1 Environmental risk factors

Young children's development is affected by a range of environmental factors, some of which protect and others damage developmental outcomes. The WHO defines environmental risk factors as "the physical, social and attitudinal environment in which people live and conduct their lives" (WHO, 2007b, p. xvi). They also provide examples of such risks, including: limited financial resources; stigma and discrimination; poor interaction with parent/caregiver; violence, abuse and neglect; and restricted access to various services, each of which is outlined further in this section (Guralnick, 2013; World Health Organization, 2012b). This is believed to play a part in the fact that disability prevalence is increased through early childhood (Spencer, Blackburn, & Read, 2009) and prevalence is higher in rural compared to urban areas (Tseng, Lai & Guo, 2015). Other research has also highlighted the impact of environmental risk factors. For example, a recent systematic review has identified the home literacy environment and familial socio-economic status as life-long predictors of reading skills (Mascheretti, Andreola, Scaini & Sulpizio, 2018). Poor housing environment such as subdivided housing units and air pollution have also been strongly associated with disabilities in children (Margai & Henry, 2003). By modifying the child's environment, the experience of disability will similarly be altered, leading to the imperative to consider interventions which assist children at the environmental level (Hafon, Houtrow, Larson & Newacheck, 2012; Rauch & Lanphear, 2012).

1.4.1.1 <u>Poverty</u>

Young children who experience poverty face a range of difficulties that may affect their wellbeing or contribute to an existing disability, including difficulty accessing adequate education and health services (David et al., 2014; WHO, 2011). In particular, poverty could lead to poor family and health functioning, and may affect social-behavioural and cognitive outcomes for children with disabilities (Allen et al., 2014; Hsiao, 2014). In addition, poverty could lead children to experiencing disability due to significant exposure to various risks like malnutrition, poor sanitation, illness, homelessness, violence and institutionalization (WHO, 2012a). Poor health, behavioural and cognitive outcomes can lead to or exacerbate multiple disabilities for children. As noted bye Yeo and Moore (2003), poverty therefore leads to a "vicious circle" (WHO, 2012b). It is known that poverty may increase the probability of disability and may also become a consequence of disability (WHO, 2011; Yeo & Moore, 2003).

In addition, poverty often goes hand in hand with other environmental risks that potentially damage children's developmental processes (Guralnick, 2013), which is often the case in developing countries (WHO, 2011). For example, families with children with disabilities will also be more likely to experience financial disadvantage due to the additional cost and effort it takes to support their needs (Filmer, 2008; Stabile & Allin, 2012; WHO, 2011). One potential intervention is therefore to improve access to services such as education and health, because these sectors can be instrumental in boosting financial resources and breaking the poverty cycle; an issue explored further throughout this thesis (Irvine, 2015a; Peterson, Mayer, Summers & Luze, 2010).

Further supporting the issue of poverty is the fact that data from 18 developing countries has shown that in most countries, a larger percentage of children with disabilities belong to families who are less wealthy (UNICEF & University of Wisconsin, 2008). Analysis of World Health Survey data that included 15 developing countries supports the results, that disability is significantly associated with poverty in developing countries (Mitra, Posarac & Vick, 2013). Meanwhile recent analysis from Indonesia also concluded that disability and poverty are positively correlated. The study also highlighted that poverty rates differ between people with and without disabilities and rates are higher in rural areas compared to urban areas. This could be affected by various factors such as impact of disability on household earnings and survival rates. Thus further research is needed to investigate the complex contextual relationship between poverty and disability in Indonesia (Adioetomo et al., 2014).

1.4.1.2 Discrimination and stigma

Discrimination is one of the main pillars of the "social model" of disability outlined above. Whether it is purposely or inadvertently the case, stigma, discrimination, negative attitudes and exclusion all impact children with disabilities and their families (Nowicki, Brown & Stepien, 2014; UNICEF, 2007, 2013; WHO, 2011). The UN Convention on the Rights of Persons with Disabilities defined discrimination as any exclusion or restriction on the basis of disability that aims to impair or annul recognition, on an equal basis with others of all human rights (United Nations, 2017). It is precisely because of such discrimination and stigma that children with disabilities are often isolated from mainstream service provision like health and education services. Children with disability will often be powerless to protect their rights due to discrimination and marginalization (UNICEF, 2007). Children's and their parents' self-esteem may decrease; they may have poor education and health outcomes and are at risk of violence and exploitation (Chiu, Yang, Wong, Li & Li, 2013; UNICEF, 2013; WHO, 2011).

Stigma may be conceptualized in terms of self-stigma (e.g. low self-esteem and shame) or public stigma (e.g. prejudice from the community), both commonly found in people with disabilities (Brakel et al., 2012). Public stigma is associated with discrimination, which means an unjust act based on early negative prejudice. For example, children with autism spectrum disorders (ASD), children that live in secluded and rural areas and/or live in conflict zones may be more vulnerable to marginalization than others (Irvine, 2015a; Werner & Shulman, 2015). More stereotypes, withdrawal and social distance are also found in people with intellectual disability compared to those with physical disability (Werner, 2015). Stigma and discrimination for people with disabilities are indiscriminately happening across the globe, in both developed and developing countries (Kayama & Haight, 2014; Parsons, Bond, & Nixon, 2015), including in Indonesia (Adioetomo et al., 2014).

Evidence in Indonesia shows that stigma and discrimination are major determinants of social participation and disability. Discrimination triggers refused medical care, not being admitted to school, and refused employment that severely affects the health and education status of people with disabilities (Brakel et al., 2012). For example, some students in South Sulawesi, Indonesia could not access a higher education level than elementary school because their parents were infected with leprosy. This lack of understanding and awareness is one of the major triggers of stigma and discrimination in Indonesia (Adioetomo et al., 2014). Various stigma-causing myths about people with disabilities are also prevalent in Indonesia, especially in rural areas (Irwanto et al., 2010). While in Jakarta, the capital of Indonesia, and other urban areas worldwide, disability is also associated with obesity which can cause greater discrimination, again pointing to the interaction between environmental risk factors (Grondhuis & Aman, 2014; Slevin, Truesdale-Kennedy, McConkey, Livingstone & Fleming, 2014; Tamin, Idris, Mansyur & Syarif, 2014).

1.4.1.3 Poor interaction between the child and caregiver/parents

Quality interaction between the child and caregiver usually weaken when a child has a disability, particularly in socially disadvantaged areas (Banks et al., 2001). High costs and support needs plus social and economic difficulties interact to create a stressful environment for the parent/caregiver (Norlin, Axberg, & Broberg, 2014; Wieland, Green, Ellingsen & Baker, 2014), especially for mothers who are often primary carers (Emerson & Llewellyn, 2008; Samadi & McConkey, 2014), although fathers too will have a heightened risk of mental health problems (Giallo et al., 2015), with the quality of interactions also impacted by children’s symptom severity (Berkovits & Baker, 2014). The stress experienced can deplete physical and mental health, reduce life-satisfaction, and also trigger divorce and abandonment among parents of children with disabilities (Fianco et al., 2015; Kwok, Leung & Wong, 2014; Lovell, Moss & Wetherell, 2015; Miodrag, Burke, Tanner-Smith & Hodapp, 2015; Reichman, Corman, & Noonan, 2008).

Parents of children with disabilities in developing countries experience more pressure in parenting their children in their community caused by various factors such as isolation.

Parents also have the challenge of raising their children by not using typical parenting practices, considering their children's special needs, which could potentially make the situation worse (Santos, Jeans, & Corr, 2016). A longitudinal study also found that poor interaction would also be more likely to happen with parents of children with developmental delays (Fenning, Baker, Baker & Crnic, 2014). The idea of improving parent–child interaction in the case of children with disabilities through intervention has proven difficult, with current evidence showing a rather unsuccessful rate, suggesting the need for further evidence in this area (Suma, Adamson, Bakeman, Robins & Abrams, 2016).

Interaction with siblings is also important for children with disabilities. Problems can arise in sibling relationships due to various family factors such as management, effort and ability, parental mutuality, family functioning and social support (Choi & Riper, 2014). A sense of sibling understanding can give children with disabilities the social and emotional attachment they need, and help reduce the probability of violence and abuse (Lobato & Kao, 2005).

1.4.1.4 Violence, abuse and neglect

Young children are exposed to the risks of violence, abuse and neglect, especially when they have a disability (Jones et al., 2012; UNICEF & University of Wisconsin, 2008). A systematic review and meta-analysis study estimated the prevalence for violence against children with disabilities was 26.7% (Jones et al., 2012). Data in seven developing countries showed that parents of children with disabilities were more likely to report physical violence than parents in other countries (UNICEF & University of Wisconsin, 2008).

Similar to stigma and discrimination, people with mental illnesses are more vulnerable to violent acts compared to people with other kinds of disabilities (Hughes et al., 2012), which impacts their social-behavioural and cognitive development (Allen et al., 2014; Shonkoff & Phillips, 2000). Meanwhile, children with intellectual disability also face increased risk of sexual abuse compared to other groups of children (Wissink, Vugt, Moonen, Stams & Hendriks, 2015). This increased risk of violence emanates from different environments such as home and family, school, residential care, workplace (e.g. children as beggars and prostitutes), and even the broader community (Lund & Vaughn-Jensen, 2012; Pinheiro, 2006; UNICEF, 2005). For example it is still a common practice in Indonesia to neglect and shackle persons with disabilities when they are deemed uncontrollable. Recent data shows that more than 57,000 persons with intellectual disabilities in Indonesia have been shackled at least once and/or neglected in a containment room. This phenomenon is a common occurrence in both urban and rural areas, from Western to Eastern Indonesia, including East Nusa Tenggara province (Human Rights Watch, 2016). While government and non-government agencies have stated that East Nusa Tenggara, including West Timor is one of the most vulnerable provinces in terms of child violence (Aziz, 2016), detailed data on this issue are unavailable.

1.4.1.5 Restricted access to basic services

Children with disabilities have an increased risk of injury (Zhu, Xia, Xiang, Yu & Du, 2012), and they will be more likely to miss crucial vaccinations and treatment for common sickness (UNICEF, 2007), both of which severely affects their health and ability to learn important developmental skills (WHO, 2012a). Through the added influence of poor socio-economic status, they are also less likely to begin early childhood education and primary school, have less positive school experiences, and lower probability of remaining in school compared to children without disability (Aron & Loprest, 2012; McIntyre, Blacher & Baker, 2006; WHO, 2011, 2012a; Wu et al., 2015).

Further, a systematic review shows that travel between home and healthcare services is problematic for mothers of children with disabilities (Van Wyk & Leech, 2016), and non-inclusive health and education services concentrated in urban areas also contribute to excluding children with disabilities (Hees, Cornielje, Wagle & Veldman, 2014; Komardjaja, 2001, 2005; UNICEF, 2007). All of the aforementioned risks are more prevalent in developing countries (UNICEF & University of Wisconsin, 2008), including Indonesia, where access to special education, inclusive education, health services, employment, and social protection programmes has been problematic until more recently (Adioetomo et al., 2014).

In summary, risks that come from the surrounding environment can severely harm the developmental process of young children with disabilities (Emerson et al., 2014; WHO, 2012b). Many co-occurring risk factors that affect family resources are considered the most important element (Ayoub et al., 2009). More specifically, poverty is associated with discrimination, poor quality of interaction, corporate punishment, parental education and parenting competence (Ayoub et al., 2009; WHO, 2012b). Considering this issue, eliminating various risks altogether would be beneficial to young children with disabilities in their development phase, rather than addressing one risk at a time.

1.5 Early intervention

1.5.1 Intervention programme and environmental risk factors

Attention to various environmental risk factors can reduce the probability of complications and prepare young children with disabilities to enter the community when they become adults. Public health approaches differentiate: (1) primary prevention to avoid or remove the source of disability in an individual or a population; (2) secondary prevention to identify disability in the early phase in an individual or a population, or preventing its spread or reducing long-term effects; and (3) tertiary prevention to reduce the impact of an already established disability by bringing back function and reducing disability related complications (WHO, 2011). WHO and the World Bank consider primary prevention important to overall improved health of populations (WHO, 2011).

In order to support development in young children with disabilities, a twin-track approach is needed (WHO, 2011). This approach recognizes the need for mainstream services such as child care, health and education, and also access to targeted services such as rehabilitation, family-focused support, and social and psychological support (WHO, 2012a). The ICF framework (WHO, 2011) has provided many points of entry when intervening to increase activity or participation with either mainstream or targeted services (Skelton & Rosenbaum, 2010).

Questions arise from policymakers regarding an effective intervention programme for mainstream service including what programmes are effective and efficient, and whether to give programmes a focal point on a specific sector like health or education or adopt a multiple purpose or more holistic programme of intervention (UNESCO, 2006). Evidence shows that comprehensive programmes that address specific environmental risk factors while providing appropriate levels of social protection and integrated, affordable basic services are important to create a better environment for young children with disabilities (Engle et al., 2007; Lansdown, 2005; McConachie et al., 2001; UNICEF, 2012), meaning numerous but coordinated and comprehensive programmes are proven to be effective in this case.

Targeted services have many possible goals and methods. Improving awareness of disability and creating a peer-support network are strategies to help children with disabilities who are threatened with stigma and discrimination (Kiuru et al., 2013; Lindsay & McPherson, 2011). Inclusive early childhood care and education is also considered helpful in order to create inclusive communities (Engle et al., 2011; UNESCO, 2003, 2009). In addition, targeted services involving parents are also crucial to improve interaction between parents and children with disabilities and reduce rates of child abuse. Intervention at an early stage is important to improve interaction between parent and child (Boström, Broberg, & Hwang, 2009; McConachie et al., 2000; Tomlinson et al., 2014). Furthermore, prevention programmes related to caregiver-child interaction are considered best to target young children due to strong reciprocal relations between mothers and children (European Agency for Development in Special Needs Education, 2005; UNICEF, 2008; Woodman, Mawdsley & Hauser-Cram, 2015). Positive parenting is one possible way of intervention that influences the interaction between parents and children with disabilities (Ellingsen, Baker, Blacher & Crnic, 2014), while optimism has been found to be an important coping strategy for parents (Ellingsen et al., 2014; Xue, Ooh & Magiati, 2014), and social support, education and counselling for parents help to ease stress has been shown to reduce violence (Heiman & Berger, 2008; Paster, Brandwein, & Walsh, 2009; UNICEF, 2008).

Interestingly, some research indicates that parents are frequently dissatisfied with formal support received (e.g. social worker, psychologist), and often find considerable support from informal sources (e.g. spouses/partners, their other children, friends) (Kenny & McGilloway, 2007). Research suggests that it is also important to increase father's (or secondary carer's) support and involvement in raising children with disabilities (Boström & Broberg, 2014). While father's role is improving in developed countries (Simmerman, Blacher & Baker, 2001), it is quite rare to see commitment to the development process of their young children in rural areas (UNICEF, 2014). Similarly, the provision of family care services is essential to help with psychosocial adjustment of children with disabilities (Dempsey, Keen, Pennell, O'Reilly & Neilands, 2009; Wilkins et al., 2010). Waiver services programme is also considered effective in improving parents' interaction and ability to care for their child (Warfield, Chiri, Leutz & Timberlake, 2014). In order to improve accessibility to basic services, prevention efforts such as inclusive education, professional mental health services and health insurance could increase access to basic services for young children with disabilities (Anderson et al., 2003; Emerson, Einfeld & Stancliffe, 2010; Soltau, Biedermann, Hennicke & Fydrich, 2015; Szilagyi, 2012).

1.5.2 Programmes currently offered by the Indonesian Government

Irwanto et al. (2010) identified various programmes currently being implemented by the Indonesian Government, designed for a person with a disability:

(1) Non-institution-based social rehabilitation, consisted of:

(a) Mobile social service unit, to provide social services for people with disabilities in remote villages; and

b) Vocation workshops, to provide people with disabilities with some occupational skills.

(2) Institutional social rehabilitation, to provide shelter and rehabilitation for people with disabilities;

(3) Family/community-based rehabilitation, to mobilize the community to support a person with a disability and their families.

(4) Social aid for disability-focused social organisation, designed to increase community participation and to expand the reach of social and rehabilitation services.

(5) Emergency aid, designed for a person with a disability experiencing neglect, discrimination, exploitation, and violence caused by natural disasters.

(6) Social insurance to provide support for people with severe disability.

Other social protection programmes also exist in Indonesia such as National Health Insurance by Social Insurance Agency (*Badan Penyelenggara Jaminan Sosial* or BPJS), Social Assistance for Children Programme (*Programme Kesejahteraan Sosial bagi Anak* or PKSA), Social Health Insurance for Informal Workers (*Asuransi Kesehatan Sosial* or Askesos), Subsidised Rice for the Poor (*Beras Bersubsidi bagi Masyarakat Berpenghasilan Rendah* or Raskin), Family Hope Programme (*Program Keluarga Harapan* or PKH), and Public Health Insurance (*Jaminan Kesehatan Masyarakat* or Jamkesmas) (Adioetomo et al., 2014). As indicated in the aforementioned programmes, government agencies still focus more on poverty-related programmes.

While there is a range of programmes, some of these (e.g., the Institutional Social Rehabilitation programme) may do little to assist children with disabilities and their families. However, a piloted Community-Based Rehabilitation (CBR) in the South Sulawesi region is considered best practice in Indonesia. This programme produces collaboration between the Community Health Centre, hospitals and community participation by cadres. It has created traditional equipment for rehabilitation treatment made from bamboo, specifically crafted to meet the needs of children with Cerebral Palsy (Ministry of Social Affairs and Ministry of Health, 2009). As part of the national education program, the government has also provided

34 special schools for children with disabilities in East Nusa Tenggara Province (Ministry of Education and Culture, 2016). Aside from this programme, the Indonesian Government still lacks an evidence-base regarding a successful intervention model for young children with disabilities (Ministry of Social Affairs and Ministry of Health, 2009).

1.5.3 Programme by Non-Governmental Organisations in Indonesia

Various Non-Governmental Organisations (NGO) and UN agencies place children and/or disability as focal points in their work. For example, the United Nations Children's Fund (UNICEF) focuses on child protection matters (UNICEF Indonesia, 2010); The United Nations Educational, Scientific and Cultural Organisation (UNESCO) aims to increase access to basic education; the World Health Organization with the CBR Model; and CBM Indonesia is developing a model to change community attitudes regarding children with disabilities (International Labour Organisation & World Bank, 2012; WHO, 2012b). Furthermore, Arbeiter-Samariter-Bund Deutschland Indonesia and Handicap International work to develop inclusive education services in Java, the Nusa Tenggara region and Sumatera (International Labour Organisation & World Bank, 2012).

Two international NGOs have tried to improve the lives of children with disabilities on Flores, East Nusa Tenggara. The programmes they implemented embrace the social model of disability approach and the CBR approach; the activities also include livelihood support, inclusive education, and founding committees to help families. Some weaknesses found in the projects are: (1) Insufficient research prior to implementation; (2) Little understanding of CBR and disability from donor and implementers; and (3) Close to no support from government for these rural communities suffering extreme poverty and little access to basic services (Berman, 2011).

Most child and disability centred programmes are education focused, typically targeting primary and secondary education. The majority of child-focused NGOs and UN agencies will consider disability as an issue that cuts across and can be addressed in programmes, but not as the primary objective. While most disability-focused NGOs and UN agencies largely invest in solving problems with older children or vocational issues, they also consider young children with disabilities. Little research effort by NGOs and UN agencies however occurs before programmes are implemented. Best practice evidence specifically for young children with disabilities in Indonesia is yet to be produced.

1.5.4 Reviews of programmes outside of Indonesia

Results from a review from the United States indicate that a single focused programme is unlikely to be as effective as holistic programmes which target multiple levels of intervention (Murphy & Christian, 2007). Meta-analytic and other studies (e.g., Protzko, Aronson & Blair, 2013; Eldevik et al., 2009; Reichow, 2012; Sullivan, Stone & Dawson, 2014; Skotarczak & Lee, 2015) have found evidence concerning the importance of early childhood nutrition, early intensive interventions such as the Early Intensive Behavioural Intervention programme, and interventions targeting family functioning and parenting skills.

More specifically, a systematic review of interventions for young children with/at risk of disability (Case-Smith, 2013) shows that interventions to promote social-emotional development designated for infants for the most part involved coaching parents to promote positive interaction. The review also found that interventions for preschool-age children typically involved giving instruction, promoting peer support and applying naturalistic behavioural techniques to increase social competence. A combined meta-analysis and systematic review of parents' perception of family-centred care for their children with physical disabilities underlined the importance of general information availability in the care that children and parents received (Almasri, An, & Palisano, 2017).

A systematic review of the Head Start programme (designed to close the readiness gap between poor young children and other children in the United States), found that this particular programme was effective in preventing developmental delays (Anderson et al., 2003). Another systematic review analysed 57 articles on parenting programmes for children with conduct problems. The review showed that such an approach significantly improved children's behaviour (Dretzke et al., 2009). Examples of particular training packages designed to increase parenting capacity for parents of children with disabilities are The Parent Plus Programme, The Stepping Stones Triple P, and Incredible Years (Bezzina, Rice, Tonge, & Einfeld, 2017; Matson, Mahan & LoVullo, 2009).

Most existing programmes target the individual, parent's capacity, epidemiologic cases, and cognitive aspects, while few programmes have been specifically designed in the rural community context to address environmental risk factors (Maulik & Darmstadt, 2007; WHO, 2011). In addition, many programmes in developing countries have been modelled on existing programmes that originated in developed nations. These programmes neglect cultural diversity because they are influenced by Western cultural values (WHO, 2012a). There is also a lack of community-defined evidence interventions for young children with disabilities. Interventions deemed culturally fit and determined as effective by the community are crucial for community in rural areas (Johnson et al., 2015). Programmes designed in the context of community will be more easily accepted by community (Tucker, 2013), and adapted by UN agencies, NGOs and government agencies (Pyer, Horton, Tucker, Ryan & Sraftl, 2010). Evidence-based practice and research in Indonesia concerning children with disabilities is scarce and there is a need for improvement (Irwanto et al., 2010; Kusumastuti et al., 2014). Evidence about effective intervention models specifically designed for young children with disabilities in secluded areas will bring benefits to rural parts of Indonesia, such as West Timor.

1.6 Theoretical and conceptual frameworks

1.6.1 Global intervention framework

Current theoretical conceptualizations of child development are frequently based on ecological and biopsychosocial approachs. Bronfenbrenner highlights the dynamics between ecological systems (WHO, 2012a), and the biopsychosocial framework emphasizes the interrelation of biological, psychological and social factors in affecting children's development (WHO, 2011). Figure 1.3 offers a simple schema for this theory.

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Figure 1.3: Biopsychosocial model (WHO, 2011)

This model recognizes that disability is a function of the interaction between genes and the environment. Physical health and child development are thus interconnected. Factors that cause poor physical health, such as malnutrition, affect the development process; similarly factors that cause poor development (e.g. violence and abuse) in turn affect physical health. This particular model has become the main framework to address disability issues (WHO, 2011).

In line with the biopsychosocial model of disability, a summary of research in developing countries (WHO, 2012a) highlighted the need for a family-centred, comprehensive cultural-sensitive model to assist the development of young children with disabilities (the WHO Community Based Rehabilitation Model, CBR). The objective of CBR is to ensure people with disabilities have equal and non-discriminatory access to service provision such as health and education. CBR has worked well in Indonesia (Kuipers &

Maratmo, 2011; O’Toole & McConkey, 1995) and other countries (Dort, Wilson & Coyle, 2014; Higashida, 2014), with evidence suggesting that CBR is promising as an early intervention tool for developmental difficulties in young children. Implementation of CBR in Indonesia started with an emphasis on medical rehabilitation at first, although more social rehabilitation programs were developed recently. Volunteers were provided by the Ministry of Social Affairs with support from various NGOs (Japan International Cooperation Agency, KRI International Corp. & Tekizaitekisho LLC, 2015). As shown in Figure 1.4, the CBR matrix has different components including health, education, livelihood, social and empowerment. Elements listed below the components provide substantial ways of working with people with disabilities and their families (WHO, 2012a). An evaluation of the CBR project in Central Flores concludes that sustainability in a CBR project will only be reached after attitudes toward disability have changed and services provided by government fulfil basic community needs (Berman, 2011). The research outlined in this thesis treats the matrix as a foundation for developing a robust, evidence based model for interventions for young children with disabilities.

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Figure 1.4: WHO community-based rehabilitation matrix (Source: WHO, 2012a)

1.6.2 Indonesian intervention framework

Indonesia uses the child and family welfare system as the conceptual framework to handle children with disabilities, as shown in Figure 1.5.

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Figure 1.5: Conceptual framework for dealing with children with disabilities (Source: Ministry of Social Affairs and Ministry of Health, 2009)

The first stage is prevention, which aims to enhance awareness and education concerning disability. The second stage targets families in early detection and intervention programmes. The third stage targets individuals with their specific needs. This research will consider this framework as the core frame to develop the model in order to help in implementation at all levels of the model.

1.7 Summary and aims of the thesis

1.7.1 Summary

In sum, this thesis follows the imperatives outlined by WHO and UNICEF in 2012 concerning the need for more worldwide focus on young children with disabilities (WHO, 2012b). The thesis has a particular focus on the Indonesian context and particularly rural areas in West Timor (Adioetomo et al., 2014) given the high prevalence of disabilities and a dearth of programmes and research designed specifically to deal with disability issues in this area. Specifically, this thesis employs multiple methods in four different studies to synthesize information from the literature and the field and to create a practical, evidence based best practice model to support young children with disabilities in West Timor and other rural area. The goal of this particular model is to recommend policy change in West Timor in order to improve the lives of young children with disabilities.

1.7.2 Aims of the thesis

To address the gaps identified in the current literature, the overarching aim of this thesis was *to develop a best practice model for addressing the needs of young children with disabilities affected by environmental risk factors.* The objectives were to: review existing interventions in Indonesia and other developing countries; collate the results with the actual experience and perception of families of young children with disabilities in Indonesia; and gather community-defined evidence to develop a best practice model. It was predicted that this research would provide a holistic model of activities that is consumer-driven and thus easily adapted by governmental and non-governmental agencies in developing countries, especially in Indonesia.

The next chapter is an exegesis which provides a detailed elaboration of the development and methodological approach taken for each of the four studies in this thesis.

CHAPTER TWO. EXEGESIS

2.1 Preamble

This chapter provides a critical rationale for the decisions made about the research in this thesis. The exegesis also supplies complementary contextual and methodological details not explained elsewhere in each of the studies.

2.2 Outline of the studies contributing to the thesis

The overarching aim of the current thesis was to develop a best practice model to support the development process of young children with disabilities in developing countries threatened by risk factors pertaining to the physical, social and psychological environment in which they live. The objective was to identify evidence based interventions in Indonesia and developing countries, and to combine these with community defined evidence to generate a new model. To achieve these objectives *study one* (chapter 3) was a scoping review of the literature, in which available interventions to support the development of young children with disabilities in Indonesia were investigated. In order to deepen the knowledge regarding effective interventions, *study two* (chapter 4) used a systematic review technique to formulate interventions addressing environmental risks faced by young children with disabilities in developing countries. *Study three* (chapter 5) involved qualitative examination of community perceptions about disability, environmental risk factors and available services in West Timor. Findings were then collated to develop a model in *study four* (chapter 6) for addressing the needs of young children with disabilities affected by environmental risk factors. Comprehensive information detailing the aims and objectives of all four studies will be elaborated in chapter 3, 4, 5, and 6.

2.3 Rationale for methodology choice: developing models through reviews and qualitative studies

This research incorporates a scoping review, systematic review, and qualitative data to produce a comprehensive thesis concerning a practical model for addressing the needs of young children with disabilities affected by environmental risk factors. Across all studies, the principles of indigenous psychology and participatory action research were applied. Methods utilised include photovoice, focus groups, interviews, and investigations involving community plus public and private institutions related to children with disability issues in West Timor such as Education Agency, Social Agency, Health Agency, Special Education Schools, and disability-focused and child-focused NGOs and UN agencies. Table 2.1 outlines study design and methodology.

Table 2.1: Study design and methodology outline

Study	Research design	Investigated variables	Data analysis	Findings
One	Scoping review	Early interventions in Indonesia	Narrative synthesis	List of interventions developed to support developmental process of young children with disabilities in Indonesia
Two	Systematic review	Early interventions in developing countries	Methodological assessment and narrative synthesis	List of interventions targeting environmental risk harming young children with disabilities
Three	Qualitative approach using interviews and photovoice	Perceptions on disability, environmental risk factors and available services	Thematic analysis	Elaboration of experience of parents and local leaders on disability issues, including services related to it
Four	Qualitative approach using focus groups and interviews	Interventions for young children with disabilities in West Timor	Thematic analysis	A best practice model containing interventions that culturally fit to be implemented for young

2.4 Scoping review

Study one was intended to provide an outlined of existing interventions in Indonesia in order to support young children's developmental process in relation to disability. Accordingly, a systematic search of the literature was conducted according to scoping review guidelines. The scoping review is relatively new, but it is an effective method to map relevant literature in a specific field (Arksey & O'Malley, 2005). Since there is no methodological standardization to date, the most common and often used technique was employed (Pham et al, 2014). (Supplementary materials utilised in the scoping review search procedure can be found in Appendix 1 and 2.) Before developing the logic model to be used in the search procedure, the author consulted with a librarian expert in systematic search procedures.

In addition to the online literature search, it was decided to do hand-search at four universities in Indonesia. This was deemed necessary since the global literature on interventions for young children with disabilities was scarce (WHO, 2012b); and the fact that Indonesia is not an English-speaking country reduced the number of online searches for English literature. A hand-search was conducted in the library of University of Indonesia, Padjajaran University, Indonesia University of Education, and Gadjah Mada University to add more relevant literature. These four universities were selected considering their quality, as they consistently rank among the top 10 universities in Indonesia (QS World University Rankings, 2017).

2.5 Systematic review

Study two was similar to study one, except for the focus of the intervention and the location where the intervention was developed. After gaining insight on the limited numbers of available interventions for young children with disabilities in Indonesia, more information on interventions to develop a practical model was needed, particularly in the context of countries with similar economies and human resources such as Indonesia. Moreover, in order to enlarge the scope of interventions to develop the practical model, this systematic review placed more emphasis on interventions designed to reduce the negative effect of various environmental risk factors. In order to locate and synthesize the literature, a systematic literature search was conducted according to systematic review guidelines.

Systematic literature reviews are a well-established method (Wright, Brand, Dunn & Spindler, 2007) used to outline the best research available on a specific topic or question (Campbell Collaboration, 2015). Guidelines from the Joanna Briggs Institute (2014a, 2014b), and Social Care Institute for Excellence Systematic Research Review Guidelines were employed for this systematic review (Rutter, Francis, Coren & Fisher, 2010). (Supplementary materials utilised in the systematic review search can be located in Appendix 3.) For this review, 10 databases were searched. In the selection process, unlike *study one* that strictly included interventions that designed specifically for young children with disabilities (below eight years of age), *study two* included interventions that targeted older individuals, as long as it also focussed on young children. This decision was made so we did not exclude important relevant interventions.

2.6 Fieldwork research

Study three and *study four* were conducted in West Timor during the fieldwork phase.

2.6.1 Ethical and research approval

Fieldwork planning started in February 2015 and ethics clearance from The University of Adelaide (see Appendix 4) was obtained by September 2015, while clearance from the Ministry of Health, Republic of Indonesia (see Appendix 5) was obtained by December 2015. Similarly, the fieldwork process also obtained approval from the Ministry of Home Affairs, Republic of Indonesia by December 2015 (see Appendix 6). *Study three* and *study four* participants were provided with an information sheet explaining the nature of the studies, voluntary participation and the right to withdraw. The author worked with illiterate participants to help them understand the research by reading it aloud, as the author is a native speaker of Indonesian language (Bahasa Indonesia). All participants were required to sign a written or verbal (for illiterate participants) consent form. Participants were provided with contact details for psychological services should they require counselling during the study. (Materials given to participants during the recruitment phase are located in Appendix 7 and 8.)

2.6.2 Indigenous psychology and participatory action research

Kim and Berry (1993) defined indigenous psychology as “the scientific study of human behaviour or mind that is native, that is not transported from other regions, and that is designed for its people” (p, 2). This approach challenges the “carbon copying” of Western psychology behaviour (Kim, Yang, & Hwang, 2006). While general psychology aims to create a universal theory, indigenous psychology emphasizes understanding psychology in the social and cultural context of each nation or community. It advocates examining the beliefs that people have about themselves and their functioning in familial, cultural, social, and ecological contexts (Kim et al., 2006). This approach dates back about 20 years (Kim, Park & Park, 2000). It is important to address the knowledge gap and clarify misconceptions about disability in indigenous communities to ensure the effectiveness of any intervention programme (Narayansamy, Ramkumar, & Nagarajan, 2014). The indigenous psychology approach will be used in the fieldwork to focus on qualitative analysis of people’s beliefs, particularly in relation to familial, cultural, social and ecological contexts.

The research was also influenced by participatory action research principles, although could not strictly be defined as following a participatory action model as respondents were not involved in all stages of the research, including study design. Participatory action research is a form of integrated research involving the community affected by the issue addressed in the research process. This approach is considered appropriate to use in indigenous contexts

(Crane & O'Regan, 2010), because the indigenous community will have the opportunity to share their thoughts and experiences that will improve critical analysis, management and research evaluation. It has been used in Indonesia on many occasions. For example, participatory action research was applied in the cacao chain research in Flores, East Nusa Tenggara (Manalili, 2009). Such research has also been used to increase the adoption of cattle and forage improvement technologies in Eastern Indonesia, specifically in South Sulawesi and Central Lombok region (Lisson et al., 2010). Additionally the research was used to increase understanding between community and stakeholders in Sumatra, Indonesia (Purnomo et al., 2014). Action research is often represented as a cycle of: observe → reflect and share → plan → act → observe (Crane & O'Regan, 2010). This thesis applied some of these principles including observe, reflect and share, and plan. The observe phase was undertaken in *study three* which provided insights on the current situation of young children with disabilities in West Timor. The reflect and share phase was completed in the focus group phase of *study four* when it was discovered that a gap existed in the community, and the plan phase was undertaken in the interview phase of *study four* that formulated activities and programmes to tackle gaps identified.

2.6.3 Data collection timeframe

Data collection took place over an eleven-month period, from December 2015 to November 2016 (see Appendix 9 for timeframe of fieldwork research). Specifically, data collection for *study three* started from December 2015 until February 2016, while *study four* data collection started from April 2016 until October 2016. Data collection for *study three* started with interview and photovoice sessions with parents of young children with disabilities and ended with interview sessions with local leaders. Data collection for *study four* started with focus groups and continued with interview sessions. Across an eleven-month period, the author occasionally attended meetings to discuss disability and/or child protection issues to better understand children with disability issues in the context of West Timor.

2.6.4 Participant recruitment

The fieldwork took place in two municipalities in West Timor, namely Kupang City (shaded white, see figure 2.1) and Kupang District (all areas surrounding Kupang City, see figure 2.1). *Study three* participants are local leaders recruited in either Kupang City or Kupang District, while all remaining participants were parents of young children with disabilities, recruited in three sub-districts of the Kupang District: Kupang Tengah (shaded green), Amarasi Barat (shaded light blue), and Semau (shaded purple, see figure 2.1). Participants of *study four* were mostly recruited in Kupang City with a few recruited in Kupang District.

Figure 2.1: Map of Kupang City and Kupang District

Participants in *study three* and *study four* were classified into two categories: parents of young children with disabilities and local leaders. Local leaders varied from village heads to leaders of NGOs. Recruiting local leaders was made easier with a letter of permission acquired from the Indonesian Government (Ministry of Home Affairs). The author first approached the institution's office and met with local leaders in order to explain the nature of the research and ask whether they wanted to participate voluntarily. Parents of young children with disabilities were recruited by taking a slightly different approach. Parents interviewed for *study three* were visited regularly (at their home) after acquiring permission from village leaders, which began in October 2015. The author began visiting parents before the formal data collection period to familiarise himself with the neighbourhood and to gain trust and build rapport with parents. Parents participating in focus group for *study four* were recruited using the parents' group programme initiated by an NGO in Kupang City. (Further information on the recruitment of the participants for *study three* and *study four* is provided in subsequent chapters.)

2.7 Qualitative research – paper three

Study three adopted qualitative research design using a combination of photovoice and semi-structured interview methods to explore perceptions of disability, environmental risk factors, and available services for local leaders and parents of young children with disabilities in West Timor.

2.7.1 Purposive sampling strategy

A purposive sampling approach was considered most appropriate to be used in *study three*. This approach was relevant to adjust to the rural community context (Patton, 2002). Purposive sampling methods for hidden populations, such as young children with disabilities, generally produce small samples and are associated strongly with qualitative research (Barratt, Ferris, & Lenton, 2015). Purposive sampling depends on the researchers' situated knowledge of the field and rapport with members of the targeted population (Barratt et al., 2015), which is advantageous for this thesis considering the author's experience and networks in West Timor. In this study, parents of young children with disabilities and local leaders were recruited.

2.7.2 Semi-structured interview

Semi-structured interviews provide flexibility in questioning to identify aspects that are culturally specific, and to ensure that the interview takes into account the needs of people who are illiterate and to gain nuanced data concerning perceptions of disability (Copeland, Luckasson & Shauger, 2014). In *study three*, the interview guide was designed so that deviations from interview questions enabled the exploration of participants' lived experiences. The author, together with his supervisors, developed two interview guides to be used for interviews with parents of young children with disabilities and local leaders.

The interview guide for parents consisted of 12 open-ended questions, while the local leaders' guide consisted of 14 open-ended questions, and both were accompanied by prompts to elicit in-depth information. One question for parents was specifically designed to explore the story behind every single photo they took. The design of questions on available services was informed by the WHO CBR framework that focuses on health, education, economic, social, and empowerment sectors (WHO, 2012a). The interview guide was employed without piloting, however the interview process was iterative and questions were refined based on previous interviews (Creswell, 2013). Refinement resulted in many additional prompts to explore various aspects. (Appendix 10 details the finalised interview schedule used in *study three.*)

2.7.3 Photovoice

Photovoice was used to enrich the data collection about community perceptions of disability. Parents of young children with disabilities were asked to take pictures of resources and needs in their community related to young children with disabilities, select the photographs that were most representative of their reality and discuss these with the author. This method is considered useful for eliciting data that may deepen understanding of experiences in the community (Plunkett, Leipert & Ray, 2013).

We conducted photovoice partially based on stages recommended by Booth and Booth (2003). However, in our study, we conducted photovoice sessions individually, not in group sessions, as suggested. The photographs were therefore taken by participants before the interview session, and were discussed in the interview session.

2.7.4 Thematic analysis

Data analysis was done through transcription of the data without using any software help. A thematic analysis approach was chosen to analyse the data by reason of the rigorous nature of the approach. It has been utilized in a wide array of topics, ranging from higher education (Due et al., 2015) to sociology and health (Riggs, Bartholomaeus & Due, 2016). It has also proved useful in a rural setting (Collins, Winefield, Ward & Turnbull, 2009). The stages of thematic analysis conducted included: 1) data familiarisation by reading and transcribing responses; 2) data coding to discover important responses; 3) collating themes to reveal potential themes; 4) reviewing the themes and naming them; and 5) choosing representative responses to the themes (Braun & Clarke, 2006; Clarke & Braun, 2013). We conducted a thematic analysis of the interview discussions and discussions that arose as part of the talk about the photos. Thematic analysis of photos and interviews was undertaken and presented together.

2.8 Qualitative research – paper four

Study four employed qualitative research using a combination of focus group and semi-structured interviews to develop a practical logic model and to also acquire responses from stakeholders in West Timor.

2.8.1 Logic and best practice models

In order to help decision makers and practitioners adapt the overall results of this thesis, we utilized the implementation science approach in formulating a best practice model.

Implementation science has been defined as the study of methods to promote systematic uptake of research findings and evidence-based practices into routine practice (ICEBeRG, 2006). The objective of this approach is to translate research findings into inputs that can be easily implemented by related stakeholders to address the gap between science and service. Implementation science has distinctive characteristics compared to other studies of methods, one of which is implementation strategies. These strategies aim to be responsive to variations in practice and service settings (Proctor et al., 2009). A review of implementation science concludes that the research has six common areas that serve as a *quality implementation framework*: assessment strategies, decisions about adaptation, capacity-building strategies, creating a structure to help implementation, technical implementation strategies, and improving future applications (Meyers, Durlak & Wandersman, 2012). While the research did not follow a specific implementation science framework, the development of the best practice model was broadly informed by the findings of this review. The aim of *study four* was to produce both practical activities to support young children with disabilities in several areas, and implementation strategies to help practitioners and policymakers to understand and adopt activities in the model. The model used the logic model template suggested by Kellogg (W. K. Kellogg Foundation, 2004).

2.8.2 Purposive sampling strategy

A purposive sampling strategy was also employed to recruit participants for focus group and interview sessions in *study four* with the same justification as *study three*. The author's network and experience in the field helped to ease the process of purposive sampling recruitment (Barratt et al., 2015). Locating participants in this study was easier than *study three* due to the fact that most participants are concentrated in Kupang City (not scattered as in the Kupang District), and all participants were registered as members of a particular institution/group. Almost all participants recruited in *study four* did not participate in *study three*, with only seven people participating in both studies.

2.8.3 Focus group

Focus groups are a qualitative data collection method in which one or more researchers and several participants meet as a group to discuss a specific topic (Shallwani & Mohammed, 2007). The purpose of this discussion is to utilize the social dynamics within the group with the help of a facilitator to stimulate participants to uncover attitudes and opinions on a topic (WHO & University of Amsterdam, 2004). The technique was considered appropriate for *study four* because it is well suited for research that will be used to develop services that meet the needs of a given population (Shallwani & Mohammed, 2007). Focus group has been employed in developing countries to investigate various social and health topics such as domestic violence (Kalokhe et al., 2015) and injury (Kalaiselvan, Dongre & Mahalakshmy, 2011).

In *study four*, the focus group guide was designed so that all participants could have the chance to express their feelings and opinions and to keep discussion focused on the selected topics. The author, together with his supervisors, developed a focus group guide to be used in focus group sessions with parents of young children with disabilities and local leaders. The focus group guide for parents and local leaders comprised seven specific topics including five sectors listed in the WHO CBR framework (WHO, 2012a). The guide was then piloted with a group of early childhood education and development (ECED) teachers to refine the research instrument and focus group topics. As previously mentioned, refinement also continued every time each session ended. A major change in the focus group guide was the change of topic from discussion on available resources in West Timor to that of existing problems in West Timor. The rationale for this change was that participants in early sessions were more active in sharing their problems instead of discussing resources. (Appendix 11 details the finalised focus group schedule used in *study four.*)

2.8.4 Semi-structured interview

Similar to study three, *study four* also employed semi-structured interviews to explore reactions of related stakeholders to the initial practical logic model developed, since most targeted participants were leaders in government and non-government institutions, making it difficult to gather them together for focus groups. The interviews also allowed the researchers to gather focussed information from an individual perspective (Shallwani & Mohammed, 2007).

The interview guide in *study four* was developed by the author and his supervisors after completing all focus group sessions. The interview guide consisted of questions eliciting their opinions about a long list of 64 activities designed to support young children with disabilities in West Timor. The interview guide was used without piloting, and the refinement process was continuous as in study three. Refinement resulted in several additional prompts to further explore activities discussed. (Appendix 12 illustrates the finalised interview schedule used in *study four.*)

2.8.5 Thematic analysis

Identical to the previous study, no software was used, so data analysis was carried out via manual transcription. Thematic analysis was also chosen for data analysis, bringing an advantage, considering the author has just completed thematic analysis in *study three*. Guidelines for thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2013) were closely followed. Thematic analysis was done once all data from focus group and interview sessions were gathered. The thematic analysis of the focus groups and interviews were done separately but with same objective, that is to refine the practical logic model.

2.9 Quality in qualitative research

To ensure rigour in analysis process and objectivity of the data, a number of processes were applied (Shenton, 2004) including the development of early familiarity with the culture of community, the maintenance of an audit trail with reflective commentaries, negative case analysis, and frequent debriefing sessions to discuss methods and analysis. An audit trail was particularly useful in debriefing sessions with supervisors, as it contained much information on changes and decisions made during the entire research process (Given, 2008). Further, the author included family/caregivers and local leaders to secure a variety of perceptions on disability, environmental risk factors and available services.

In *study four,* various methods were used to improve the quality of the research, as suggested by Shenton (2004), including the use of both focus group and interview methods, developing rapport with the participants, maintaining an audit trail, negative case analysis, and also frequent sessions with supervisors to discuss progress of the study. The inclusion of many stakeholders ranging from parents of young children with disabilities, leaders from health, education, social, and other government agencies, rectors of universities, to leaders of religious institutions further enriched the quality of the inputs necessary to build the practical logic model.

2.10 Reflexivity

Reflexivity is important in qualitative research, as it addresses researcher bias and helps to ensure validity of the study (Creswell, 2013). Through the use of an audit trail, the author documented all hypotheses, preconceptions, and expectations related to the interview process, to identify preconceived biases (Malterud, 2001). For example, there was an expectation that parents might be difficult to locate due to their tendency to hide their children due to the stigma associated with disability, as explained in chapter 1. Another expectation was that they might be difficult to engage in interviews, considering the stress caused by stigma and the related burden of their children’s disabilities. For these reasons, the author spent some time before data collection to source potential participants, and familiarise himself with some parents of young children with disabilities.

More reflexivity considerations were also documented in the audit trail after the completion of each interview session. Through reflection, the author critically considered his personal responses and relationships with study participants (Smith & Firth, 2011). The reflection process resulted in several characteristics that potentially impacted participants' willingness to participate in the study and content of the interview, as outlined below.

The first issue to consider is that while the author is Indonesian, he is *not originally from West Timor*, and this possibly impacted the ability of the author to relate to parents and turned the initial discussion and engagement into a formal one. It was believed that when parents are engaged formally, they tend to be not so open in discussion compared to casual engagement. This may have resulted in parents reluctantly accepting the invitation to participate in the study and socially desirable responses to interview questions.

Secondly, *being a PhD student in an overseas university* might also have created a social status imbalance in the relationships between the author and participants. As the author's experience has shown, a young student affiliated with a university outside of Indonesia will be treated as a person who "knows everything" in the community, therefore they need to be treated as distinguished person too in social interactions. This could also result in negativity as mentioned above. To address these potential issues, the author spent about four months prior to data collection, conducting interviews in the local language and meeting on more than one occasion to facilitate and obtain informed consent.

A positive effect is the *communications skills of the interviewer* developed over years living and working with local leaders and grassroots individuals in rural areas of Indonesia, including West Timor. The author is used to building rapport, communicating with participants at low or and high education levels, and also government and non-government institution leaders. The author already has a strong *network* of stakeholders related to children and disability issues. This has been particularly helpful in the recruitment process.

Through an audit trail of *study four*, the author identified several additional thoughts and ideas that differed from those in *study three* which could result in preconceived biases. It was expected that parents of young children with disabilities would have problems in expressing their opinions in a group. In order to help them, the author designed the focus group session to be as relaxed as possible with some practical jokes. The author also allowed free time before the focus group session began in order to provide opportunity for participants to chat among themselves. It was also expected that leaders from various institutions would have problems in managing to talk to a brief time period, either in focus group or interview sessions. The author then tried to facilitate by politely concluding lengthy discussion, effectively stopping them and giving other participants the opportunity to respond, providing the opportunity to share the next question.

More reflexivity thoughts were also documented in the audit trail after the completion of each focus group and interview session. The reflection process resulted in a characteristic of the author that potentially affected participants' inclination to take part in the study and content of the interview:

Requesting participation twice (in study three and study four) in some institutions potentially impacted institutions in participating in interview sessions. Some individuals in the institutions even asked "we thought it's over already?" highlighting their lower enthusiasm to participate. This could result in participants reluctantly accepting the invitation to participate and responses to interview questions that were not well thought through.

A positive reflection from interview sessions was that most participants were excited to adopt some of the activities discussed in the session in their institutions. Some participants even asked whether they could have the list of activities discussed in the interview session. Another positive reflection is that most participants were enlightened from the interview session, because they gained new insights on disability issues and how to deal with them. This *motivated the author* to continue with interviews even after reaching 20 participants. The author felt that the process of social change had already begun in those interview sessions, and more participants interviewed meant more influential leaders will be influenced to support young children with disabilities in the future.

CHAPTER THREE. INTERVENTIONS SUPPORTING THE DEVELOPMENT OF YOUNG CHILDREN WITH DISABILITIES AT ENVIRONMENTAL RISK IN INDONESIA: A SCOPING REVIEW

3.1 Preamble

This study reviews interventions addressing the developmental process of young children in Indonesia. The review included both academic literature, as well as government, UN, and non-government agency reports. The review was subsequently used as part of the development of the best practice model.

3.2 Statement of authorship

Title of paper: Interventions supporting the development of young children with disabilities at environmental risk in Indonesia: a scoping review

Publication status: Published

Publication details: Kiling, I. Y., Due, C., Li, D. E., & Turnbull, D. (2018b). Interventions supporting development of young children with disabilities at environmental risk in Indonesia: a scoping review. SAGE Open, 8 (1). doi: 10.1177/2158244018754935

3.2.1 Principal author:

Name of principal author (candidate): Indra Yohanes Kiling

Contribution to the paper: Responsible for primary authorship of this research, and correspondence with reviewers and journals. Responsible for the literature search design and process, analysis, and writing of the manuscript.

Overall percentage: 80%

Certification: This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.

Signature: Indra Yohanes Kiling *Date:* 01/08/2018

3.2.2 Co-author contributions:

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate to include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

Co-author: Prof. Deborah Turnbull

Contribution to the paper: Input on review design, database searches, interpretation of findings, and writing of the manuscript. Oversight of article progress including publication process. Provided editorial and structural feedback.

Signature: *Date:* 01/08/2018

Co-author: Dr. Clemence Due

Contribution to the paper: Input on review design, database searches, interpretation of findings, and writing of the manuscript. Provided editorial and structural feedback.

Signature: *Date:* 01/08/2018

Co-author: Dr. Dominggus Elcid Li

Contribution to the paper: Input on interpretation of findings and writing of the manuscript.

Provided feedback on drafts.

Signature: *Date:* 01/08/2018

3.3 Abstract

The purpose of this article is to examine the current literature addressing interventions to support the developmental process of children of early age with disabilities in Indonesia, who are threatened with significant environmental risk. To achieve that, a scoping review was conducted. The following databases were searched: PsycINFO, PubMed, Embase, CINAHL, ERIC, Social Services Abstracts, and Scopus, as well as the reference lists of all included studies. We searched 46 open access Indonesian journals and conducted hand-searches at the four main Indonesian universities. Searches were conducted of Google Scholar and the websites of Indonesian government and UN and nongovernmental agencies to identify gray literature. These agencies were also personally contacted to identify relevant reports. Eight studies met our inclusion criteria. The existing research investigates on various interventions including two studies utilizing strategies indigenous to Indonesian. Environmental risk factors were not addressed directly by all the interventions. The eight studies targeted all areas of early childhood development. Several limitations were found in these studies' methodology, and they also used similar research designs. This review highlights the need of more rigorous and culturally relevant research to fulfill the developmental needs of young children with disabilities in Indonesia.

3.4 Introduction

There are approximately 4.2 million children experiencing disabilities in Indonesia, with an estimated prevalence in the general population of 21.3% (2006 figures; South-East Asia Regional Office–World Health Organization [SEARO-WHO], 2013). While this prevalence is extremely high, those living outside the main centers are at added risk due to the "the physical, social and attitudinal environment in which people live and conduct their lives" (World Health Organization [WHO], 2007, p. xvi). Such environmental risks include poverty, stigma and discrimination, poor interaction with parents and caregivers, violence, abuse and neglect, and limited access to programs and services (Maloni et al., 2010; WHO, 2012b).

Environmentally at-risk young children are defined as those who experience one or more of these risks, to the extent that their development is negatively impacted as a consequence (Guralnick, 2013). Given the additional burden experienced by these children, early-intervention programs focusing on reducing environmental risk are needed to ensure that their development and well-being is not impacted further. This early childhood development phase, which comprises of cognitive, sensory motor, communication and social-emotional factors, is crucial as it impacts upon the entire course of an individual's life (WHO, 2012b).

Various early-intervention programs for a range of disabilities have been developed and reviewed. For example, a recent meta-analysis (Reichow, 2012) provides strong evidence for Early Intensive Behavioral Intervention programs for improving outcomes for children with autism spectrum disorder (ASD). Similarly, a systematic review of the Head Start program for school readiness in children affected by poverty in the United States has been found to be effective in preventing developmental delays (Anderson et al., 2003).

While these two examples demonstrate that early-intervention programs have had some success in improving outcomes for young children with disabilities, most of the existing programs are devised for children in Western or developed countries. Very few programs have been specifically designed in the context of rural communities; in addition, they tend not to consider environmental risk factors (Maulik & Darmstadt, 2007) thus further limiting generalizability to low- and middle-income countries such as Indonesia (Mishra & Gupta, 2006). Moreover, programs devised in partnership with local communities will provide better outcomes for children given that they will arguably be more culturally appropriate and draw upon locally available resources and knowledge (WHO, 2011).

Despite the need for such interventions, government, UN agencies and nongovernmental organizations (NGO) based in Indonesia continue to focus their attention and resource programs for physical health priorities such as malaria, avian influenza, nutrition, and child mortality (UNICEF Indonesia, 2010). Against this backdrop, this article addresses the following research question:

Research Question 1: What is known from the existing literature about the interventions specifically designed to support development of young children with disabilities affected by environmental risk factors in Indonesia?

Thus, we aim to add to similar studies from low- and middle-income countries (Njelesani, Couto, & Cameron, 2011), by identifying what further research is required for addressing unmet developmental needs for children with disabilities in these contexts. The results from this review should help government agencies and NGOs in Indonesia and other low- and middle-income countries to decide what evidence-based interventions are available to be adapted into national- and provincial-level policy.

3.5 Methods

3.5.1 Scoping review

Scoping reviews provide an important method through which to overview and map the relevant literature in a specific field of study (Arksey & Malley, 2005). Similar to systematic reviews and meta-analyses, they are considered comprehensive and rigorous enough to stand-alone as a form of project (Arksey & Malley, 2005). There are two main differences between systematic reviews and scoping reviews. The first is that a systematic review usually has a well-defined research question with specific study designs that are noted in advance. Scoping reviews are more relevant where previous research in an area is sparse and, as such, have a broader focus that includes different study designs. The second difference is that while systematic reviews include an assessment of the quality of the extant studies, scoping reviews aim to provide an overview of research in an emerging area, and do not necessarily aim to provide extensive evaluation of quality. As such, scoping reviews are considered appropriate in considering emerging cross-cultural research where traditional quality evaluations may be inappropriate or exclude studies that are potentially important contributions to the literature.

This study followed five stages identified as important to scoping reviews based on published guidelines (Arksey & Malley, 2005): (a) identifying the research question, (b) identifying relevant literature, (c) selecting the literature, (d) charting the data, and (e) collating, summarizing, and reporting the results. Furthermore, as Levac, Colquhoun, and O'Brien (2010) suggest, we outline the research and practice implications stemming from the results of this study.

3.5.2 Study inclusion and exclusion criteria

For studies to be included, they had to meet all of the following inclusion criteria: (a) be an empirical evaluation of an intervention with the objective of supporting the developmental process of young children with disabilities (therefore we excluded opinion pieces and review literatures), (b) address intervention targeted at young children in the early childhood period (prenatal to 8 years of age), (c) address an intervention targeted at any type of disability as defined by the International Classification of Functioning, Disability and Health (WHO, 2011), and (d) address an intervention conducted in Indonesia. To increase the scope of the research, we included studies regardless of publication year, and in the gray literature, such as those in the main government, nongovernment and UN agencies' reports as well as theses from the four main Indonesian universities.

3.5.3 Types of participants

Participant inclusion criteria included a focus on young children, defined as those below 8 years of age (WHO, 2012b). The United Nations Convention on the Rights of Persons With Disabilities (CRPD) declares that people with disabilities include those with long-term impairments which in interaction with existing barriers may hamper their participation in the community (United Nations, 2006), and thus, a broad definition of disabilities was applied in this study.

3.5.4 Outcomes and nature of the intervention

All types of interventions were considered, including those that focused on one particular outcome or multiple outcomes. Thus, interventions could address any or all of the following areas of the early childhood development phase: cognitive, sensory motor, communication, and social-emotional.

3.5.5 Search methods

The first author conducted the searches in consultation with the co-authors and an experienced research librarian (Learning and Research Services, University of Adelaide). The following academic databases were searched: PsycINFO, PubMed, Embase, CINAHL, ERIC, Social Services Abstracts, and Scopus using a logic grid (available by contacting the first author), as well as the reference lists of all included studies. Open access Indonesian journals not necessarily indexed in the aforementioned databases were also searched ($N = 46$ journals). Hand-searches were conducted in the libraries of the four main Indonesian universities (University of Indonesia, Padjajaran University, Indonesia University of Education, and Gadjah Mada University). To locate gray literature, searches were conducted of Google Scholar and the websites of Indonesian government (using “go.id”) and UN and nongovernmental agencies (The Ministry of Education and Culture, The Ministry of Social Affairs, UNICEF, Plan Indonesia, World Vision, ChildFund, Handicap International). These agencies were also personally contacted by the first author to identify relevant reports.

3.5.6 Study selection

First, all authors discussed decisions about study inclusion and exclusion. The subsequent steps were conducted by the first author in consultation with the other authors. The titles returned by the initial search were categorized as relevant, not relevant, or possibly relevant. The abstracts of the relevant and possibly relevant titles were reviewed. The full-text of articles considered relevant or possibly relevant were read to make final decisions concerning inclusion. There was no blinding of authorship.

3.5.7 Charting the data

The first author used a data-charting form (Levac et al., 2010) designed for scoping reviews of mixed-method studies to extract the data. A descriptive review method was used for each included study as follows: the author/s, year of publication, country in which the research took place, aim of the study and research question/s, study design, the age of study participants, type of intervention, outcomes, results, main findings, and limitations. Two additional aspects were assessed: the type of resources used (universally available/only locally available) and the area of early childhood development targeted by the intervention (cognitive, sensory motor, communication, social-emotional). After extracting the data, the first author consulted with the others to determine whether the obtained information was consistent with the research question.

3.5.8 Collating, summarizing, and reporting the results

Data collation and summarization was done using both a table and text ("Results" section), followed by a discussion of research, practice, and policy implications (Levac et al., 2010), in the "Discussion" section.

3.6 Results

A total of 1,832 records were identified with 1,548 excluded based on duplication and irrelevant titles (as determined by the inclusion criteria outlined previously). A total of 284 abstracts of studies were screened and 59 studies were included to be reviewed in full. Google scholar identified 418 articles as potentially relevant, with two studies included for full review. The search of the Indonesian government websites identified three studies for full review. The search of the 46 Indonesian open access journals identified five studies to be reviewed in full. The review of 29 NGO and UN agencies' websites revealed one study to be included. The search of the four Indonesian university libraries found nine studies to be included. To summarize then, a total of 20 titles were included from gray literature to be reviewed in full-text. After reviewing the full-text of all relevant articles, eight studies were eligible and included in the scoping review (see Figure 3.1).

3.6.1 Excluded studies

Seventy-one articles were excluded following the review of the full-text. Studies were excluded if they did not provide the age of the participants, were purely descriptive in nature, and considered at-risk children rather than those with a current disability. Studies that did not provide the age of the participants tended to describe children in relation to current school status, which in low- and middle-income countries may not be correlated with age due to the tendency for children with disabilities to begin kindergarten or preschool past the early childhood period (WHO, 2011).

3.6.2 Descriptive summary of the studies

Manuscripts were published between 2006 and 2014. Three of the articles were published in open access, peer-reviewed academic journals and were based on bachelor degree theses from the State University of Surabaya (Kurniawati & Madechan, 2013; Putri & Widajati, 2013; Sekarwati & Riyanto, 2013; see Table 3.1).

3.6.3 Chronological distribution of studies

Despite not limiting our search to specific dates, all of the included studies were relatively recent, with the oldest study being published in 2006 (Citrasari, 2006). Half of the included studies were published more recently between 2013 and 2014.

3.6.4 Geographic distribution of studies

Six of the eight studies examined interventions conducted in Java. This may be as a consequence of the fact that the hand-search of university libraries was confined to the four main institutions on Java, and the open access journal that published three of the included studies is published by a state university in Java (Kurniawati & Madechan, 2013; Putri & Widajati, 2013; Sekarwati & Riyanto, 2013). The other two studies (Chandra, 2007; Dewiyanti, 2007) did not cite the exact location, but were completed for fulfillment of a degree in Gadjah Mada University, the national university in Java.

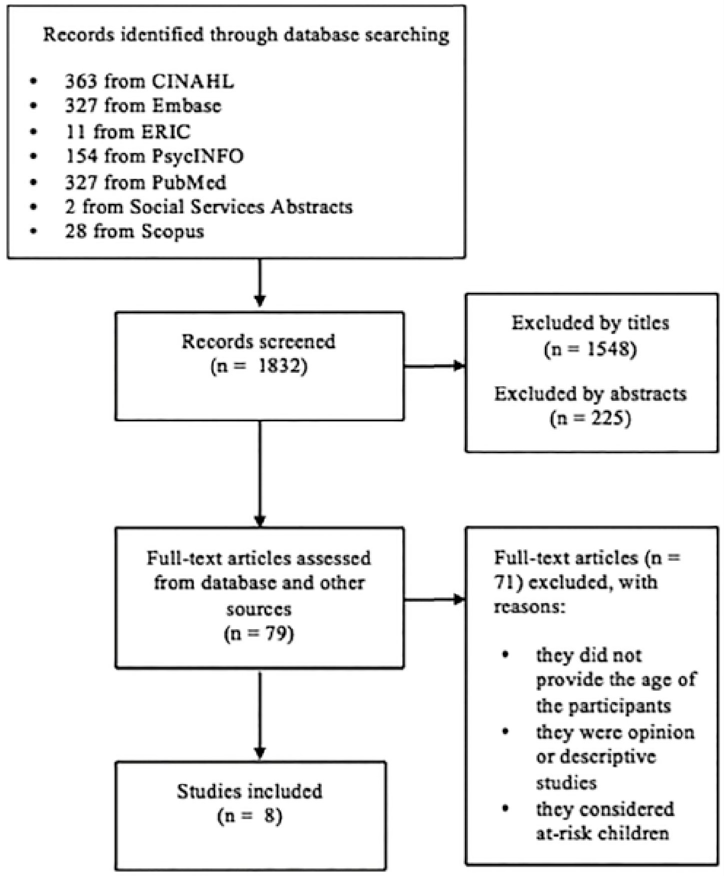

Figure 3.1: Flowchart of study selection

3.6.5 Intervention recipients

Participants included boys and girls aged between 3 and 7 years of age. Diagnoses included ASD (Chandra, 2007; Dewiyanti, 2007; Kurniawati & Madechan, 2013; Putri & Widajati, 2013), intellectual disability (Rahim, 2014; Sekarwati & Riyanto, 2013), hearing impairment

(Citrasari, 2006), and visual impairment (Wardhani, 2007). Thus, the extant research has considered both physical and mental health disabilities, with a particular focus on ASD.

3.6.6 Range of interventions

The studies examined a variety of programs with implementation length from 6 days (Citrasari, 2006) to a period of 3 weeks (Sekarwati & Riyanto, 2013), with between six sessions (Citrasari, 2006) and 21 sessions (Sekarwati & Riyanto, 2013) conducted. The two studies addressing physical impairment (Citrasari, 2006; Wardhani, 2007)) included skills-based training for the children to identify parts of their body so as to improve "self-awareness." A therapeutic approach was utilized by three studies: specifically, Cendana aromatherapy (Rahim, 2014), behavior therapy (Dewiyanti, 2007), and music therapy (Chandra, 2007). The other three studies used various interventions, including traditional dance, a board game, and question and answer activity.

Thus, six of the eight studies examined interventions incorporating universally available resources such as the maze-matching board game (Sekarwati & Riyanto, 2013), behavior therapy (Dewiyanti, 2007), and picture cards (Citrasari, 2006). Two studies employed local approaches including the Lenggang Alit dance (Kurniawati & Madechan, 2013) and Cendana wood unique to Indonesia and nearby areas (Rahim, 2014). The interventions addressed all areas of early childhood development: cognitive (Citrasari, 2006; Wardhani, 2007); sensory motor (Chandra, 2007; Dewiyanti, 2007; Kurniawati & Madechan, 2013; Sekarwati & Riyanto, 2013), communication (Putri & Widajati, 2013), and social-emotional (Rahim, 2014).

3.6.7 Research design and outcomes

All of the studies used the single-case experimental design with outcomes presented as the frequency of the targeted behavior at each data collection period. This outcome measure was obtained through observation by the researcher who also provided the intervention.

3.6.8 Results of the included studies

All studies reported improvement on outcomes. Data were typically presented in graphical format that was often difficult to assess (Citrasari, 2006; Wardhani, 2007). Results were frequently presented in relation to percentage of nonoverlapping data (PND) which is the extent to which data in the baseline (A) versus intervention (B) phases do not overlap, suggesting an improvement in outcomes where there is little or no overlap (Parker & Vannest, 2009). Three studies reported 0% PND (Putri & Widajati, 2013; Rahim, 2014; Sekarwati & Riyanto, 2013). One study (Kurniawati & Madechan, 2013) reported 12.5% PND, while four studies did not specify PND, but still claimed that the interventions were effective as per increases or decreases in the frequency of the targeted behavior (Chandra, 2007; Citrasari, 2006; Dewiyanti, 2007; Wardhani, 2007).

3.6.9 Analysis of the studies as a whole

Overall then, the body of literature is small with interpretation severely hampered by limitations in research design, data analysis and reporting, and the potential for researcher bias. A central limitation of the research relates to the ways in which disability was defined. Most of the studies examined very specific forms of disability, such as ASD, and thus did not consider the broader environmental context. Some studies referred to "children with special needs" instead of "children with disability." The use of the term "children with special needs" highlights the emphasis on education in relation to children with disabilities, as this term is typically used in Indonesia only in an educational context (Citrasari, 2006; Kurniawati & Madechan, 2013; Rahim, 2014; Sekarwati & Riyanto, 2013). This emphasis could be due to the fact that Indonesian law has particular provisions related to the right to education for children with special needs, including "special" education if appropriate (Primus, 2014). Another shortcoming is that none of the included studies made statements regarding approval from properly constituted human research ethics committees.

Table 3.1: Descriptive summary of the relevant studies

Author and source	Participant	Study design	Intervention	Outcome	Results
Kurniawati and Madechan (2013); Jurnal Pendidikan Khusus	7-year-old child with ASD (unspecified gender)	Single-case experiment, A-B design	Lenggang Alit dance; 15 daily sessions, 30 min duration in classroom	Gross motor constraints (e.g. jumping and running aimlessly)	Gross motor constraint behaviour was reduced; positive-level change from Phase A (baseline) to Phase B (intervention) and PND of 12.5%
Putri and Widajati (2013); Jurnal Pendidikan Khusus	7-year-old child with ASD (unspecified gender)	Single-case experiment, A-B design	Video mediated question and answers; 16 daily sessions, 35 min in classroom	Speech activities (e.g. saying words)	Speech activity was increased; positive-level change between Phase A and B, PND of 0%
Sekarwati and Riyanto (2013); Jurnal Pendidikan Khusus	5-year-old boy with intellectual disability	Single-case experiment, A-B design	Maze-matching board game; 21 daily sessions, 20 min in kindergarten classroom	Fine motor skills (e.g. using pencils)	Fine motor activity was improved; positive-level change between phases, PND of 0%
Citrasari, N; Thesis for Magister of Profession Psychology in Child-Clinical Psychology University of Indonesia, 2006	3-year-old girl with hearing impairment	Single-case experiment, A-B design	Training with picture cards; six daily sessions, 30 min in child's house	Pointing self-body parts correctly	Increase in child's ability to identify her body parts; positive-level change between phases, visual analysis (qualitative approach) showed positive change
Chandra, A; Thesis for Magister of Profession Psychology in Clinical Psychology Gadjah Mada University, 2007	4-year-old boy with ASD	Single-case experiment, A-B-A-B design	Waltz music therapy with electronic keyboard; 12 daily sessions; 90 min in child's house	Repetitive behaviours (e.g. hand waving)	Repetitive behaviour was reduced; positive-level change between phases
Dewiyanti, A; Thesis for Magister of Profession Psychology in Clinical Psychology Gadjah Mada University, 2007	6-year-old child with ASD (unspecified gender)	Single-case experiment, A-B design	Behaviour therapy; 10 daily sessions; 30 min in child's house	Independent behaviours (e.g. wearing shirts)	Increase in independent behaviour; visual analysis (qualitative approach) showed positive-level change between phases
Wardhani, D. A.; Thesis for Magister of Profession Psychology in Child-Clinical Psychology University of Indonesia, 2007	4-year-old boy with visual impairment	Single-case experiment, A-B design	Training with tactile strategy; 11 daily sessions, 30 min in child's house	Pointing self-body parts correctly	Increase in participant's ability to identify body parts except hair and eyes; visual analysis (qualitative approach) showed positive-level change
Rahim, R. S.; Thesis for Bachelor of Education in Special Education, Indonesia University of Education, 2014	7-year-old girl with intellectual disability	Single-case experiment, A-B-A design	Cendana aromatherapy with vaporizer technique; 15 daily sessions, 30 min in kindergarten classroom	Aggressive behaviours (e.g. hitting other person)	Aromatherapy successful in reducing aggressive behaviour but without long-term effect; positive-level change between phases, PND of 0%

Note: ASD = autism spectrum disorder; PND = percentage of nonoverlapping data.

3.7 Discussion

This scoping review explored the existing literature about interventions designed to support the development of young children with disabilities in Indonesia. Despite the scale of childhood disability, this is the first published review that we are aware to form a coherent picture of current knowledge. Only eight articles met the inclusion criteria and none of these were published in international journals. More research might have been found however, had we extended our search of university libraries given that this was one of the main sources of the identified research. This finding might also apply to other low- and middle-income countries where publishing is mainly done in domestic platforms.

3.7.1 Intervention date and site

The chronological distribution of the studies indicate that it has only been in the last 12 years that researchers have paid attention to researching interventions for young children with disabilities. This situation is similar to that of other countries in the South-East Asia region (e.g., Cambodia, Vietnam), which typically pays more attention to adults with disabilities (SEARO-WHO, 2013). At the same time, the fact that half of the included studies were published recently could be viewed as a signal of a positive momentum to address the challenge of caring for young children with disabilities.

The geographical focus of the research deserves note and highlights the disparity of research being conducted between the main island of Java and other jurisdictions in Indonesia. This finding has also been noted in reviews of research about disability from other low- and middle-income countries such as Vietnam (Ha, Whittaker, Whittaker, & Rodger, 2014) and Namibia (Coomer, 2013). Certainly, the geographic spread of Indonesia across a vast archipelago makes the dispersion of resources more difficult, and our results highlight the need for programs and research that take account geographical location, as environmental risk and poorer access to services are more acute outside of the main centers.

3.7.2 Nature of intervention

A wide range of interventions were employed including two that utilized local resources—specifically Lenggang Alit dance and Cendana aromatherapy. Lenggang dance is native to the

Malayu or Melayu tribe and has many variations (Indonesia.travel, n.d.), while Cendana is a wood that can be easily found in East Nusa Tenggara province, Indonesia. Cendana oil has been used for many purposes, including aromatherapy ("Mengembalikan harum cendana," 2010).

This may reflect the movement within Indonesian universities to utilize local knowledge and resources in the design of locally specific interventions (Sugiarto, 2015). This is occurring in alignment with the position that local knowledge will be more suitable to explain and solve local challenges rather than generalized research from the so-called "WEIRDos" (Western, Educated, Industrialized, Rich, and Democratic) countries (Jones, 2010). This particular movement is also taking place in other countries in Asia, namely, South Korea, Philippine, China, and Taiwan (Kim, Yang, & Hwang, 2006), and indicates that we can expect more of locally specific intervention research in the future.

3.7.3 Objective of intervention

The studies were broad in terms of the developmental aspects addressed and included cognitive, sensory motor, communication, and social-emotional focus. This is exceptional considering the dearth of research, workforce, and services in Indonesia. It might be partly explained by the disciplinary background of the researchers, which included both psychology and special education. However, the lack of involvement of social science researchers and practitioners is curious, considering that the Ministry of Social Affairs is the leading agency tasked with to tackling disability issues in Indonesia.

Noticeably, none of the interventions took account of environmental risk and focused directly on the specified disability suggesting a narrow individualistic approach. This narrow approach is in contrast to that indicated in other reviews from countries such as Tanzania which document that environmental conditions are readily incorporated into research from that country (Njelesani, Couto & Cameron., 2011).

3.7.4 Methodology and duration of intervention

The included research was generally of poor quality. The single-subject design used in the included studies is popular for examining the efficacy of interventions for children with disabilities, as it is simple and less complex than other approaches (Cook & Bennett, 2014). The choice of design might have been additionally influenced by the difficulties with recruiting participants due to stigma, an environmental risk factor that is at play in much of Indonesia (WHO, 2011) and other low- and middle-income countries (WHO, 2012b). Nevertheless, more research using robust designs with pre-powered sample sizes is necessary to improve outcomes for children living with disabilities in these settings.

The review also indicates that improvements in research procedure and especially ethics oversight is needed to avoid harm. Furthermore, the included interventions appeared to be very time and resource intensive, occurring averagely 2 weeks and conducted by a trained professional (albeit a student). Such an approach is unlikely to be able to be disseminated at the scale required to improve outcomes at the population level given the dearth of workforce and services.

3.7.5 Implications for disability rehabilitation

The results from this review indicate an emphasis on home- and class-based interventions with a lack of research about community-based interventions. This is concerning given WHO reports indicating that such an approach is ubiquitous in the South-East Asia region (SEARO-WHO, 2012). There is clearly a need to improve the documentation of community-based rehabilitation as well as to better prepare workers in this area to utilize local resources to take account of the inter-related effects of disability and poverty (van Pletzen, Booyens, & Lorenzo, 2014).

3.7.6 Future research

This review should provide useful information for policy makers and practitioners working with young children with disabilities in low and middle-income countries such as Indonesia. Development of evidence-based interventions utilizing local resources is critical. Available resources such as religious leaders (e.g., priests, ustads) and other local practitioners may address the issue of access by offering people-centered, integrated primary health services such as suggested by the Global Strategy for Health (Campbell et al., 2015). Internet-based approaches may also be beneficial considering the Indonesian government's recent efforts to improve Internet-access (Noor, 2015), which is also happening in other low- and middle-income countries (West, 2015). Taken together, initiatives such as these might prove to be useful in improving access to basic and targeted services thus assisting Indonesia and other low- and middle-income countries to achieve global development goals such as those recently restated by the United Nations (2015).

3.8 Conclusion

This scoping review provides an overview of the current available evidence regarding interventions designed to support the development of young children in Indonesia. The fact that only eight articles with minimal quality were found after searching the published and unpublished literature highlights the need for more contextually relevant research. This review highlights the need for more research to ensure access to evidence-based, context-specific, and culturally appropriate services to address childhood disability in Indonesia and other low- and middle-income countries.

3.9 Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

3.10 Funding

The author(s) disclosed receipt of the following financial support for the research and/or authorship of this article: The first author is sponsored by the Indonesia Endowment Fund for Education (LPDP) for this study and the whole PhD programme at The University of Adelaide.

CHAPTER FOUR. INTERVENTION RESEARCH ADDRESSING ENVIRONMENTAL RISK FACTORS FOR YOUNG CHILDREN WITH DISABILITIES IN DEVELOPING COUNTRIES: A SYSTEMATIC REVIEW

4.1 Preamble

This systematic review was designed to discover interventions addressing childhood disability and environmental risk factors in developing countries with economies similar to Indonesia. Given the low number of studies identified in the scoping review of Indonesian research, the decision was made to broaden the review to include similar countries. To improve adaptability of the interventions, only those developed and tested in developing countries with a similar human development index to that of Indonesia were reviewed.

4.2 Statement of authorship

Title of paper: Intervention research addressing environmental risk factors for young children with disabilities in developing countries: a systematic review

Publication status: Published

Publication details: Kiling, I. Y., Due, C., Gyss, C., Li, D. E., & Turnbull, D. (2018a). Intervention research addressing environmental risk threatening young children with disabilities in developing countries: a systematic review. Disability and Rehabilitation. doi: 10.1080/09638288.2018.1509142

4.2.1 Principal author

Name of principal author (candidate): Indra Yohanes Kiling

Contribution to the paper: Responsible for the primary authorship of this research and also correspondence with reviewers and journals. Responsible for the literature search design and process, analysis and writing of the manuscript.

Overall percentage: 80%

Certification: This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.

Signature: Indra Yohanes Kiling *Date:* 01/08/2018

4.2.2 Co-author contributions:

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate to include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

Name of co-author: Prof. Deborah Turnbull

Contribution to the paper: Input on review design, database searches, interpretation of findings, and writing of the manuscript. Oversight of article progress including publication process. Provided editorial and structural feedback.

Signature: *Date:* 01/08/2018

Name of co-author: Dr. Clemence Due

Contribution to the paper: Input on review design, database searches, interpretation of findings, and writing of the manuscript. Provided editorial and structural feedback.

Signature: *Date:* 01/08/2018

Name of co-author: Dr. Dominggus Elcid Li

Contribution to the paper: Input on interpretation of findings and writing of the manuscript. Provided feedback on drafts.

Signature: *Date:* 01/08/2018

4.3 Abstract

Purpose: Young children living with disabilities in developing countries face a range of environmental risks that may impact their development. However, very little research has explored how to provide interventions for, or support to, this group of children and their families. In this systematic review, we examined studies which evaluated interventions to address environmental risk factors in developing countries. *Method:* 10 databases were searched. Websites of organisations active in disability and children's issues were also searched. *Results:* 48 studies met our inclusion criteria (11 qualitative, 29 quantitative and 8 mixed methods). The findings indicate that the impact of environmental risk factors on development might be ameliorated by providing disability screening services, community-based interventions, and targeted and inclusive basic services. The review also identifies key barriers to supporting these children as stigma and discrimination. Key enablers include religious support and community education. *Conclusions:* Comprehensive interventions from screening services to inclusive basic services are needed, as well as collaboration from related stakeholders and utilization of local resources.

Keywords: disability, young children, intervention, developing countries, systematic review

4.4 Introduction

The WHO indicates that there are nearly 100 million children worldwide with disabilities (WHO, 2011), with most living in developing countries. While demands for social and health services are increasing in developing countries (Dowd & Manton, 1992; Kusumastuti et al., 2014), the quality of available services remains poor (Maulik & Darmstadt, 2007). For example, in the Indonesian context, the gap in primary school attendance rates between children living with and without disability is 60%, while in secondary education, there is a 58% gap (WHO, 2011).

At the same time, there is a dearth of research examining interventions for childhood disability in developing countries, and as such, there is very little evidence upon which to build new approaches (Maulik & Darmstadt, 2007). This is particularly pronounced for children growing up in developing countries who also face environmental risks such as poverty, abuse, or lack of available services (WHO, 2012b). Against this background, the aim of this systematic review was to synthesize existing research about interventions for young children living with disability and experiencing environmental risk factors in developing countries.

4.4.1 Terminology

The WHO defines environmental factors as “the physical, social and attitudinal environment in which people live and conduct their lives” (WHO, 2007b, p.xvi). Further, the organisation lists five categories of environmental factors: (1) products and technology, (2) natural environment and human-made changes to environment, (3) support and relationships, (4) attitudes, and (5) services, systems and policies.

In relation to specific risk factors, the WHO provides examples such as limited financial resources, stigma and discrimination, poor interaction with parent or caregiver, corporal punishment or other punitive parenting measures, violence, abuse and neglect, and restricted access to various services (Guralnick, 2013; WHO 2012b).

In terms of actual disability, the UN states in the Convention on the Rights of Persons with Disabilities that “persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006, p. 4). A related issue is that of developmental disability, which has been defined by the Administration on Developmental Disabilities as “a physical and mental impairment that begins before age 22 that inhibits a person’s capacity to do at least three of the following tasks: (1) Take care of themselves (dress, bathe, and eat), (2) speak and understand clearly, (3) learn, (4) walk/move around, (5) make decisions, (6) live independently, and/or (7) earn and manage an income” (Shannon & Tappan, 2011, p. 1469).

Empirical research based on all types of disability is needed to have specific health, education, rehabilitation, social and support needs (WHO, 2011). Of relevance to this review is research that indicates that prevalence rates of disability are higher in rural areas in all nations including developing countries (WHO, 2011).

4.4.2 Previous research addressing interventions for children living with a disability

A previous systematic review focusing on children of all ages found only four studies evaluating an intervention for children with pervasive developmental disorders in developing countries (Hastings, Robertson & Yasamy, 2012). The current systematic review aims to build on that number by considering young children specifically. While various early intervention programmes exist, the majority have been developed in high-income, predominately Western countries, and take into account environmental risk factors only generally. Examples include meta-analyses from the United States, the United Kingdom and Australia, highlighting intensive interventions for parental implementation (Skotarczak & Lee, 2015). Similarly a review of family-centred approaches indicated that while such services are increasingly common, no mention is made about the potential impact of culture or country of origin. This lack of attention to children with disabilities living in developing countries is also seen in a number of other meta-analyses and systematic reviews (Andrews, Falkmer & Girdler, 2015; Lindo, Kliemann, Combes & Frank, 2016; Lindsay & Edwards, 2013).

As such, the majority of literature in this area relates to interventions designed and tested in high-income countries, with only a small number of programmes specifically designed for use in either rural contexts, or in developing countries (Maulik & Darmstadt, 2007). As a result, very little is known about best practice for interventions for young children living with disabilities in developing countries who also face environmental risk factors. We have previously conducted a scoping review addressing interventions for young children with disabilities in Indonesia, which has a high rate of childhood disability in the context of environmental risk (Kiling, Due, Li & Turnbull, 2018b). This systematic review is intended to complement the scoping review by identifying best practice interventions published from 42 developing countries with a medium Human Development Index like that of Indonesia (e.g. India, Bangladesh, Timor Leste, South Africa). Thus our aim is to review interventions for young children living with disabilities in developing countries who are exposed to environmental risk factors.

4.5 Methods

We used standardized and recognized conventions for data collection and analysis (Joanna Briggs Institute, 2014a; Joanna Briggs Institute, 2014b). Similarly, data synthesis and analysis processes were conducted according to the Social Care Institute for Excellence Systematic Research Review Guidelines (Rutter et al., 2010).

4.5.1 Study inclusion

In order to be included, the study had to: (1) address an evaluation of an intervention addressing environmental risk factors impacting the developmental process of young children with disabilities. The targeted environmental risk was defined by the researchers after analysing the nature of the intervention; (2) include children or parents of children in the early childhood period defined as zero to eight years of age: broad age groups were accepted if they included children 0-8 years of age as well; (3) be conducted in a country with a medium Human Development Index similar to that of Indonesia (UNDP, n.d.), but not Indonesia itself; (4) be published in English; and (5) be published between 2006 and 2016.

We decided to limit the time frame to between 2006 and 2016 to ensure that the interventions included were relevant to the modern context. Given lack of research in this area, we also reviewed grey literature and unpublished studies such as those conducted by

NGOs and UN agencies, provided that they reported primary empirical data, as well as unpublished dissertations.

4.5.2 Types of participants

While the WHO [5] defines the 'young' childhood period as being between the prenatal period and eight years, as prenatal interventions such as screening are generally not available in developing countries (Parry, 2012), this review included children from birth to eight years of age, a period when disability may become obvious. Disability was defined broadly, in accordance with the UN definition and WHO, as outlined previously.

4.5.3 Outcome and design

The review included all reports of interventions addressing environmental risk factors that could harm the developmental process of young children with disabilities, such as poverty, stigma and discrimination, poor interaction between children and parents, violence and abuse, and limited access to basic or essential services (WHO, 2012b). Interventions could focus on one particular factor or multiple factors, and could be in the form of treatment or therapy. All study designs were considered, provided that the paper reported on primary empirical data.

4.5.4 Search methods

The following electronic databases were searched: PsycINFO, PubMed, Embase, ERIC, Social Services Abstracts, CINAHL, Cochrane Central Register of Controlled Trials (CENTRAL), The Campbell Collaboration, Scopus, and ProQuest Dissertations & Theses Global. A logic grid was developed with advice from an experienced medical librarian to search the PubMed database and then adapted for subsequent searches (see Appendix 1). The following three main search terms were used: "disability", "intervention", and "developing countries" and a complete list can be obtained from the first author. To locate grey literature, searches were conducted of UN agencies and NGO websites considered relevant to the research question: the WHO; UNICEF; The Disability Rights Fund; Handicap International; The International Council for Education of People with Visual Impairment (ICEVI); Save the Children International; Plan International; World Vision Research Institute, and ChildFund International. In addition, we searched the reference lists of research articles we included. As outlined further below, all titles were initially screened by the first author. Assessment of full-text articles selected from abstracts and title screening was then conducted independently by two authors (IK and CG) who discussed differences until consensus was reached. (The search was conducted between 26th May 2015 and 30th September 2015 and updated between 8th May 2017 and 13th May 2017.)

4.5.5 Data analyses and methodological quality appraisal

The findings were synthesized using a thematic approach, a method commonly used to summarize qualitative and quantitative studies in systematic reviews (Lucas, Baird, Arai, Law & Roberts, 2007). Quality assessment of qualitative, quantitative, and mixed methods studies was done using the Mixed Methods Appraisal Tool (MMAT), an approach utilized worldwide that provides critical appraisal methods for different study designs (Pluye & Hong, 2014). Criteria assessed included: quality of data sources, analysis process, description of randomization, selection bias, integration of quantitative and qualitative data, and consideration of the researchers' influence on the study. The methodological quality is provided in the form of a percentage score with a minimum of 25% and maximum of 100%.

4.6 Results

4.6.1 Description of the included studies

The initial database search produced 3037 results (see Figure 4.1). Of these, 2879 were excluded at the state of reviewing titles and abstracts, leaving 158 studies. After reviewing the full text of these studies, a further 113 articles were excluded.

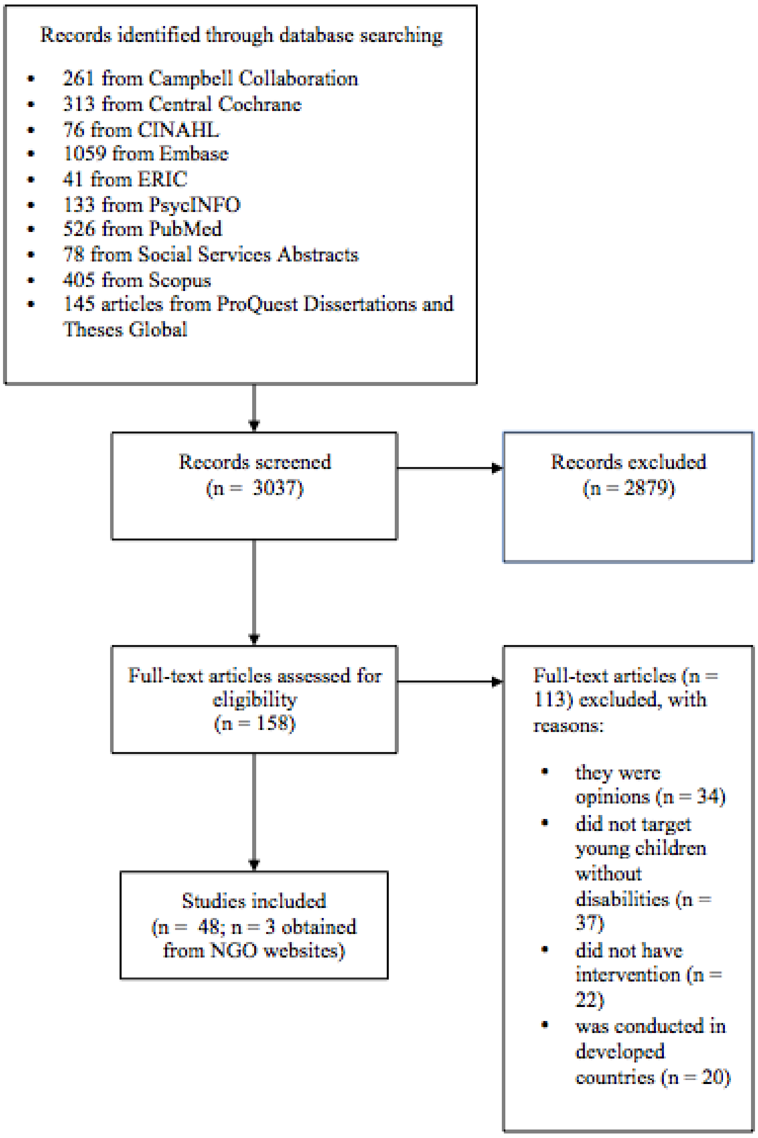

Figure 4.1: Flow diagram of paper selection

This left a total of 45 articles; three additional studies were then included after searching UN agencies and NGO databases making a total of 48 included studies: 11 reporting qualitative studies, 29 reporting quantitative studies and 8 reporting mixed methods studies. Table 4.1 supplies key characteristics of the included studies. Tables 4.2, 4.3, 4.4, and 4.5 in each sub-section provide details of each of the included studies plus notes on quality, as defined by the MMAT tool.

More than half of the studies used quantitative approaches (60% $n = 29$), especially non-randomized designs such as non-randomized controlled trials, cohort studies and cross-sectional studies (56% $n = 27$). Eleven studies (23%) were qualitative in nature; eight utilised interviews and eight (17%) studies used mixed methods design. The majority (both qualitative and quantitative studies) had samples between 20 and 100 participants (35% *n* = 17). The most common study locations were the South Asian region, particularly India and Bangladesh (52% *n* = 25), and Africa (42%, *n* = 20).

Neonates and/or infants were the most common age group of participants in the included studies (50% *n* = 24), and adults reporting on early childhood disability were the second most common group of participants (40% *n* = 19), highlighting the reliance on parents/caregivers and service providers to provide data concerning young children living with disabilities. In terms of disability, the most common impairment was hearing impairment (29% *n* = 14); this is closely related to hearing screening as the most common type of intervention (29% *n* = 14). 73% of the studies concentrated on urban areas (*n* = 35), while only 33% were conducted in rural areas (*n* = 16). Almost all of them dealt with environmental risk factors associated with services, systems and policies (98%, *n* = 47). The other two most common environmental risk factors were physical and emotional support (31% *n* = 15), and individual attitudes (21% *n* = 10).

Thematic analysis resulted in identifying four categories of interventions:

Table 4.1: Characteristics of studies

First year of publication	**Number of studies**	**% of total studies**
2006–2010	22	46
2011–2015	26	54
Study design		
Quantitative non-randomized (non-randomized controlled trials, cohort, case-control, cross-sectional)	27	56
Qualitative	11	23
Mixed methods	8	17
Quantitative descriptive	1	2
Quantitative randomized controlled trial	1	2
Sample size		
$n < 20$	4	8
$20 \leq n < 100$	17	35

First year of publication	**Number of studies**	**% of total studies**
100 ≤ *n* < 200	7	15
200 ≤ *n* < 1000	8	17
n ≥ 1000	12	25
Region of study		
South Asia	25	52
Africa	20	42
South-East Asia	9	19
Middle East	5	10
Latin America/Caribbean	4	8
Oceania/Pacific	3	6
Eastern Europe	3	6
Western Europe	2	4
North America	1	2
East Asia	1	2
Study participant characteristics		
Age group		
Newborns/infants (0 to 2 years)	24	50
Preschool (3 to 5 years)	15	31
Primary school (6 to 11 years)	10	21
High school (12 to 18 years)	2	4
Adults (>18 years)	19	40
Type of impairment		
Hearing impairment	14	29
Several/multiple kinds	11	23
Developmental disability	8	17
Cerebral palsy	5	10
Autism spectrum disorder	5	10
Mental & intellectual disability	3	6
Foot impairment	2	4
Visual impairment	1	2
Religion		
Christian	2	4
Buddhism	2	4
Non-religion	2	4
Catholic	1	2
Hindu	1	2
Place of residence		
Urban	35	73
Rural	16	33
Remote	2	4
Participant group		
Children	31	65
Related key informants (teachers, health workers, social workers)	15	31
Parents/caregivers	13	27
Type of intervention		

First year of publication	**Number of studies**	**% of total studies**
Disability screening		
Hearing screening	14	29
Developmental screening	11	23
Community based		
Community-based rehabilitation	3	6
Targeted services		
Family-centred/home-based rehabilitation services	4	8
Rehabilitation centre	2	4
Ponseti method rehabilitation	2	4
Application	1	2
Training and support for parents	1	2
Parent counselling	1	2
General services		
Education services	7	15
Healthcare services	6	12
Environmental risk factors dealt		
Services, systems and policies (education, health, economy, etc.)	47	98
Physical and emotional support from family, friends, etc.	15	31
Individual attitudes/general opinions of family, friends, professionals, etc.	10	21
Products and technology (food, drink, assistive devices, etc.)	6	12
Natural and human-made changes to environment	1	2

4.6.2 Disability screening intervention

The most utilized intervention was that of early identification of disabilities through screening tests (*n* = 25 studies). All of these studies addressed the environmental risk of poor or unavailable services, systems or policies through the provision or formulation of screening tools or formats. The most common type of screening was that for infant hearing with a range of tests being applied such as oto-acoustic emissions (Berg, Papri, Ferdous, Khan & Durkin, 2006; Friderichs, Swanepoel & Hall, 2012; Imam, El-Farrash, Taha & Bishoy, 2013; Kanji, Khoza-Sangase & Ballot, 2010; de Kock, Swanepoel & Hall, 2016; Mathur & Dhawan, 2007; Olusanya et al., 2007; Scheepers, Swanepoel & le Roux, 2014; Swanepoel, Ebrahim, Joseph & Friedland, 2007; Swanepoel, Hugo & Luow, 2006; Vishwakarma et al., 2015) and the automated auditory brainstem response (Imam et al., 2013; de Kock et al., 2016; Moodley, 2016; Olusanya et al., 2007).

The studies were conducted mainly in hospital and clinic settings (see for example Eldin et al., 2008; Friderichs et al., 2012), and were judged to not be affected by selection bias. The involvement of the authors in the screening process was varied with only one study involving authors who were also the screeners (Friderichs et al., 2012).

A number of findings were noted. These included problems associated with poor follow-up and coverage (Kanji et al., 2010; Olusanya et al., 2007; Swanepoel et al., 2007; Swanepoel et al., 2006), ineffectiveness of the tests and/or interventions (Moodley, 2016; Vishwakarma et al., 2015), as well as the negative impact of high costs (Nair et al., 2009; Ramesh et al., 2012), with community-based screening being suggested as a potential way to improve the uptake of screening tests in developing countries (Eldin et al., 2008; Ramesh et al., 2012), although it needed improvement in terms of system delivery (Vishwakarma et al., 2015).

Examining developmental and neurodevelopmental disability was the next most common form of screening (11 studies). In terms of quality, the studies tended not to be affected by selection bias, but author involvement in the screening process may have impacted results overall. Most of the screening tools used in the studies were adapted from established tools produced in developed countries such as the Bayley Scale of Infant Development (Bhave, Bhargava & Kumar, 2010) and the Denver Developmental Screening Test (de Kock et al., 2016; Mathur & Dhawan, 2007), with one study using a tool developed from the WHO that was found to be widely reliable (Scherzer, 2009). Overall the findings demonstrated positive effectiveness and feasibility in developing countries (see Table 4.2).

Table 4.2: Descriptive summary of the relevant studies on disability screening intervention

Study and reference	Study design	Population (n=sample size)	Intervention	Quality assessment score & bias risk	Environmental risk factors addressed	Objective (author involvement)	Study findings
Berg et al. (2006)	Quantitative, cohort prospective	4003 children between the ages of 2 and 9 years in Kishoreganj village, Bangladesh	2 screening methods: (1) Conditioned play audiometry; (2) Oto-acoustic emissions/ tympanometry	100%; no risk of bias identified	Services, systems and policies	To find a rapid and feasible way to screen for hearing impairment (one author involved as trainer for screening)	Conditioned play audiometry was feasible for most children in the 6-9 years age range, oto-acoustic emissions/tympanometry is feasible for younger (2-5 years) children
Bhave et al. (2010)	Quantitative, instrument development and validation	Mothers of children aged 6 to 24 months attending a medical clinic in India (n=142)	Lucknow Development Screen (LDS)	75%; no risk of bias identified	Services, systems and policies	To develop and evaluate LDS (authors involved in developing and testing the test)	LDS' sensitivity is 95.9% and specificity is 73.1%, effective to be used for screening in the community
Chambers, Stronach & Wetherby (2016)	Mixed methods with observation technique, instrument preliminary testing	67 children aged 12 to 24 months in South Africa	Communication and Symbolic Behaviour Scales-Developmental Profile (CSBS DP)	75%; no risk of bias identified	Services, systems and policies	To document the performance of a group of English-speaking children on the CSBS DP and to compare this performance with the original standardization sample (authors involved in testing)	The internal consistency was generally acceptable except for one cluster score. CSBS may be a promising culturally appropriate screening tool
Eldin et al. (2008)	Quantitative, screening test	228 children in nine Arabic speaking countries including Egypt	The Modified Checklist for Autism in Toddlers (M-CHAT)	75%; recruitment of participants unclear, might be biased	Services, systems and policies	To determine the feasibility of using M-CHAT for an early onset developmental disorder in poor countries (authors involved in screening the children)	The sensitivity (0.86), the specificity (0.80) and positive predictive value (0.88) were high although the sample was not large enough to generalize the results

Study and reference	Study design	Population (n=sample size)	Intervention	Quality assessment score & bias risk	Environmental risk factors addressed	Objective (author involvement)	Study findings
Friderichs et al. (2012)	Quantitative	2018 infants between ages of 0 and 14 from eight primary healthcare clinics in the Cape Metropolitan area	Community-based infant hearing screening programme using distortion product oto-acoustic emissions	100%; no risk of bias identified	Services, systems and policies	To evaluate the efficacy of programme (authors were not involved in screening and in training)	Overall coverage rate across eight clinics was 32.4% (2018 infants). The average follow-up rate for rescreens at clinic level was 85.1%
Imam et al. (2013)	Prospective cohort study, quantitative	150 neonates at Ain Shams University Hospital, Egypt	Transient Evoked Oto-acoustic Emissions (TEOAE) and Auditory Brain Stem Response	100%; no risk of bias identified	Services, systems and policies	To compare the targeted, risk-based hearing screening and screening of the well-baby populations (authors involved in screening process)	Universal neonatal screening (using TEOAE) would detect more cases than targeted screening, allowing for early intervention
Kanji et al. (2010)	Retrospective, passive archival design	86 South African Neonates in a public sector hospital	Oto-acoustic emissions screener	75%; no risk of bias identified	Services, systems and policies	To determine the follow-up return rate for a hearing screening programme (no fieldwork was done)	Of the 86 neonates who were referred for a follow-up screening, only 31.4% returned
Khan et al. (2010)	Quantitative, instrument validation	4 study populations of infants (n=161) in Bangladesh for reliability and validity testing	Rapid Neurodevelopmental Assessment (RNDA)	100%; no risk of bias identified	Services, systems and policies	To determine the reliability and validity of RNDA (authors involved as trainers for testers)	The RNDA was proved to have high reliability and validity for both younger and older children
Khan et al. (2013)	Quantitative, instrument validation	77 young children in Bangladesh	Rapid Neurodevelopmental Assessment (RNDA)	100%; no risk of bias identified	Services, systems and policies	To validate RNDA in >2- to 5-year-old children in a developing country (authors involved as trainers for testers)	Interrater reliability ranged from good to excellent

Study and reference	**Study design**	**Population (n=sample size)**	**Intervention**	**Quality assessment score & bias risk**	**Environmental risk factors addressed**	**Objective (author involvement)**	**Study findings**
de Kock et al. (2016)	Quantitative retrospective	7452 infants screened in South Africa	Universal newborn hearing screening	100%; no risk of bias identified	Services, systems and policies	To evaluate the outcomes of distortion product oto-acoustic emissions (DPOAEs) and automated auditory brainstem response (AABR) in South Africa (authors were not involved in the screening process)	AABR screening offers lower initial referral rates and a higher true positive rate compared to DPOAE
Mathur & Dhawan (2007)	Quantitative, screening test	1000 newborn in an Indian tertiary hospital	TEOAE	100%; no risk of bias identified	Services, systems and policies	To formulate an alternative strategy for universal infants hearing screening (author involvement not clear)	Screening all neonates within the first 48 hours of life is impractical because the specificity of TEOAE is lowest at that age
Mohamed et al. (2016)	Quantitative cross-sectional	5546 Egyptian toddlers	M-CHAT	75%; no risk of bias identified	Services, systems and policies	Evaluating use of M-CHAT (authors involved in distributing the test)	Failure of M-CHAT in 1320 out of 5546 toddlers in identifying children that suspected to have autism spectrum disorder and needs further evaluation
Moodley (2016)	Quantitative, diagnostic data analysis	230 children enrolled in an early intervention programme in South Africa	Early Hearing Detection and Intervention (EHDI)	100%; no risk of bias identified	Services, systems and policies	To determine process used for diagnosis of paediatric hearing loss in South Africa, and to profile the age of testing for each component of the diagnostic test battery (no fieldwork was done)	Services across regions and across the public and private sector in South Africa are not equitable. Each region is unlikely to complete a full, comprehensive diagnostic evaluation

Study and reference	Study design	Population (n=sample size)	Intervention	Quality assessment score & bias risk	Environmental risk factors addressed	Objective (author involvement)	Study findings
Nair & Russell (2013)	Quantitative, reliability and validity test	100 children for study 1, and 385 children in study 2	Developmental Assessment Tool for Anganwandis (DATA-II)	100%; no risk of bias identified	Services, systems and policies	To develop, standardize, and validate a developmental scale for children, 3-4 years of age (author not involved in data collection)	All items except four items were endorsed by parents suggesting a good content validity. DATA-II is ready to use in Anganwadis
Nair et al. (2009)	Quantitative, screening test validation	100 toddlers attending Anganwandis hospital in India for consistency and validity test, 429 toddlers for standardization	Developmental Assessment Tool for Anganwandis (DATA)	100%; no risk of bias identified	Services, systems and policies	To develop, standardize, and partly validate a developmental scale for toddlers (author not involved in data collection)	All items but one item were endorsed by parents suggesting a good content validity. DATA is a brief, simple and sound measure to use in Anganwandis
Ngoun, Stoey, Ende and Kumar. (2012)	Quantitative, screening tool	Two pilot screenings screen children of both genders and aged from 1 month to 6 years in Cambodia (N=100 and N=63)	Angkor Hospital for Children Developmental Milestone Assessment Tool (AHC DMAT)	100%; no risk of bias identified	Services, systems and policies	To create a culturally appropriate screening tool for screening neurodevelopmental disability (three authors served as screeners)	The final AHC DMAT consists of 140 milestones
Olusanya et al. (2007)	Quantitative, cross-sectional descriptive study evaluating national level programmes	16 professionals (paediatricians, audiologists, and otolaryngologists) from various countries	Infant hearing screening programmes using oto-acoustic emissions and/or automated auditory brainstem response	100%; no risk of bias identified	Services, systems and policies	To investigate the initiatives and progress towards early detection of infants with hearing loss in developing countries from various regions (no fieldwork was done)	Coverage is generally above 90% but poor follow-up rates remain a challenge in some countries

Study and reference	Study design	Population (n=sample size)	Intervention	Quality assessment score & bias risk	Environmental risk factors addressed	Objective (author involvement)	Study findings
Ramesh et al. (2012)	Quantitative, screening test	425 Indian neonates of whom 20 had confirmed severe-profound hearing impairment in a hospital.	Low cost mechanical calibrated noisemaker	100%; no risk of bias identified	Services, systems and policies	To evaluate the strategy of screening neonates till 6 months of age (authors were not involved in the screening process)	The sensitivity and specificity was high with least false positive referrals for 70 and 80 dB (A) noisemakers
Scheepers et al. (2014)	Retrospective quantitative study	Children in two hospitals (n=954 & n=2135) in South Africa	Universal newborn hearing screening using oto-acoustic emissions	100%; no risk of bias identified	Services, systems and policies	To describe screen refusal and follow-up characteristics (authors not involved in screening, but involved in the interviews)	Screening coverage, initial referral rates and follow-up return rates differed significantly and were below benchmarks. The most frequent reasons for screen refusal were related to costs (72%)
Scherzer (2009)	Quantitative, screening test	300 paediatric outpatients aged 6 weeks to 7 years in Cambodia	Developmental Milestone Chart	100%; no risk of bias identified	Services, systems and policies	To offer an alternative approach to assessing childhood developmental status (authors involved in the trials)	Utilizing local culturally appropriate developmental milestones are recommended for training purposes and regular clinic use
Swanepoel and Almec (2008)	Quantitative	100 South African mothers attending a clinic in Tshwane city, South Africa	Early detection and intervention attitudes questionnaire	100%; no risk of bias identified	Services, systems and policies; Individual attitudes/general opinions	The study investigated the attitudes mothers in relation to the early detection and intervention of infant hearing loss (authors involvement not clear)	99% indicating the desire to have their baby's hearing screened after birth and a high acceptance of hearing aids

Study and reference	Study design	Population (n=sample size)	Intervention	Quality assessment score & bias risk	Environmental risk factors addressed	Objective (author involvement)	Study findings
Swanepoel et al. (2007)	Retrospective quantitative study	6241 newborns were screened in a private hospital in South Africa	Early Hearing Detection and Intervention programme with TEOAE	75%; no risk of bias identified	Services, systems and policies	To provide preliminary results of the programme towards advocating for and guiding future programmes (no fieldwork was done)	Coverage of 75% was attained. Only 32% of the rescreens were completed at the hospital
Swanepoel et al. (2006)	Quantitative, screening test	510 infants (0-12 months of age in two clinics South Africa	Distortion Product Oto-Acoustic Emissions (DPOAE) and tympanogram	75%; no risk of bias identified	Services, systems and policies	To investigate a hearing screening programme (the authors were not involved in the screening)	Coverage with DPOAE amounted to 95% of the sample ears compared to tympanogram covered amounting to 94%. Poor follow-up rate was also discovered
UNICEF & University of Wisconsin [46]	Quantitative survey	205,674 children from 20 countries including Bangladesh, Ghana, Iraq	Ten Questions (TQ) screening for child disability	100%; no risk of bias identified	Services, systems and policies	An analysis of the TQ results from 20 countries (the authors were not involved directly in the screening)	TQ were reliable in 20 countries. Completion rates also high across the participating countries
Vishwakarma et al. [47]	Quantitative, screening test	3020 babies in India	UNHS and THS (targeted hearing screening)	100%; no risk of bias identified	Services, systems and policies	To compare between UNHS and THS in Indian context (the authors were not involved in the screening)	UNHS was difficult due to some system failure and a lot of time was wasted doing the different procedure. THS was much easier and false positive and negative were lesser

4.6.3 Community-based rehabilitation (CBR)

Community-based rehabilitation is a strategy that targets disability in resource-limited environments through a multi-sectoral approach. Within broader development programmes, this approach aims to integrate people with disabilities into society by focussing on health, education, livelihood, social functioning, and empowerment (van Pletzen, Booyens & Lorenzo, 2014). Three of the included studies addressed CBR (Kuipers, Wirz & Hartley, 2008; Narayan & Reddy, 2008; van Pletzen et al., 2014) in the context of multiple environmental risk factors including: such poor quality/unavailability of assistive products and technology; poor services systems and policies; harmful natural environment and damaging human-made changes to environment; negative individual attitudes; and inadequate physical and emotional support. The authors were not involved in primary data collection activities in any of the three studies.

All three studies mentioned the importance of strengthening the ability and skill of CBR workers in order to improve the effectiveness of rehabilitation activities in developing countries. Two studies stressed the importance of providing capacity training for CBR workers (Kuipers et al., 2008; Narayan & Reddy, 2008). Specifically, one study (Kuipers et al., 2008) mentioned that the training should address rehabilitation and management-related issues. The other study (van Pletzen et al., 2014) found that CBR workers' ability in using local resources in rehabilitation activities is pivotal in addressing the interrelated effects of poverty and disability.

Table 4.3: Descriptive summary of the relevant studies on community-based intervention

Study and reference	Study Design	Population (n=sample size)	Intervention	Quality assessment score & bias risk	Environmental risk factors addressed	Objective (author involvement)	Study findings
Kuipers et al. (2008)	Mix-method analysis of documents	37 evaluation reports from 36 disability and development projects in 22 countries	Community-based rehabilitation (CBR) – comprehensive rehabilitation services for people with disabilities	75%; risk of findings might related to researchers' influence	Products and technology; Services, systems and policies; Natural environment; Individual attitudes/general opinions; Physical and emotional support	To synthesize previous CBR reports with dominantly qualitative approach (no fieldwork was done)	The methodology was found to be feasible and productive. CBR should be more connected and collaborative at governmental, political, organisational and community levels
Narayan & Reddy (2008)	Quantitative, training programme	25 participants including 23 Community Coordinator and 2 Community Development Workers in India	CBR	75%; no risk of bias identified	Services, systems and policies; Physical and emotional support	To give training middle level functionaries in an existing CBR programme (author was not involved in giving training)	The training programme was effective in providing knowledge, skills and competencies to the participants

Study and reference	Study Design	Population (n=sample size)	Intervention	Quality assessment score & bias risk	Environmental risk factors addressed	Objective (author involvement)	Study findings
van Pletzen et al. (2014)	Qualitative	16 informants engaging with disability in Botswana, Malawi, and South Africa	CBR	75%; risk of findings might related to researchers' influence	Products and technology; Services, systems and policies; Individual attitudes/general opinions; Physical and emotional support	To explore the extent to which community-based disability workers bring local resources to bear on development work (authors were not involved in the interviews)	Community-based disability workers' experience of disability in resource-limited communities may constitute an important local resource to address poverty and disability issues

4.6.4 Targeted services/programmes

Targeted services/programmes in this review refers to interventions that specifically target young children with particular kinds of disabilities, most notably cerebral palsy (Adams et al., 2012; Hamblin & Musa, 2006; Morgan & Tan, 2011; Palit & Chatterjee, 2006) and/or their parents. Eight studies considered such approaches (see Table 4.4). Half of these addressed family centred/home-based services (Hamblin & Musa, 2006; Morgan & Tan, 2011; Shin et al., 2009; Storbeck & Pittman, 2008) for improving physical and emotional support. Other interventions included training and support for parents (Adams et al., 2012); rehabilitation centre intervention (Divan et al., 2015; Maloni et al., 2010); mobile application (Nahar, Jaafar, Ahamed & Kaish, 2015); parent counselling (Palit & Chatterjee, 2006); and the Ponseti rehabilitation method (Evans, Chowdhury, Kabir & Rahman, 2016; Perveen et al., 2014).

Eight studies were affected by the bias of having the researchers' influence the findings (Adams et al., 2012; Divan et al., 2015; Evans et al., 2016; Hamblin & Musa, 2006; Morgan & Tan, 2011; Nahar et al., 2015; Perveen et al., 2014; Storbeck & Pittman, 2008). For example, one study (Storbeck & Pittman, 2008) noted a risk of bias since some of the authors worked in the NGO who introduced the programme that was evaluated in the research. All 11 studies reported positive results from their interventions, indicating the possibility of replication or adoption of the interventions.

Table 4.4: Descriptive summary of the relevant studies on targeted services/programme

Study and reference	Study design	Population (n=sample size)	Intervention	Quality assessment score & bias risk	Environmental risk factors addressed	Objective (author involvement)	Study findings
Adams et al. (2012)	Case series, mixed methods approach	Caregivers and their children with cerebral palsy in Bangladesh aged 1-11 years (n=37)	Training and support	50%; risk of bias since participants identified mainly through NGO network	Products and technology; Physical and emotional support	To promote child health and wellbeing through nutrition approaches (authors involved as trainer)	All but two caregivers reported feeling less worried and more optimistic about their child's problems
Divan et al. (2015)	Qualitative methods	Parents, pre-school and primary school teachers, special educators (n=98)	Parent-mediated intervention for Autism Spectrum Disorder in South Asia (PASS)	75%; risk of findings might related to researchers' influence	Services, systems and policies; Physical and emotional support	Reports on the systematic adaptation of evidence-based intervention in India and Pakistan (authors involved in interview and focus group)	PASS shares the core theoretical foundations of the original Preschool Autism Communication Therapy but is adapted in several aspects to enhance acceptability, feasibility, and scalability
Evans et al. (2016)	Mixed methods, retrospective with interview	151 children with congenital clubfeet attended a clinic in 2011 (n=99)	Ponseti method	100%; risk of bias since an author is not neutral as a clinic staff where the intervention was implemented	Products and technology; Services, systems and policies	To review the results for children 4 years after treated with Ponseti method, with treatment commencing before age of 3 years (authors involved in interview)	99% children could walk and run. Parents were very happy with their child's feet (97%), the cost for treatment was deemed unaffordable by 60%
Hamblin & Musa (2006)	Qualitative action research	20 children and their families in Kolkata, India	Family-based rehabilitation services	50%; risk of findings might related to researchers' influence	Services, systems and policies; Individual attitudes/general opinions; Physical and emotional support	To plan and implement a rehabilitation services project (authors participated in observation and reflection)	Parents were motivated to help their children achieve their maximum potential

Study and reference	**Study design**	**Population (n=sample size)**	**Intervention**	**Quality assessment score & bias risk**	**Environmental risk factors addressed**	**Objective (author involvement)**	**Study findings**
Maloni et al. (2010)	Descriptive qualitative	Mother of children with disabilities receiving services at paediatric rehabilitation facility in Bangladesh (n=11)	Multiple treatments including traditional, rehabilitative and medical interventions	100%; no risk of bias identified	Services, systems and policies; Physical and emotional support	To describe how the perceptions of disability influence the care sought by mothers (author involved in the interviews)	Centre for Rehabilitation of the Paralysed is considered giving comprehensive parental education, child's prognosis and home management strategies
Morgan & Tan (2011)	Qualitative, case study	24 parents of children with cerebral palsy aged 3-12 years in Cambodia	Family-centred care	75%; risk of findings might related to researchers' influence	Services, systems and policies; Individual attitudes/general opinions; Physical and emotional support	To examine the perceptions of parents regarding family-centred rehabilitation practices (authors involved in interviews)	Parents valued family-centred practices in rehabilitation, with many of the preferences of parents similar to parents in Western contexts
Nahar et al. (2015)	Mixed methods with interview	5 blind participants and 1 sighted and 2 blind experts	Braille learning application	75%; risk of findings might related to researchers' influence	Services, systems and policies; Products and technology;	To evaluate usability of Braille learning application (authors involved in interview and testing)	The application design scored an overall satisfaction level of 4.53 out of 5 by all respondents
Palit & Chatterjee (2006)	Quantitative, experiment	222 parents enrolled into programme, 50 parents evaluated the programme in India	Parent-to-parent counselling programme	100%; no risk of bias identified	Services, systems and policies; Individual attitudes/general opinions; Physical and emotional support	To minimize the gap between caregivers and the child with cerebral palsy and multiple disabilities (authors were not involved in the programme)	80% of parents favoured this programme and acknowledging it as most effective

Study and reference	Study design	Population (n=sample size)	Intervention	Quality assessment score & bias risk	Environmental risk factors addressed	Objective (author involvement)	Study findings
Perveen at al. (2014)	Quantitative prospective study	400 children were randomly selected in Bangladesh	Ponseti method	100%; risk of bias since some authors are from the NGO who introduced the programme	Products and technology; Services, systems and policies	To review the physical and functional outcomes of children with congenital clubfoot deformity after treatment with the Ponseti method (author involved in the assessment process)	Most children could walk independently (99.0%). Parental satisfaction was very high, but cost of 3000 Taka ($US 38.48) was deemed unaffordable by 59%
Shin et al. (2009)	Randomized controlled trial	30 preschool-aged children in Vietnam. 16 were assigned to intervention group and 14 to a control group	Home-based intervention programme	75%; no risk of bias identified	Services, systems and policies	To examine the impact of a 1-year intervention for young children with intellectual disabilities (authors involved in training the teachers)	Children whose mothers had higher levels of education performed better in adaptive functioning
Storbeck & Pitman (2008)	Mixed methods design	32 infants and their families in South Africa	Home-based intervention programme (HI HOPES)	50%; risk of findings might related to researchers' influence	Services, systems and policies; Physical and emotional support	To examine data on infants and families registered with HI HOPES in order to track the effectiveness of the programme (authors not involved as interventionists)	The report shows that, though the sample is small, there is a high level of satisfaction from families who have received services

4.6.5 Inclusive healthcare and education/basic services

In this review, we define inclusive healthcare and education services/general services as those designed for all members of the community rather than those with specific disabilities. Nine studies investigated these inclusive basic services (see table 4.5). All but three studies (Ellingsen, 2011; Ha et al., 2014; Irvine, 2015b) were affected by the bias of the researchers being involved in service delivery. All but one study (Petaia, 2010) had the authors involved somehow in the data collection phase.

Overall, the nine studies provide some important insights into reducing environmental risk factors, with four studies addressing service delivery needs in the form of inclusive education, while also reporting on improvements in attitudes, and physical and emotional support for children (Handicap International & Christoffel-Blindenmission, 2006; Malak, 2013; Meyers, 2014; Petaia, 2010). Three studies (Handicap International & Christoffel-Blindenmission, 2006; Malak, 2013; Petaia, 2010) highlighted the challenge of building the capacity of stakeholders to implement inclusive education.

Pre-service teachers in particular were reported as having unfavourable attitudes towards teaching children with special needs in regular classrooms (Malak, 2013). In Meyers' study (2014), it was reported that the global movement of inclusive education was used to justify change in old special school programmes. Key barriers to implementation of inclusive general services were stigma and discrimination (Divan et al., 2012; Ellingsen, 2011; Ha et al., 2014; Handicap International & Christoffel-Blindenmission, 2006; Irvine, 2015b), while the key element to success was attending school (Coomer, 2013; Divan et al., 2012; Handicap International & Christoffel-Blindenmission, 2006). Other important elements in achieving improved basic and inclusive general services were religious support (Divan et al., 2012), special educators (Divan et al., 2012), and community-based groups (Ha et al., 2014).

Additionally one study developed the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY), the classification guide from WHO, into one more applicable to clinical and research settings (Ellingsen, 2011). The ICF-CY facilitates the measurement of health and disability in children and youth. While not testing a direct intervention, this study may provide a practical system to help improve overall health practices.

Table 4.5: Descriptive summary of the relevant studies on basic healthcare and education/general services

Study and reference	**Study design**	**Population (n=sample size)**	**Intervention**	**Quality assessment score & bias risk**	**Environmental risk factors addressed**	**Objective (author involvement)**	**Study findings**
Coomer (2013)	Qualitative exploratory	Parents and caregivers of children with mental disabilities and disorders, teacher and support staff from schools in Namibia (n=41)	Healthcare resources	75%; risk of findings might related to researchers' influence	Services, systems and policies	To explore the challenges parents/caregivers face to access mental healthcare resources (author conducted the focus group)	School was considered as the best support provider for the child and the family because the schools help to facilitate access to healthcare services
Divan et al. (2012)	Qualitative	Families of children with autism spectrum disorder (ASD) and key community stakeholders in Goa, India (n=98)	Healthcare and education services	75%; risk of findings might related to researchers' influence	Services, systems and policies; Physical and emotional support	To understand the unmet needs of families raising a child with ASD (authors conducted interviews)	Religious support and special educators were the main advocates for most of the families providing educational inputs and emotional help
Ellingsen (2011)	Quantitative using survey	151 international experts from various countries including South Africa and India	ICF-CY Developmental Code Sets	100%; no risk of bias identified	Services, systems and policies	To enhance the utility of ICF-CY in clinical and research settings (authors involved in all phases of the research)	Four unique code sets were created and endorsed by a sample representing 27 countries and at least 13 different disciplines
Ha et al. (2014)	Mixed methods, Qualitative ethnographic and online survey	27 parents of children with ASD and 17 key informants in Vietnam. 125 completed questionnaires, 75% were women	Healthcare and education services	75%; no risk of bias identified	Services, systems and policies	To describe the services available and barriers preventing families of children with ASD accessing services (authors involved in all aspects of data gathering)	Available services are expensive and lacking. A number of parent-led groups have formed to support parents and public education and advocacy on ASD

Study and reference	**Study design**	**Population (n=sample size)**	**Intervention**	**Quality assessment score & bias risk**	**Environmental risk factors addressed**	**Objective (author involvement)**	**Study findings**
Handicap International & Christoffel Blindenmission (2006)	Action research, mixed methods	8021 children with disabilities in Bangladesh; 23,556 people in India	Community Approaches to Handicap in Development (CAHD) project	50%; risk of findings might related to researchers' influence	Services, systems and policies; Individual attitudes/general opinions; Physical and emotional support	To improve inclusion of people including with disabilities in mainstream development activities (authors are NGOs, involved with community in the programmes)	8021 children with disabilities in Bangladesh are directly enrolled in education; 43 children included in schools and 58 children receiving stipends in India
Irvine (2015b)	Qualitative case studies with comparative approach	People in Northern Ireland, Mozambique and South Africa (n=42)	National disability policies	100%; no risk of bias identified	Services, systems and policies	To determine progress of inclusion on people with disabilities based on the implementation of post-conflict policies (author is a doctoral student, involved in all data collection phases)	While policies have been developed, the resources have not been allocated properly. Specific department for disability in South Africa has not worked
Malak (2013)	Qualitative	20 pre-service teachers in Bangladesh	Inclusive education	75%; risk of findings might related to researchers' influence	Services, systems and policies; Individual attitudes/general opinions; Physical and emotional support	To explore pre-service teachers' responses to include students with special education needs in regular classrooms in primary schools (author involved in the interviews)	Pre-service teachers have unfavourable attitudes to include students with SEN in regular classrooms

Study and reference	Study design	Population (n=sample size)	Intervention	Quality assessment score & bias risk	Environmental risk factors addressed	Objective (author involvement)	Study findings
Meyers (2014)	Qualitative participant observation	Interview sample: 69 members of Nicaraguan disability-related associations and 12 members of international NGOs	Inclusive education and one-stop education services	75%; risk of findings might related to researchers' influence	Services, systems and policies; Individual attitudes/general opinions; Physical and emotional support	To demonstrate the way activists use the perceived lack of disability consciousness as justification for forcing change in grassroots organisations (author is a doctoral student, involved in all data collection phases like)	A local initiative one-stop rehabilitative and education programme was considered positive by many parents in the community, but was forced to change other activists
Petaia (2010)	Case study, qualitative approach	1200 children with disabilities in Samoa	Inclusive education	25%; risk of findings might related to researchers' influence	Services, systems and policies; Individual attitudes/general opinions; Physical and emotional support	To showcase a system that would be sustainable for inclusive education (author is a leader in ministry, not involved directly in the programme)	Challenges found were to build the capacity of stakeholders and finding people with enough time to be able to translate material

4.7 Discussion

The aim of this review was to identify best practice interventions for young children living with disabilities in developing countries (medium Human Development Index) and facing environmental risks. The review should be useful for service providers and policymakers devising interventions for application in developing countries such as Indonesia. A total of 48 studies met the inclusion criteria with research coming mainly from India, Bangladesh and South Africa. Most of the quantitative studies were sound in terms of methodology, although only one used a randomised controlled trial design (Shin et al., 2009). All but two (Irvine, 2015b; Maloni et al., 2010) qualitative studies were quite weak in giving consideration to the researchers' influence on the findings. Most mixed methods studies also did not reflect on potential problems posed from the integration process of qualitative and quantitative data. Similar findings have been noted in another relevant systematic review (Lindsay & Edwards, 2013) and point to the need for future research to include robust designs such as randomised trials as well as methods for avoiding potential bias in mixed methods studies.

The most common interventions identified in our review were disability screening programmes, community-based rehabilitation, targeted services for children with disabilities and their caregivers, and inclusive general health services. Notwithstanding the shortcomings of the research, the overall conclusion was that these approaches might contribute to addressing environmental risk factors faced by children with disabilities in developing countries.

The review identified several key aspects for the successful implementation of these interventions. With respect to screening services for hearing impairment, it was suggested that using a test such as the TEOAE, while adjusting for cost, might be generally beneficial. In relation to developmental screening, adapting existing and more established tools to fit local cultural context may eliminate the risk factor of inappropriate basic services (Bhave et al., 2010; Chambers et al., 2016). It is suggested that more intervention adaption research is required in order to improve generalizability of findings from developed western settings (Skotarczak & Kee, 2015).

The review identified that CBR has been widely implemented in developing countries (WHO, 2011) and concluded that the global rehabilitation programme is considered effective in empowering communities and children with disabilities. At the same time, high-level evaluations of CBR were relatively scarce. Besides encouraging CBR workers to utilise local resources, such as community-based health and education services as suggested by our review, it is also important for them to recognise the unique environmental risk factors facing different countries such as the high prevalence of HIV in Papua, Indonesia, caste/cultural hegemony in India, and the common practice of corporal punishment in most of Eastern Indonesia.

The majority of reviewed research into targeted services addressed the needs of children with cerebral palsy, suggesting the need for investigations into other types of common disabilities such as Down syndrome. The included studies indicated that improving the interaction of children with their caregivers is indeed possible (Adams et al., 2012; Hamblin & Musa, 2006) and suggested that home- and family-based interventions have potential for addressing both the developmental and environmental aspects of disability. The development of home-based interventions is also required for high-income countries, where hospital-based interventions seem to dominate (Petaia, 2010). A key implication of the review findings is that it may be desirable to galvanise local resources such as health centres and religious services at a national level to spread coverage of targeted services.

The review also identified key obstacles to providing services, chiefly amongst these, stigma and discrimination. Potential mechanisms for addressing these challenges might include religious support as well as community education (Divan et al., 2012). It has also been suggested that government workers should be better educated to ensure a higher level of commitment to implementing disability policies (Irvine, 2015b). The review also identified the importance of school context. Indeed, it has been suggested that schools may be better strengthened in their role to serve as the leading institution in creating an inclusive community environment (Coomer, 2013). Certainly evidence from developed countries indicates that the school has a role to play in providing social contact, which is regarded as an important component of successful interventions (Lindsay & Edwards, 2013). Other suggestions are to improve the capacity of community-based kindergartens in facilitating inclusion and reducing stigma.

Related to this is the need to improve education systems in developing countries to avoid mainstream teachers becoming overburdened in providing inclusive education (Malak, 2013). Regulating the roles of special education teachers and mainstream teachers is also important in order to ensure the success of inclusive education. Additionally, curriculum within the higher education sector might be reviewed in order to better prepare basic service workers for inclusive service provision. At the same time, it has been argued that systems and policy need to be in place in developing countries to not only facilitate inclusive education but also sustain special schools (Meyers, 2014). In this context the development of future research and programmes might benefit from the development code set of ICF-CY developed by Ellingsen (2011). Further, our review found that most interventions focus on disability in general (Handicap International & Christoffel-Blindenmission, 2006; Irvine, 2015b; Malak, 2013; Meyers, 2014; Petaia, 2010). In comparison, in developed countries, while this is the case for interventions for younger children, interventions for older children tend to be more specific in nature (Lindsay & Edwards, 2013).

The review also identified the types of environmental risk factors commonly addressed in the extant research. Interestingly, although stigma and discrimination were identified as major barriers, only 25% of studies took into account individual attitudes and only 35% addressed physical and emotional support. The main environment risks dealt with were services, systems and policies, underlining the key problem of service unavailability in developing countries. Few studies addressed risk related to lack of products and technology and natural and human-made environmental change. While these are challenging areas to address, especially in resource-limited settings, a recent innovative project coming from Indonesia might serve as a template for efforts in other settings. In this project sponsored by an international NGO, parents are encouraged to plant commodity-based trees, such as teak and mahogany, as a mechanism for saving for children's education (Tanjung, 2015).

This systematic review provides an overview of interventions for addressing environmental risk factors faced by children with disabilities living in developing countries with similar circumstances to those of Indonesia. As such, it addresses a gap in the evidence base which to date has been limited to systematic reviews of interventions in higher income countries. Generalizability of the findings from this review is limited to jurisdictions with a medium Human Development Index. Another point to stress is that some studies included older children. These were included for pragmatic reasons so as to not unnecessarily limit the results of included relevant interventions such as CBR. The majority of the reports pointed to positive findings, which might reflect publication bias. Further, while quantitative studies were generally judged as robust, qualitative and mixed methods studies were marked with limitations affecting the interpretation of findings. It is also important to note that the findings are from a limited evidence base and while we comment on areas such as education, our review has not been exhaustive in this regard. Nevertheless, the review identifies the main types of interventions with potential as well as the barriers to and enablers of programme implementation. It is hoped that the review will inform researchers and policymakers responsible for service and programme development and implementation in developing countries.

4.8 Acknowledgement

The first author would like to thank the Indonesia Endowment Fund for Education (LPDP) for their help in funding the PhD programme.

4.9 Declaration of interest

The authors report no conflicts of interest.

CHAPTER FIVE. PERCEPTIONS OF DISABILITY, ENVIRONMENTAL RISK FACTORS AND AVAILABLE SERVICES AMONG LOCAL LEADERS AND PARENTS OF YOUNG CHILDREN WITH DISABILITIES IN WEST TIMOR, INDONESIA

5.1 Preamble

The qualitative study in this chapter addressed the perspectives of parents and local leaders by utilising the interview and photovoice approach for data collection. The study was designed to complement and add to the information obtained in the previous two reviews in order develop the best practice framework.

5.2 Statement of authorship

Title of paper: Perceptions of disability, environmental risk factors and available services among local leaders and parents of young children with disabilities in West Timor, Indonesia

Publication status: Published.

Publication details: Kiling, I. Y., Due, C., Li, D. E., & Turnbull, D. (2018c). Perceptions of disability, environmental risk factors and available services among local leaders and parents of young children with disabilities in West Timor, Indonesia. Disability and Rehabilitation. doi: 10.1080/09638288.2018.1466924

5.2.1 Principal author

Name of principal author (candidate): Indra Yohanes Kiling

Contribution to the paper: Responsible for the primary authorship of this research and also correspondence with reviewers and journals. Responsible for the research design and process, fieldwork, analysis and writing of the manuscript.

Overall percentage: 80%

Certification: This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.

Signature: Indra Yohanes Kiling *Date:* 01/08/2018

5.2.2 Co-author contributions:

By signing the Statement of Authorship, each author certifies that:

i. the candidate's stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate to include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate's stated contribution.

Name of co-Author: Prof. Deborah Turnbull

Contribution to the paper: Input on research design, research questions, interview schedule, interpretation of findings, and writing of the manuscript. Oversight of article progress including publication process. Provided editorial and structural feedback.

Signature: *Date:* 01/08/2018

Name of Co-Author: Dr. Clemence Due

Contribution to the paper: Input on research design and methodology, support in data collection tools (cameras), research questions, interpretation of findings, and writing of the manuscript. Provided editorial and structural feedback.

Signature: *Date:* 01/08/2018

Name of co-Author: Dr. Dominggus Elcid Li

Contribution to the paper: Input on interview schedule, help in connecting with several stakeholders related to the research, interpretation of findings and writing of the manuscript. Provided feedback on drafts.

Signature: *Date:* 01/08/2018

5.3 Abstract

Purpose: As an underdeveloped region of Indonesia, West Timor faces a significant challenge with childhood disability compounded by environmental risk factors such as poverty, discrimination and stigma, and limited access to basic services. However, very little is currently known about how this important social issue is viewed from the perspective of parents and local leaders, who play an influential role in local society. The aim of this research was to explore the views of these groups towards childhood disability, within an environmental risk context. *Method:* Data were collected via semi-structured interviews and photovoice with 23 parents and 15 local leaders including a midwife, priest, headmaster and staff from international and local non-government organisations. *Results:* The results of the study suggest that local culture, including religion, has a strong influence on the perceptions of disability and environmental risk factors, while available services are seen by parents as being inaccessible. *Conclusions:* Implications of the results are presented together with multi-sectoral recommendations for best supporting parents raising children with disabilities in rural areas in low-income jurisdictions such as West Timor.

Keywords: disability, young children, environmental risk, available services, photovoice

5.4 Introduction

Data from 2006 to 2015 indicate that disability in Indonesia ranges from 4.3% to 21.3% of the population depending on the methodology used (Adioetomo et al., 2014; Amannullah, 2016; SEARO-WHO, 2013). For children aged between birth and 14 years, disability prevalence stands at around 2 per cent and some 4 per cent of 15 to 19 year olds are living with a disability (UNICEF Indonesia, 2013). Such data however are underestimates as surveys often focus on the poverty aspects of disability and fail to take account of medical and other social aspects. It is increasingly recognised that early childhood experience, that is, from birth to eight years of age (WHO, 2012b) can significantly influence outcomes into adolescence, early adulthood and beyond (WHO, 2007a). This experience is especially crucial for young children with disabilities in developing countries who frequently struggle to flourish due to the frequent lack of basic services and other environmental risk factors (Maulik & Darmstadt, 2007), defined by the WHO in terms of the physical, social and attitudinal context in which people live and conduct their lives (WHO, 2007b). Environmental risk factors such as poverty, stigma and discrimination, lack of attachment, institutionalization, violence, exploitation and neglect, humanitarian situations and limited access to services have all been shown to negatively impact developmental outcomes (WHO, 2012b). These risk factors can either independently cause childhood disability, or together worsen the impact of existing disability (Park, Turnbull & Turnbull, 2002).

Existing research from developing countries indicates that in many cases, inherited beliefs that stem from culture and religion often result in traditional treatment seeking, including that from religious leaders, or relying on traditional herbal medicines (Maloni et al., 2010). In addition, cultural beliefs about childhood disability, for example, considering the child as 'cursed' (Bayat, 2014), can lead to discrimination towards both parents and children, including exclusion from education services, institutional neglect, physical violence and bullying (Ha et al., 2014). Christianity has also been theorised to have contributed to such beliefs in some locations with a common view being that disability is the will of God and that it is the responsibility of humans to accept God's plan (Grech, 2016). Added to this is that children with disabilities were often viewed by colonisers as having minimal economical value thus leading to further discrimination (Grech, 2015).

Parents in many developing countries have noted little economic or social support for their children, and the quality of available services is often perceived to be low (Ha et al., 2014; Maloni et al., 2010). In India, for example, research has shown that the majority of parents with children with developmental disabilities experience problems accessing rehabilitative services (Juneja, Jain, Singhal & Mishra, 2012). Together with perceived discrimination from healthcare workers, similar challenges have been reported by parents of children with mental disabilities in Namibia (Coomer, 2013). Additionally, parents themselves can be affected; recent research from Malawi, for example, points to parents experiencing mental health problems such as suicidal ideation and ideas about filicide (Masulani-Mwale, Mathanga, Silungwe, Kauye & Gladstone, 2016).

Given the diverse risks and barriers to healthcare faced by children living in developing countries, early intervention programmes that take into account local culture and available resources are required (Maloni et al., 2010; WHO, 2012b). In response to such calls, we have conducted a comprehensive systematic review to identify evidence-based interventions for application in developing countries (Kiling, Due, Gyss, Li & Turnbull, 2018a). This has been accompanied by a scoping review of research emanating from Indonesia (Kiling et al., 2018b). Together, this work is designed to be used by service providers and policymakers to implement culturally relevant and effective interventions. Another aspect to implementing scalable interventions is to consider the perspectives and experiences of end-users, especially parents and service providers (Lindsay & Edwards, 2013). Thus the aim of this study is to examine views about childhood disability, within an environmental risk context, of a broad range of people including parents and local leaders such as NGO staff and healthcare providers. Ultimately, our aim is to use the findings from this study to augment previous reviews, to provide stakeholders in West Timor and the rest of Indonesia with a best practice framework for improving services for children with disabilities.

5.5 Methods

5.5.1 Study location and description of authors

The study was conducted in West Timor, located on Timor Island, East Nusa Tenggara, a province of Indonesia. The UN estimates that there are approximately 4.2 million children with disabilities in Indonesia (Melisa, 2013). Composed of five regencies and one municipality, West Timor has 1.8 million people who contribute more than one-third of the total population of East Nusa Tenggara (Badan Pusat Statistik – Statistics of East Nusa Tenggara Province, 2017). The majority of West Timor's population belongs to an

Indigenous group known as the Atoni, or Dawan (Highlander) (Ormeling, 1956). Other Indigenous groups include the Belu, known also as the Tetun and the Helon, who live mainly on the island of Semau (Ormeling, 1956). From 2010 to 2015, East Nusa Tenggara province ranked lowest in the Human Development Index (Badan Pusat Statistik – Statistics of East Nusa Tenggara Province, 2017). Young children in West Timor are vulnerable to multiple risks, including poverty, malnutrition, substandard home environments, and lack of access to education (Durkin, 2002; Grantham-McGregor et al., 2007). As such, many children are prone to health conditions or experience disability (Li et al., 2013).

The first author who conducted the fieldwork is a native Indonesian speaker who comes from North Sulawesi province. Prior to the study, he had spent two years working in another area in East Nusa Tenggara province, and had also worked and resided in West Timor for around three years, where he had worked with several government and non-government organisations dealing with disability and children. The other two authors (CD and DT) are from Australia and prior to the current study had little experience in Indonesia. The final author (DL) is a native Indonesian and Timorese speaker with extensive experience in research in West Timor, especially with marginalised communities. He has close relationships with several government and non-government organisations, especially those dealing with migration issues.

5.5.2 Design and ethics

Data were collected via interviews and photovoice (Pope, Ziebland & Mays, 2000). All participants were compensated for their time with small souvenirs brought from Australia (e.g. key chains) and the interviewer kept an audit trail throughout the research process. The interpretation of all data was discussed with two cultural elders in Kupang City, to ensure local relevance and validity. Ethics approval was obtained from the Human Research Ethics Committee at The University of Adelaide, as well as the Committee of Health Research Ethics in the Ministry of Health, Republic of Indonesia.

5.5.3 Participants

A multiple-step purposive sampling frame was used as follows. The first author approached the two relevant leading organisations (Social Agency and Handicap International) to obtain demographic data and an overview of numbers of parents of children with disabilities in the study area. These two organisations define disability in terms of The ICF of WHO (WHO, 2007b) and this definition was also applied in this study. After visiting eight sub-districts to determine the numbers of children with disabilities and the cultural context of the community, three sub-districts were chosen for the following reasons. Kupang Tengah sub-district was selected because of its relatively high number of young children with disabilities. Amarasi Barat was selected due to its strong cultural influence as the capital of the old Timor Kingdom known as Amarasi. This influence derives from the presence of the former King's grandson as well as the regular practice of ceremonies marking life events and rites of passage such as weddings, births, deaths and the harvest. We considered this as important, given our aim of understanding respondents' perspectives in a broad environmental context. Semau was chosen because of its location on an island separated from the mainland, resulting in it being affected by a range of unique environmental factors associated with relative isolation, as well as being inhabited by an Indigenous group that was different to other sub-districts.

The first author then approached specific village leaders to obtain permission to visit the village and to suggest potential participants. Subsequently, he approached families identified by the village leaders and/ or other villagers as having at least one child aged zero to eight years old living with a disability. Potential participants were approached in their home or place of work, such as rice fields, to gain consent and to subsequently collect data. He made daily visits to the participating villages in the four months leading up to the formal data collection period.

Parents, defined as biological parents or primary care givers, were eligible for the study if they had a child aged below eight years of age with a disability as defined by the

World Health Organization (WHO, 2012b). While initial data concerning the number of children with a disability were gathered from the agencies noted above, in order to be included, parents had to personally identify their child as disabled, since this study relied upon parents recounting their views about life with their child. The first author approached 19 families, 12 families in Kupang Tengah sub-district, 4 families in Amarasi Barat sub-district, 3 families in Semau, all of which were identified by village leaders and/or villagers. Fifteen families (10 in Kupang Tengah; 2 in Amarasi Barat; 3 in Semau) identified one or more of their young children as having a disability and agreed to participate. In the case of eight families, one member was interviewed. In the case of six families, two members were interviewed and in one family, three members were interviewed. This resulted in 23 family member participants. This relatively low number of families approached (n = 19) may partly be as a consequence of young children with disabilities being 'invisible' or hidden by their parents inside and not being taken to health or education services (details about the participant sample are provided in Table 5.1). Twenty-three parents of sixteen children with disabilities participated in the study, including nine biological mothers, seven biological fathers, six biological aunts, and one foster mother. The mean age of the participants was 33 years, with an average of two children under their care.

Table 5.1: Demographic characteristics of participating parents and carers

Pseudonym	**Relationship to child**	**Age (years)**	**Employment**	**Ethnicity**	**Religion**	**Education level**	**Child's age (years)**	**Child's gender**	**Impairments**	**Total no. of children in family**
Gardis	Mother	48	Home care	Flores	Catholic	Senior high school	7	F	Mental	3
Teos	Father	36	Freelancer	Rote	Christian	Senior high school	3	F	Physical	1
Marsha	Mother	25	Private employee	Rote	Christian	Bachelor				
Angel	Aunt	30	Home care	Timor Leste	Catholic	Senior high school	5	M	Mental	1
Mika	Mother	32	Teacher	Timor Leste	Catholic	Senior high school				
Pajo	Father	45	Farmer	Timor Leste	Catholic	Not attended school	7	M	Physical	5
Goreti	Aunt	19	Home care	Timor Leste	Catholic	Senior high school				
Selus	Father	49	Public employee	Timor	Christian	Senior high school	7 (twins)	Both F	Both mental & physical	5
Sien	Mother	39	Home care	Timor	Christian	Elementary school				
Ria	Aunt	38	Home care	Timor	Christian	Junior high school				
Beti	Mother	25	Home care	Kiser	Christian	Junior high school	7	M	Physical	3
Yota	Mother	27	Farmer	Timor Leste	Catholic	Not attended school	3	M	Both mental & physical	2
Jaha	Aunt	24	Home care	Rote	Christian	Senior high school	8	F	Both mental & physical	3
Jois	Mother	32	Public employee	Rote	Christian	Senior high school				
Maria	Mother	26	Private employee	Flores	Christian	Junior high school	5	M	Physical	3
Tulu	Father	31	Motorcycle taxi driver	Savu	Christian	Elementary school				
Tinus	Father	30	Farmer	Timor	Christian	Elementary school	3	F	Physical	3
Wemi	Mother	38	Home care	Timor	Christian	Junior high school	6	F	Mental	5
Hege	Aunt	38	Home care	Sabu	Christian	Senior high school	8	M	Mental	1
Susan	Aunt	43	Teacher	Sabu	Christian	Diploma				
Yurni	Foster mother	49	Entrepreneur	Timor	Christian	Senior high school	7	M	Physical	4
Jefri	Father	43	Farmer	Rote	Christian	Not attended school	3	M	Physical	12
Oce	Father	42	Entrepreneur	Helon Timor	Christian	Senior high school	4	F	Mental	4

M= Male; F= Female

Local leaders were recruited from various leading Indonesian institutions providing direct and indirect services for children with disabilities and their families. These included workers in governmental and NGO agencies, and local community leaders such as a school headmaster, a village head, and a priest. These local leaders hold great importance for improving services for children with disabilities, as they are responsible for designing and executing programs such as inclusive education, community health services, and spiritual services. Leaders from NGO agencies are vital for initiating change in the disability sector in a context where the government puts more focus on economic matters. We first approached the head of each institution to obtain permission, and then made an appointment for interviews either with themselves or another middle level leader who they appointed. All interviewed leaders were Indonesian and had received training on disability issues such as inclusive education.

A total of 16 leaders were approached, with 15 agreeing to participate (six females and nine males). The mean age of local leaders was 43 years of age. (Further details can be found in Table 5.2.)

Table 5.2: Demographic characteristics of local leader participants

Pseudonym	**Age (years)**	**Sex**	**Occupation**	**Length of work in current position (years)**	**Ethnicity**	**Religion**	**Last education**
Yasinta	27	F	Midwife in community health centre	6	Rote	Christian	Diploma
Yunda	41	F	Head of the village	5	Rote	Christian	Master
Nesi	40	F	Priest	4	Timor	Christian	Bachelor
Rumi	38	F	Head of local disability NGO	7	Timor	Catholic	Senior high school
Joko	26	M	Staff in international NGO	< 1	Java	Christian	Master
Trudis	42	F	Staff in international NGO	1,5	Flores	Catholic	Bachelor
Okto	59	M	Cultural leader	26	Timor	Christian	Senior high school
Aten	32	M	Staff in local NGO	2	Rote	Christian	Bachelor
Vian	48	M	Headmaster of inclusive elementary school	2	Timor	Christian	Bachelor
Pilus	47	M	Section head in education agency (province level)	5	Flores	Catholic	Bachelor

Pseudonym	Age (years)	Sex	Occupation	Length of work in current position (years)	Ethnicity	Religion	Last education
Ningsih	46	F	Head in child protection body (city level)	3	Java	Christian	Bachelor
Gogon	52	M	Section head in social agency (province level)	2	Rote	Christian	Bachelor
Mawadu	56	M	Head in people's prosperity agency (province level)	2	Sabu	Christian	Bachelor
Naleto	46	F	Section head in health agency (province level)	10	Sabu	Christian	Master
Uda	45	M	Head of local NGO	10	Flores	Catholic	Master

M= Male; F= Female

5.5.4 Procedure and data analysis – parents

Parental data were collected through photovoice followed by audio- and video-taped face-to-face semi-structured interviews. Photovoice is useful for eliciting data that may provide nuanced understandings of participants' lived experiences. It is highly useful for engaging participants from marginalised communities who may be hesitant or unable to speak about their circumstances (Plunkett et al., 2013). We hoped that the use of photovoice might help parents with low levels of formal education and inexperience in verbally portraying their situations, to more easily explain their situations. Interested participants were lent a camera, if they required one, and asked to take pictures of resources and needs in their community associated with their young children with a disability. They were then given a week to take the pictures, after which the first author met with the participants at a place of their convenience to discuss the photographs and conduct the interviews. The interview guide was developed in line with an indigenous psychology approach in order to examine beliefs in familial, cultural, social and ecological contexts (Kim et al., 2006). Particular issues explored included their perceptions and causes of disability, types of treatments or support that parents had sought, and their perceptions of available services. Some key questions were "Why do you take this photo?"; "What does it mean?"; "According to you, what is your child's condition called?"; "What do you think caused your child's condition?"; "What kind of treatments have you sought for your child?"; "What hampers or worsens your child's condition?"; "What do you think of the available general services like health or education services?”. On average, participants took 12 photographs each and interviews ranged from 15 minutes to one hour with an average time of 27 minutes.

The first author conducted the interviews, including discussions about the photographs in the Kupang-Malay language, a mixture of urban Timorese and Indonesian, and then translated and transcribed in English. Thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2013) was undertaken using quality guidelines for qualitative research (Tracy, 2010). Coding was done through a combination of inductive and deductive methods. Specifically, coding was first done according to the primary aim of the research to identify participants’ perceptions of disability, risk factors for disability, and adequacy of services. An inductive approach to coding was then also applied to specify any additional themes that were identified by participants. The global theme of protective factors was identified from this inductive approach.

The first author devised initial codes from three transcripts. Following the coding of the first three transcripts, two other authors (CD and DT) coded three other transcripts using the initial codes and these authors then met to discuss the codes. After that, the rest of the transcripts were coded by the first author and checked by the other two authors. The data from the parents and the local leaders were firstly separately coded into themes by the first author. Through a step-by-step interactive process between the authors, the themes from the two data sets were then analysed together to produce the organising and global themes. There was broad agreement from parents’ and local leaders’ data, but there was also some differences which are identified in the results section.

The descriptions of the photos were coded separately from those of the interviews, following an approach similar to that described above. After reflecting again on the research question, we decided to combine the codes from the two datasets under one set of themes, and photos were then selected to provide a visual illustration of the themes.

5.5.5 Procedure and data analysis – local leaders

Local leaders were interviewed using related questions, adapted to obtain information about their institutions' role in working with young children with disabilities, as well as their understandings of disability, and its causes and treatments. Some key questions were "What is disability according to you?"; "What do you think causes and worsens disability?"; "What do you think of the general services available?"; "What has been done in your institution for young children with disabilities?"; "What can your institution do in the future?". Interviews lasted on average 45 minutes (no photovoice data were collected). The approach to analysis was the same as that for the parental dataset.

5.6 Results

Figure 5.1 shows the thematic map of data from parents and local leaders, including the two original global themes related to the research question (perception, causes and treatment; risk factors), as well as an additional theme identified by the respondents, that of protective factors. The map shows 12 organising themes and 27 basic themes according to whether they arose from the datasets of parents or local leaders.

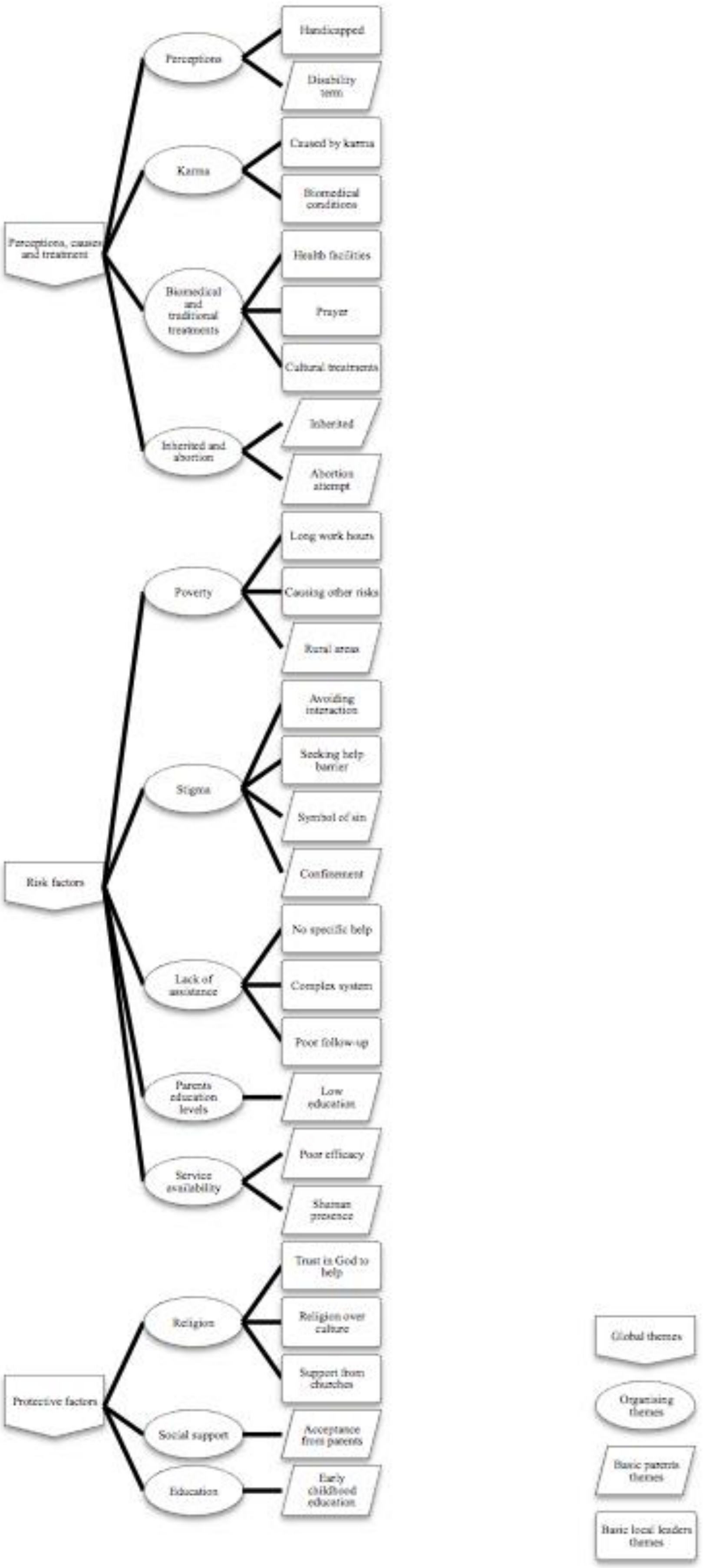

Figure 5.1: Thematic map illustrating themes that emerge from analysis

5.6.1 Perceptions, causes and treatment of disability

This global theme encompasses four organizing themes addressing: perceptions of disability and the use of associated terms; karma as a cause; the blend of biomedical and traditional treatments; and inheritance and abortion as putative causes. Nine basic themes shaped this global theme, three from parental data and six from local leaders' data.

5.6.1.1 Perceptions of disability

The majority of parents were unfamiliar with the term 'disability', they only knew of the old term 'handicap', which is associated with stigma in the community. They also mentioned the term 'abnormal' to define their children's condition. For example, in a representative statement, Maria (parent) said that:

> *It is called imperfection; the meaning is that, abnormal, he [her child] is less normal unlike us, like that.*

Other participants emphasised physical impairments in defining their children's condition; they only mentioned mental impairments after probing from the interviewer. Most of the participants said that they never received a clear diagnosis of their children's condition, so they mostly described the condition according to the symptoms shown by the child, for example:

> Jaha (parent): *Yes she can't talk, and her bones are also not strong enough. She can't stand, sit and her neck cannot be straight, can be steady but only for a while, after that her neck will drop again.*

When answering questions about the disability itself such as "What is your child's condition?" some parents instantly resorted to describing the putative cause of the disability in ways that suggested they had limited insights into the actual diagnosis, and lacked a clear understanding of the condition from a medical perspective.

> Yota (parent): *It is because when she was born, her head was swollen. Swollen in here [pointing to part of the head]. Then, the doctor told us to buy this medicine, about $50 per tablet. Then the swell[ing] got better. Emm, then, two months later, her body got a high fever, must be hela dalam [inner seizures] that caused her to be like this.*

In contrast with parents' accounts, local leaders were more familiar with the term disability; they mentioned that it was the new term for handicap, and some leaders even fluently elaborated that disability is the interaction between physical impairments and activity or participation, as follows:

> Rumi (local leader): *Em if me, according to my opinion, disability is emm, a person who has impairment, impairment either intellectual, sensory, or physical, that has limitation in his/her interaction with the environment.*

> Joko (local leader): *Disability… em, it is a, in my opinion disability is a physical or non-physical condition, that hampers a person in daily activities.*

Overall the local leaders realised that the term disability is preferred over that of handicap, which is stigmatising and can lead to isolation of people with disabilities. Further, many of them reported that they had begun using disability in their regular dealings in the community.

5.6.1.2 Disability is seen as a result of karma

When asked about the cause of their child's disability or handicap, parents reported both biomedical causes, and those stemming from traditional knowledge. In relation to biomedical causes, parents typically focused on early childhood fevers, hereditary diseases, premature birth, low birth weight, reverse delivery, abortion attempts and after-birth accidents. For example, Goreti (parent) stated that her nephew's disability resulted from a lantern falling, as seen in Figure 5.2.

Figure 5.2: Photograph of hand-made lantern taken by Goreti, used to illustrate how household items can cause injury

> Goreti (parent; explaining why her nephew is unable to wear shoes and walk in comfort): *This is lantern and food. When he had the cause of burn in his leg is when this food and lantern, ahh there was no electricity and that was when he was lying around and his older sister was feeding him. But accidentally her hand touched the*

> *lantern and the lantern fell down, and then the kerosene got poured to [sic] his leg and the fire burned him, so his leg become… yes that's the cause of it.*

However, most parents focused on 'traditional' causes such as breaking cultural rules. Parents perceived these wrongdoings as causing disability through a form of karma, or a form of punishment from wrongdoings. For example, Goreti (parent) took the photograph seen in Figure 5.3, and stated:

> *This house in the back represents our ancestor's belief, which is called 'adat'. This is where we store all the remnants, tools, we store inside that house. There's a belief, every time we want to eat baby corn, we cannot eat baby corn or even baby vegetables. After all has been done, the ritual, then we can eat… If eaten, then the person will get danger or sickness inside them; it is the warning from our ancestors.*

Figure 5.3: Photograph of the house taken by Goreti, where a ritual must be enacted before eating baby vegetables

5.6.1.3 Parents draw upon both biomedical and traditional treatments for their children

Parents commonly reported seeking multiple treatments, both medical and traditional for their children. The most advanced health services for treatment and therapy were located in general hospitals, which were generally some distance away. Most parents only went to hospital to get medicines (e.g. see photograph taken by Gardis (parent) in Figure 5.4), and rarely returned for follow-up treatment, with the most common obstacle being the distance between home and hospital.

Figure 5.4: Photograph of medicines and vitamins taken by Gardis, to show the constant need for medicines

Most parents also noted that they had taken their children to the local community health centre (government-initiated health centre, providing general health services provided by health workers such as medical doctors, nurses, midwives, etc.), since they are usually the closest facility for parents to access medical services and medicines. In general, many parents stated that they tried medical treatment initially, but used traditional treatments when medical treatments did not work, or became inaccessible or unaffordable. For example, many parents discussed traditional interventions such as praying, attending the local shaman, herbal concoctions, or cultural rituals (e.g. feeding children a pig's tail). Catholic nunneries were also frequently consulted for treatment purposes, although Jois (parent) reported that the method was possibly harmful.

> *After that, there has been no more [treatment], only in that time when she was two years old, we took her again to that Catholic nunnery, we took her there for another therapy, but [in there, they] tied her hands, her legs, and after that she returned home crying continuously. Maybe her body was in pain or something.*

Other traditional treatments included undertaking cultural rituals such as the mother walking over her child naked, or burning her hair to be inhaled by her child. The local shaman played a large part in these traditional treatments, as stated by Tinus (parent):

> *That time we used this [sic] leaves... em, what is those leaves... Noni leaves. This is to cool the pain. This is because from what is it, this shaman said to use those leaves. So we used, and then we even used banana leaves. We used that too.*

5.6.1.4 <u>Disability is inherited and caused by attempted abortion</u>

In contrast with parent participants, local leaders highlighted heredity as the main causal explanation, followed by attempted abortion. Attempts at abortion were seen as mostly triggered by the stigma of having a child outside marriage. For example:

> Ningsih (local leader): [Abortion] *Can also [happen] because of drugs. Pregnancy that is not wanted by the parents, maybe because of forbidden relationship or anything*

> *else, or because of cannot hold out the shame so parents decided to abort the foetus by using drugs etc., that eventually cause disability.*

In addition to attempted abortion, local leaders noted a range of causes of disability related to pregnancy, including experiencing violence, risks when delivering the baby, and poor nutrition as stated below:

> Nesi (local leader): *Besides that, also nutrition. Nutrition is most important when, em, a mother get pregnant. When the mother, according to medical science, human brain development, fetus brain between zero to three months. If in that particular pregnancy period (the fetus) does not get enough nutrition for the brain, it will negatively influence the next development phase.*

They also discussed the concept of *karma* or a curse believed by the community in West Timor, noting that this could cause an evil spirit or ghost to disturb the body of the person, leading to disability.

5.6.2 Risk factors

This study identified five risk factors: poverty, stigma, lack of assistance, parents' education levels and service availability, associated with seven basic themes from the local leader data set and six themes from the parental data.

5.6.2.1 Poverty

The most common risk factor mentioned by parents was poverty. This was particularly seen as a risk to children because it resulted in long working hours, including work which sometimes took parents away from their children. For example:

Jois (parent): *The other thing is that I have to work everyday, starts in the morning, and then finishes at evening, mostly at night time.*

Poverty was also seen as a trigger for other risks such as malnutrition, poor sanitation, difficulty accessing services, and home and community environments which parents identified as sometimes posing a risk to children. Figures 5.5 and 5.6 illustrate the impact of poverty in relation to potentially dangerous home environments (Figure 5.5), and poor sanitation (Figure 5.6).

Figure 5.5: Photograph of high bedstead taken by Selus, to show risk of injury

Figure 5.6: Photograph of toilet taken by Jefri, to show poverty and poor sanitation

Poverty was also reported by local leaders as the major risk factor in the community, with some respondents suggesting that almost all of the families of children with disabilities living outside Kupang (the main urban centre) were living in poverty. For example:

> Uda (local leader): *Our organisation often dealing directly with families [of children with disabilities], one factor that indeed, really burdening, encountered by most families with poor family economy.*

> Yunda (local leader): *Well from my point view, most (of the parents) have 'soft' economy, most of them. For example, em, her father (referring to a child with disability in her community), he tends to be lazy, not willing to work hard, even though he actually able to work hard*

5.6.2.2 <u>Stigma</u>

Parents indicated that they frequently avoided public places or socialising due to their child’s disability, leading to social isolation. For example:

> Goreti (parent): *Maybe this child, there are many of his friends who keep their distance from him, maybe because of his physical condition, his leg, maybe he still [feels] some ridiculing, or the feel[ing] of don’t want to socialise with other friends. There are still some who tease him.*

Stigma also impacted other areas of family life, including access to education. In particular, parents indicated that they were hesitant to enrol their children at school due to a fear that their child would be a burden. For example:

> Angel (parent): *My son, maybe when he attends school maybe other children, we are afraid that [he] drags [sic] other parents’ child? We want to support him but we also must consider other children too.*

At the same time, not all parents experienced discrimination by other members of the community, as evidenced in the following excerpts.

> Mika (parent): *Our neighbours usually don't have anything against us, no, they don't complain.*

> Beti (parent): *Everything is fine in here [in the community].*

In line with parental reports, stigma was also seen as a risk factor by local leaders, both in terms of unwanted pregnancies (i.e. for women who were not married), and as a result of community views about disability more broadly. In particular, local leaders noted that children with disabilities could be seen in communities as a symbol of sin within families, leading to incentives to hide the child at home. For example, local leaders cited instances of young children confined in animal stalls. Trudis (local leader) also reported witnessing a young child tied with a rope inside a bedroom to keep the child inside as stated:

> *There was a little boy, one of our staff found this boy in his home, he was tied in his room. He could not go anywhere. Their parents used a rope so that this boy could not go anywhere.*

Stigma was also seen within the education system, as noted by Gogon (local leader):

> *The proof is that, even in inclusive school, the name is inclusive school but the teacher's attitude and treatment to children with disabilities in that school were… it was too depressing to tell.*

5.6.2.3 Lack of assistance

Parents noted that there were no specific programmes designed for young children with disabilities and/or their parents by either government or NGO agencies. Moreover, many of the parents felt dissatisfied with government help, noting that receiving any sort of assistance often came with complex administrative tasks before receiving aid, and no follow-up. For example:

> Tulu (parent): *If we only have meetings after meetings [training and socialization], only discuss about this and that, it will not bring any change [to the child], it is useless, those everyday meetings. Every meeting they only talk about that [parenting, information concerning children etc.].*

5.6.2.4 Parental education levels

Providing a rather different perspective, local leaders perceived that the low education level of parents played a role in harming the development of their child. For example:

> Trudis (local leader): *The first thing is awareness, parents' awareness about child's condition, why their child has that condition, how to treat them, emm, many parents did not realize that this child has same rights just like other children.*

> Yasinta (local leader): *Yes, and then… Maybe it's because of their lack of education so we have to go to them and give them explanation. This child should be referred to hospital or not.*

Low levels of education were seen as leading to a range of other risk factors, such as discrimination, malnourishment, poor sanitation, institutionalization/foster care, low access to services, exploitation/politicisation, and child neglect. Almost all local leaders mentioned that they felt that parents neglected children living with disabilities as quoted below:

> Aten (local leader): *Well in my opinion, maybe em, depends on their (referring to children with disabilities) parents yeah. Means that often when they know their children have special needs, but parents feels that it could not be healed or it is how it is meant to be, they will neglect their children.*

5.6.2.5 Service availability

While local leaders did identify some available services (e.g. visits from community health centres, and school health services), they noted that the effectiveness of these services was hindered by a range of issues including lack of elite (top leaders) commitment to disability issues, complex administrative matters, lack of knowledge and professionalism from health workers, distance, limited resources and lack of specialisation. In addition, local leaders noted there was a particular lack of programmes targeting young children with disabilities:

> Naleto (local leader): *We still do not have special treatment for them [young children with disabilities]. Even we do not have special ticket window for them. No we still don't have one.*

In addition, both fear and costs related to these formal healthcare services were seen as a barrier to their use, with local leaders explaining that shamans were preferred by the community due to fear of needles or medicines and because they are free:

> Okto (local leader): *So indeed the belief and trust to shaman was more dominant than to available doctors. And then, they [parents] were helped because with shaman they don't need to pay. While [if they see a] doctor they should pay, so the economical factor is in there.*

As a result, local leaders suggested that a useful way forward would be for shamans to work with formal healthcare workers, a point which will be discussed further below. Local differences in experiences are highlighted by quotes from parents such as:

Yurni (parent): *Well, in Semau, hospitals, special schools are far away from here, but our elders said that parents are the most important teachers so I teach him so that he can take care of himself, well slowly, activities like taking a bath is mastered by him.*

5.6.3 Protective factors

The previous two global themes resulted from a deductive approach to analysis, using the aim of the research as a guide, while the global theme of protective factors emerged from an inductive approach. This global theme explains the three major factors believed to be associated with offsetting disability and the associated difficulties, religion, social support, and education for young children.

5.6.3.1 Religion

Many parents saw religion as the most effective protective factor, with respondents stating that their trust in God to help their children had brought hope and motivation in difficult times. For example, Mika (parent) took the photograph in Figure 5.7, and noted that:

> *He is a gift from God, and I have one, I have two things that I believe. The first thing is that God has more power, so I believe more in God because God is the creator and the ruler. He is the one in charge of life's breath. So anything we asked will be given by God. It could also be found in Bible, ask so it will be given to you; knock so the door will be opened to you.*

Figure 5.7: Photograph of Bible and rosary beads taken by Maria, to show that everything that happens is God's will

Religion was also seen as helping parents in a practical sense. Specifically, since all parents were Christian, all reported receiving help from the church for the care of their children, including annual financial assistance, and the opportunity for stimulation and socialisation in Sunday school. Local leaders also expressed such a view and noted the influence of the church given its cultural prominence and geographical coverage.

5.6.3.2 Social support

Social support especially in the form of acceptance within the family was frequently regarded as an important protective factor. Further, it was sometimes characterised as a kind of mediator in the face of lack of community support. For example, Trudis (local leader) stated:

> *So they who accept and have the awareness, when the family gives love, they will confidently say to their community, in everywhere they go, they will say, this is my child, his/her condition is like this, he/she has ability of this, what we want as family is this. So that is the role of parents, community will change or not, it depends on parents.*

5.6.3.3 Early childhood education attendance

In addition, early childhood education attendance was seen as an important protective factor. For example:

> Pilus (local leader: *When the child enrols in early childhood education post, given stimulation, I believe they could [be better]. So every time [the child is] given [stimulation], sooner or later the child will be back to normal, even though not 100%.*

Parents also mentioned that their children enjoyed educational activities including all of the associated objects such as school uniforms, books, and pencils:

> Jaha (parent): *Well she, whenever she saw her relatives, her friends around the same age with her, or her older sister here, whenever she goes to school, we often tries [sic] to persuade her, 'hon, you want to go to school don't you?', there's this time, we asked her, 'you want to go too?', she was really excited, really happy, then also she is excited every time we told her a story from a book. If you show her this one [book], that one [book], she really happy. She wants to attend school.*

> Tulu (parent): *Well he often, when his older brother is working on homework, he also wants to take a book, a pen or pencil, well he will start to draw randomly in the book. Well I often let him be, because he also wants to learn how to write.*

5.7 Discussion

Through exhaustive qualitative investigations, this study has identified a comprehensive range of views held by parents and local leaders about childhood disability in the context of environmental risk. Such data has the potential to inform academics, practitioners and policymakers in developing countries to develop culturally appropriate interventions to improve childhood functioning and wellbeing. The research findings support previous somewhat similar research highlighting that poverty, stigma and distance to health and education facilities negatively influence the development of children with disabilities in developing countries (Coomer, 2013; Ha et al., 2014; Juneja et al., 2012; Maloni et al., 2010). Our study confirms that these environmental risk factors are salient from the perspective of parents as well as local leaders who are well placed to be influential in affecting change.

Importantly we have identified some specific cultural beliefs which might be malleable to change in the longer term.

Our study adds new information about the terms that parents use in discussing disability. Even though the term "handicap" is no longer used by those working in the area (Gov.UK, 2014) and in fact was replaced 30 years ago (Devlieger, 1999), the parents in our study still used this term. Responses suggested understandings in line with the "medical model" which defines disability purely in individual terms divorced from the broader environmental context, which may hinder parents in pursuing their children's rights in the community. This finding resembles the situation on the Ivory Coast, where parents also still used the term "handicapped children" and "mental handicapped" to describe developmental disability (Bayat, 2014). In contrast, most local leaders are familiar with the broader environmental model of disability suggesting that, given their networks and status within the community, they might be leveraged as a resource for improving awareness amongst parents of their children's rights to access inclusive services to enhance participation and functioning.

It is essential to understand the factors which influence parents' perceptions of disability, as these factors appear to determine help-seeking behaviour as well as choices for treatments or interventions (Danesco, 1997; Maloni et al., 2010). This study has identified specific key cultural beliefs, such as karma, which may be making an impact in this respect. Specifically, most parents stated that they preferred traditional help such as shamans, herbal concoctions and cultural rituals. This practice is likely to be related to the fact that, despite being mostly Christian, the *Dawanese* people also practice animism, the belief that ancestors retain a spiritual form and an ongoing role in people's lives (Dhavamony, 1995; Taum, 2004). Against a backdrop of deep seated cultural beliefs, providing shamans with basic knowledge and skills in evidence-based explanations and approaches may go towards supporting parents to obtain support from mainstream services (UNICEF Indonesia, 2010).

Many participants expressed the belief that wrong behaviour is the principle cause of illness. *Neketi,* the process to absolve this bad behaviour, is through confession and prayer, which explains various rituals conducted by shamans and parents in this study (Bunga, Manao, Kana & Rihi, 1996; McWilliam, 2002). This viewpoint appears to be common in developing countries (Ha et al., 2014; Samadi & McConkey, 2011). At the same time our study found that religion and religious beliefs might also serve as a protective factor for parents due to the practical support provided by the churches. As a resource readily available even in remote areas, the church has been able to motivate parents to support their children by providing spiritual and psychological services for enhancing parental wellbeing, a finding supported by other research from other developing countries such as Guatemala (Grech, 2016).

Both parents and local leaders noted that the stigma associated with having a child with a disability was an important risk factor. Again, this may stem from traditional cultural beliefs of karma (Ha et al., 2014); in the current study this was particularly salient in relation to children born outside marriage. Given the importance of key elders and cultural figures in West Timor and similar settings, it is suggested that healthcare providers, such as community healthcare centres (in the case of Indonesia), could work with community leaders to increase mental health literacy and reduce stigma. With improved understandings of physical and mental health and access to reliable sources of health information, local leaders would have increased ability to work with community members to disseminate accurate health information and reduce harmful practices resulting from stigma (Vass, Mitchell & Dhurrkay, 2011). Similarly, empowering local leaders (e.g. the church and cultural figures) who provide social support to parents would also work to ensure that existing perceived protective factors, such as religion, are able to work to further improve the lives of young children with disabilities.

Finally, in relation to the finding that distance is a key barrier to accessing appropriate healthcare services, it is important to consider the role of technology. For example, the People Prosperity Bureau of East Nusa Tenggara province and the Coordinating Ministry of Human Development and Culture Republic Indonesia (Indonesia.go.id, 2014) have begun to propose inclusive village programmes to create a grassroots approach to improve household livelihood, digital data availability, and overall availability and quality of services (Kemenkopmk.go.id, 2015). Even with many threatening environmental risk factors, rural places like West Timor have social resources like religion and culture that could be utilised to create a supportive environment. It is acknowledged that forcing community change without regard to the social environment would not work with the indigenous community, since cultural identity is perceived by the Dawan people as significant (Windi & Whittaker, 2012).

The study has several limitations. Differences in perceived status between the interviewer and participants may have impacted on the quality of the data obtained. While the interviewer spent three years residing in West Timor, he is not originally from there, which may have impacted his ability to relate to parent participants and lead to socially desirable responses. To offset this possibility, the interviewer made weekly visits to the participating villages in the four months leading up to the formal data collection period. The power differential was further minimized by conducting interviews in the local language, with several stages for the informed consent process. Several participants described the same child, which may have impacted on the richness of the data. Since numbers of young children with disabilities were limited in some sub-districts, expanding the area of the target population is recommended for future studies in order to secure more participants. Further while three transcripts were independently coded by two other members of the research team, the original transcripts were not subjected to forward and backward translation to ensure accuracy (WHO, 2018).

In conclusion, the enactment in 2016 of the Indonesian Disability Law (Presiden Republik Indonesia, 2016) provides momentum for change. While the law is somewhat limited in scope and addresses primarily early screening for children in primary schools, an ideal start would be for evidence-based early interventions to be included in derivative regulations. In addition to the enhanced roles previously suggested for local leaders, they could also serve as local enforcers of the disability law and regulations, given that law enforcement is a vital issue in Indonesia and other developing countries (Edward, 2014). Overall, a comprehensive framework that addresses the complex social, economic and cultural issues highlighted in this study is required.

5.8 Acknowledgement

The first author would like to thank the Indonesia Endowment Fund for Education (LPDP) for their help in funding the PhD programme.

5.9 Declaration of interest

The authors report no conflicts of interest.

CHAPTER SIX. ADDRESSING THE PROBLEM OF CHILDHOOD DISABILITY: A CASE STUDY OF INDONESIA

6.1 Preamble

The previous three studies provided information about interventions for children with disabilities in the form a scoping review, a systematic review and a qualitative investigation. In this study, participants in focus groups and interview sessions critiqued the information collated in the previous stages for the final development of the best practice model.

6.2 Statement of authorship

Title of paper: Addressing The Problems of Childhood Disability: A Case Study from Indonesia

Publication status: Unpublished and unsubmitted work written in manuscript style

6.2.1. Principal author

Name of principal author (candidate): Indra Yohanes Kiling

Contribution to the paper: Responsible for the primary authorship of this research and also correspondence with reviewers and journals. Responsible for the research design and process, fieldwork, analysis and writing of the manuscript.

Overall percentage: 80%

Certification: This paper reports on original research I conducted during the period of my Higher Degree by Research candidature and is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in this thesis. I am the primary author of this paper.

Signature: Indra Yohanes Kiling *Date:* 01/08/2018

6.2.2 Co-author contributions:

By signing the Statement of Authorship, each author certifies that:

i. the candidate’s stated contribution to the publication is accurate (as detailed above);
ii. permission is granted for the candidate to include the publication in the thesis; and
iii. the sum of all co-author contributions is equal to 100% less the candidate’s stated contribution.

Name of co-Author: Prof. Deborah Turnbull

Contribution to the paper: Input on research design, research questions, interview schedule, interpretation of findings, and writing of the manuscript. Oversight of article progress including publication process. Provided editorial and structural feedback.

Signature: *Date:* 01/08/2018

Name of co-Author: Dr. Clemence Due

Contribution to the paper: Input on research design and methodology, support in data collection tools (cameras), research questions, interpretation of findings, and writing of the manuscript. Provided editorial and structural feedback.

Signature: *Date:* 01/08/2018

Name of co-Author: Dr. Dominggus Elcid Li

Contribution to the paper: Input on interview schedule, help in connecting with several stakeholders related to the research, interpretation of findings, and writing of the manuscript. Provided feedback on drafts.

Signature: *Date:* 01/08/2018

6.3 Abstract

Young children with disabilities in West Timor, Indonesia are threatened with significant environmental risk factors, which have the potential to hamper their development process. The aim of this research was to develop a best practice model consisting of practical activities that could be easily adapted and implemented by practitioners and other stakeholders. Results from three previous studies conducted by the authors were combined with the results from focus groups and interviews in this current study. Twenty-one parents of young children with disabilities and 55 local leaders (kindergarten teachers, Sunday school teachers, community health centre workers) participated in focus groups, while 35 participants were interviewed. The best practice model consists of 41 activities across eight themes, including those for health, education and religion. Implications of the model are presented together with other recommendations for improving services and interventions for young children with disabilities in West Timor.

Keywords: disability, young children, best practice model, environmental risk, Indonesia

6.4 Introduction

Disability is defined by the International Classification of Functioning, Disability and Health (ICF) as the umbrella term for impairments, activity limitations and restrictions on participation in the community (WHO, 2013). Using the UN definition, there are approximately 4.2 million children (i.e. between the pre-natal period to eight years of age) experiencing disabilities in Indonesia (Melisa, 2013), with an estimated prevalence in the general population of 21.3% (2006 figures) (SEARO-WHO, 2013).

Young children's development is affected by a range of environmental factors that either protect or damage developmental outcomes. These risks, (e.g. limited financial resources and restricted access to various services) (WHO, 2012b), contribute to the fact that disability prevalence increases in early childhood (Spencer et al., 2009). There is an extensive body of evidence for some interventions for young children with specific disabilities in urban developed areas, for example, the Early Intensive Behavioural Intervention programme for children with autism spectrum disorder (Eldevik et al., 2009; Reichow, 2012), The Parent Plus Programme, The Stepping Stones Triple P, and Incredible Years for children with developmental disabilities (Matson et al., 2009). However, few programmes have been specifically designed for the rural context, nor for addressing environmental risk factors (Maulik & Darmstadt, 2007). Given the diverse environmental risks (e.g. distance to facilities and stigma surrounding disability) faced by children living in developing countries, early interventions developed according to local culture and available resources are required (Maloni et al., 2010). Interventions that have a cultural fit would more easily be trusted and accepted by parents in developing countries, therefore improving their commitment to the programme.

6.4.1 Context to current study

In an effort to address this lack of data, three separate studies have already been conducted. The scoping review on interventions supporting young children with disabilities in Indonesia found that some interventions have utilised resources with a cultural fit; however, all evaluations were marked by significant methodological limitations (Kiling et al., 2018b). The systematic review on interventions for young children with disabilities in developing countries found that the impact of risk factors could be potentially reduced by providing disability screening services, community-based rehabilitation (CBR), and comprehensive targeted and general services (Kiling et al., 2018a). Further, interviews with parents of young children with disabilities and local leaders in West Timor, a rural part of Indonesia, (Kiling, Due, Li & Turnbull, 2018c), suggested that most available services were not meeting children’s needs, and that there is a growing necessity to take into account local cultural practices in designing interventions.

These three separate studies served as background for a consultative process to produce a best practice model for young children with disabilities in Indonesia. Specifically, this current study draws upon the results of this previous work to develop the model using an Implementation Science approach. Defined as “the scientific study of methods to promote the systematic uptake of research findings into routine clinical practice…” (ICEBeRG, 2006, p.1), Implementation Science aims to transfer research-based practices to service settings (Ogden & Fixsen, 2014). This study also used community-defined evidence to complement the Implementation Science approach. Such an approach refers to a process whereby community members define the evidence base in their own terms, representing a more bottom-up approach when compared to the conventional evidence paradigm (Johnson et al., 2015).

The purpose of the best practice model is to provide an evidence-based, culturally relevant framework for governmental and non-governmental agencies to adapt in West Timor and elsewhere in Indonesia or in other developing countries with similar contexts, for supporting young children with disabilities who face environmental risk factors.

6.5 Methods

6.5.1 Study site and ethics

West Timor is located on the island of Timor in East Nusa Tenggara province, Indonesia. Composed of five regencies and one municipality, West Timor has 1.8 million people that contribute more than one-third of the total population of East Nusa Tenggara (Badan Pusat Statistik-Statistics of East Nusa Tenggara Province, 2017). The majority of West Timor’s population belongs to a group known as the *Atoni* or *Dawan* (Highlander) (Ormeling, 1956).

From 2010 to 2015, East Nusa Tenggara province was consistently ranked among the lowest bottom three in the Human Development Index (Badan Pusat Statistik, 2017).

According to a national survey, there are 5,775 children with a disability in East Nusa Tenggara, and as many as 1,236 children with disabilities in West Timor or about 1% of the total population of children in East Nusa Tenggara (Badan Pusat Statistik-Statistics of East Nusa Tenggara Province, 2017). It is predicted that the actual numbers are actually higher, since children in West Timor are vulnerable to multiple risks, including poverty, malnutrition, substandard home environments and lack of access to education (Durkin, 2002; Grantham-McGregor et al., 2007).

Ethics approval for the study was obtained from the Human Research Ethics Committee at The University of Adelaide, as well as the Committee of Health Research Ethics in the Ministry of Health, Republic of Indonesia. The study was carried out in Kupang City and Kupang District, West Timor, Indonesia. Permission to collect data was also given by the Ministry of Home Affairs, the Governor of East Nusa Tenggara Province, and the Mayor of Kupang City and Regent of Kupang District.

6.5.2 Previous research methodology and findings

As described above, three studies were completed prior to the development of the best practice model as outlined in this paper (Kiling et al., 2018a; Kiling et al., 2018b; Kiling et al., 2018c). The initial study, a scoping review of interventions to support the development of young children with disabilities in Indonesia (Kiling et al., 2018b), found only eight methodologically weak studies. A subsequent broader systematic review of interventions addressing environmental risks threatening young children with disabilities in developing countries (Kiling et al., 2018a), found a total of 48 studies. This systematic review found evidence for CBR, disability screening services and targeted and inclusive general programs. A qualitative study including thematic analysis was then conducted designed to explore the perceptions of local leaders and parents of young children with disabilities in West Timor, Indonesia. Areas of investigation included general perceptions of disability, risk and protective factors (Kiling et al., 2018c). A total of 23 parents and 15 local leaders (e.g. government agency leaders, NGO leaders, village leaders, etc.) participated.

6.5.3 Current study (procedure)

6.5.3.1 Step 1 – Collation of materials from previous studies to develop first prototype

The author summarised the findings from the previous three studies and discussed these with the supervisors. For example, the scoping review suggested the possibility of incorporating local resources for interventions to ensure cultural relevancy, while the systematic review indicated the importance of training for disability screening in developing countries, together with the potential of inclusive village programmes, early childhood services, child forums, and empowering parents to run self-help groups. The qualitative study provided information about the resources available in West Timor to support future programmes, and further evidence about the role of local knowledge and culturally relevant interventions.

6.5.3.2 Step 2 – Application of the prototype into the Kellogg framework

Following discussion within the team, the information was collated for the initial logic model (see Appendix 14), using the methods outlined in the WHO CBR Matrix (WHO, 2012b) and by the W.K. Kellogg Foundation (2004). Such an approach has been used extensively for developing best practice models and as an evaluation tool for community-based programmes (Helitzer et al., 2010). The information was classified into the following components: strategies, assumptions, risk and protective factors, resources, activities and outcomes. These components were mostly inspired from the template provided by Kellogg (W. K. Kellogg Foundation, 2004). The strategies component included those approaches previously identified as generally successful or representing potentially best practice in the context of West Timor.

The assumptions component defined how and why the identified strategies might work in West Timor and in other rural areas. The risk and protective factors and resources components were derived from the qualitative data as well as local knowledge. The activities component defined the processes and actions to be part of programme implementation. A total of 11 activities were divided into five areas, namely health, education, economy, social and empowerment. Finally the outcomes component outlined some of the expected benefits in terms of developmental support for the children.

6.5.3.3 Step 3 – Initial testing of the model using focus groups

The author carried out fieldwork for this step in Kupang City and Kupang Regency, from April 2016 to October 2016. The study employed focus groups to gather data for developing the model and later interviews were used for checking the response of consumers to the model. An Indigenous psychology approach was utilized to focus the data collection process in local familial, cultural, social and ecological contexts (Kim et al., 2006). This approach is particularly relevant in understanding psychology in the social context of a specific community. Focus group questions aimed at eliciting practical information about proposed activities. Higher level and more abstract concepts such as broad strategies and assumptions were not addressed. Questions in lay language were asked in the following order: definition of childhood disability, risk and protective factors, and activities and outcomes. The discussion was aided by the use of a visual guide in the form of a poster-size diagram of the initial logic model (See figure 6.1). Participants were asked their opinions about the initial prototype model and whether they had something to add or remove. Discussions ranged from 71 minutes to 146 minutes with an average of 85 minutes. All focus groups were audiotaped and conducted in Kupang-Malay.

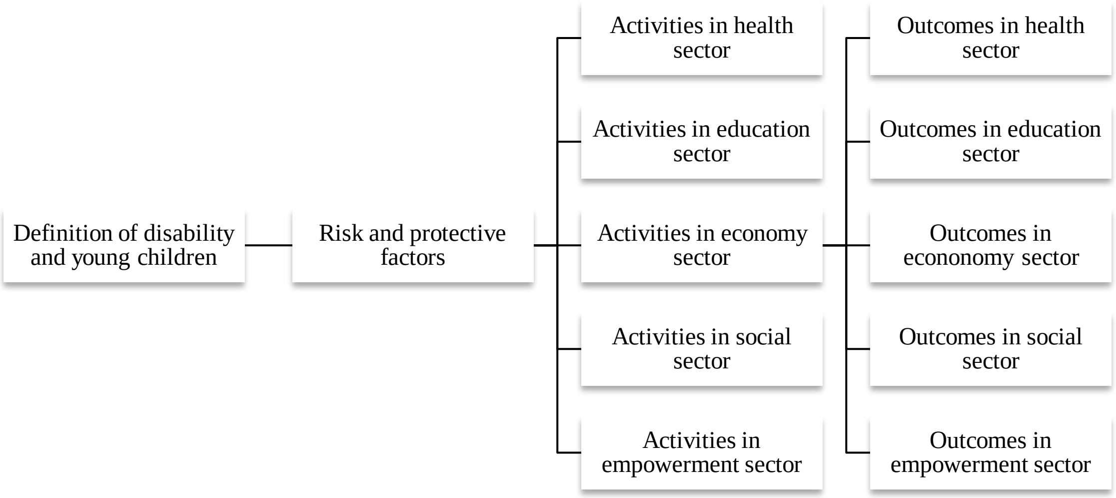

Figure 6.1: Diagram of initial logic model presentation in focus groups

A total of 21 parents (mothers, aunts and grandmothers) and 55 local leaders (NGO workers, kindergarten teachers, Sunday school teachers, and community health centre workers) participated in 10 focus groups, two focus groups with parents and eight focus groups with local leaders. Only female parents were available and willing to participate in the discussion, reflecting their role in the family within Indonesian culture. Parents were recruited using a purposive sampling approach. Initially the author approached the Handicap International office in Kupang City to identify parents of young children with disabilities involved in parent groups that the organisation had previously initiated. He then visited two group coordinators who subsequently introduced him to parents. Parents were eligible for the study if they had a child aged below eight years of age who they perceived as living with a disability. Two focus groups with parents were held in the houses of parent group coordinators, a place where they often gathered. The parents' ages ranged from 27 to 50 years. Thirteen parents were full-time housemothers, and the ethnicity of parents included Timor, Sabu, Sumba, Rote, Flores, and Batak. Six parents had been educated to high school level and one had a diploma degree. Their children had various physical impairments and/or development difficulties including delays in walking and in speaking, low vision, and emotional disorders. (Further details on demographics data can be accessed in Appendix 13.)

Fifty-five local leaders consisting of 15 kindergarten teachers, 12 Sunday school teachers, 16 community health centre workers, and 12 NGO workers participated in eight different focus groups. Participants came from two separate sub-districts, Kupang City and Kupang District, selected because of the relatively high number of children with disabilities living in these areas. Local leaders were eligible for the study if they had worked in their current job for at least six months. Two focus groups with kindergarten teachers were held in their classrooms. Two focus groups with Sunday school teachers were completed in churches, while two focus groups with community health centre workers were held at the employing centres. The other two focus groups with NGO workers were held in a university classroom. Ages ranged from 18 to 63 years, with time in current job ranging from six months to 38 years. Most local leaders had completed their secondary education, with only two persons with only junior high school level education. (See Appendix 13 for more details). As with the focus groups for the parents, these focus groups were audiotaped and conducted in the Kupang-Malay language.

Suggestions in the form of individual extracts from the focus group data were translated into English then used to enrich and update the logic model. This was done by the author in conjunction with discussions with the supervisors. This produced a model including 64 activities which were only very roughly grouped at this stage as follows: health (14 activities), education (14 activities), economy (6 activities), social (16 activities), and empowerment (14 activities). Some examples included community-based screening (health sector), improved infrastructure accessibility (social sector), and youth empowerment (empowerment area).

6.5.3.4 Step 4 – Final testing of the model using interviews

The final step entailed conducting a series of interviews with leaders with either personal or professional experience of childhood disability to finesse and finalise the model. These interviews focussed on assessing the activities component of the model by obtaining respondents' opinions about the extent to which they might apply in West Timor. Interviews ranged from 41 minutes to 132 minutes with an average of 71 minutes and were mainly conducted in Kupang-Malay (one interview with UNICEF Kupang's staff was conducted in English). Thirty-five participants took part in 29 interviews, with three sessions being conducted as a group interview. Participants included rectors of universities, heads of government agencies and NGO project coordinators, as well as a mother who provided feedback from a parent's point of view. Ethnicity varied and included an American and an Indonesian from the UNICEF office in Kupang (See Appendix 13 for full details). Sessions were audiotaped and transcriptions were completed in Kupang-Malay.

6.5.3.5 Step 5 – Final production of the model

After completion of focus groups and interviews, data were transcribed into Kupang-Malay first, and transcripts from three focus groups (one from parents, two from local leaders) and three interviews were translated into English to be checked by the research team. Data were then formally analysed using a thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2013) incorporating both deductive and inductive approaches. The emergent themes were checked through informal discussions with two cultural elders in Kupang City, to ensure local relevance and validity. The model was also checked by the research team to remove any data contradicted by the evidence base about treatments and interventions for supporting children with disabilities. Finally, themes were named according to the relevant sectors for the recommended activities as follows: multi-sectoral, health, education, economy, social, empowerment, religion and data improvement. Most of these themes resulted from the deductive approach which was informed by the WHO CBR matrix (WHO, 2012a), while the themes about multi-sectoral, religion and data improvement came about as a consequence of the simultaneous inductive approach to analysis.

6.6 Results

The resultant logic model comprises of a series of 41 activities in eight sectors, with six central activities spread across all sectors (Figure 6.2). For simplicity and practicality of use, the demonstration of the model focuses on the components of activities, assumptions and implementation activities.

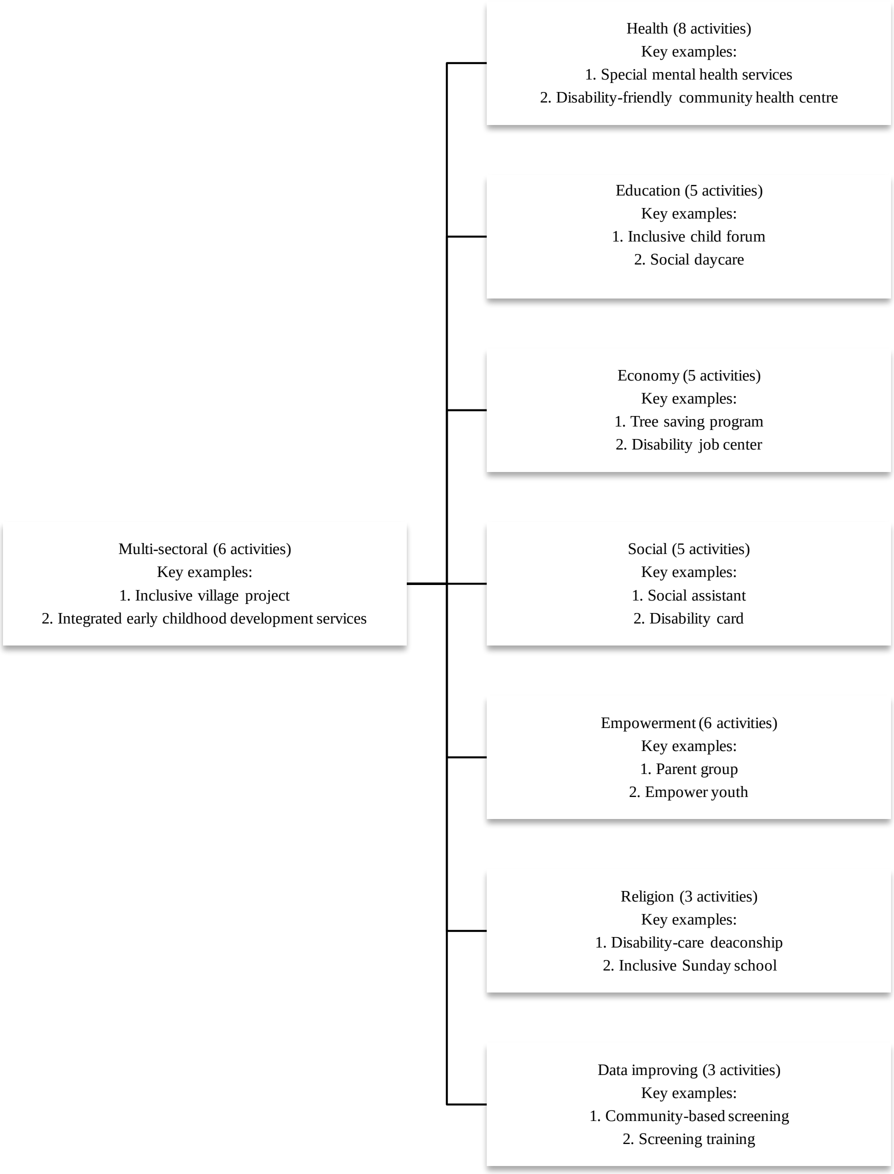

Figure 6.2: Diagram of logic model

6.6.1 Multi-sectoral theme

This theme includes six broad activities covering multiple sectors (Table 6.1). It highlights the importance of ensuring that all services including those for religion and education are inclusive and integrated. Central to this theme is collaboration in order to ensure that services are not duplicated. A key example is that of the Inclusive village project (Kemenkopmk.go.id, 2015), which has been tried in other parts of Indonesia, but yet to be piloted in West Timor.

The Disability Law of 2016 (Presiden Republik Indonesia, 2016) now requires higher education institutions for teacher training to provide curricula for inclusive education. Study participants suggested that similar regulations might also be implemented more broadly across the higher education sector. While acknowledging budget implications, improvement of infrastructure accessibility was also deemed urgent by participants.

Example quotes include:

> PD (NGO project coordinator – focus group): *Yes I think, in health (courses) for health workers must not (only) about early screening eh. But if possible disability could be inserted in the curriculum too. So these health workers would already have knowledge on disability services from college. That's it, yeah.*

> FB (Rector of university – interview): *If only the ministry (of higher education) would oblige all infrastructure development in campuses to be designed with accessibility for people with disabilities, that would be great. If that happens, it would be great.*

Table 6.1: Final logic model: multi-sectoral theme

Activities	Assumptions	Implementation strategies
1. Inclusive village project	1. Inclusive village could become the catalyst for other programmes 2. Improve services at village level	1. Social agency or people prosperity bureau or community development agency become the executor 2. Inclusive village has been implemented in Yogyakarta province 3. Need regulation first at ministry level 4. Build inclusive village based on inclusive province momentum 5. Start from model village first, could be from urban area first 6. Existing programme from stakeholders could be integrated with inclusive village programme
2. Integrated inclusive ECED services	1. Below five guidance programme and ECED still not integrated even though targeting same issues	1. Integrated ECED regulation already existed 2. Integrated ECED model initiated by NGO in the past 3. Integrated ECED must focus on quality first, then quantity 4. Integrated could mean one place, or coordinated activities 5. Inclusive village will facilitate integrated ECED 6. Implement pilot programme in one village 7. Regional planning body (BAPPEDA) must be involved in coordinating the programme
3. Inclusive education/ services in curriculum & training	1. All teachers need to understand inclusive education 2. Other public service workers need to be prepared too 3. Has not been started by any stakeholder 4. Poor implementation of inclusive education in society	1. Start advocating the programme at ministry level 2. Government agencies (health agency, people prosperity bureau) should advocate universities, focus on training, socializing new disability law 3. Should be available to all universities 4. Should cover all disabilities 5. Need derivative regulations to support 6. Past efforts in improving curriculum by family planning agency and DPOs 7. Training should cover rural areas 8. Training should be continuous to model school
4. Mentoring for young adults to prevent disabilities	1. Prevent disabilities 2. Reduce number of citizens and also violence	1. Conducted with cooperation of family planning agency, church, cultural leaders and health workers 2. Mentoring should focus on villages 3. Mentoring exists in church and community health centres

Activities	Assumptions	Implementation strategies
5. Health monitoring in schools	1. Inclusive school has reporting system to community health centre, but not all centres involved 2. Help bridge monitoring between education stage (e.g. preschool to elementary)	1. Must be coordinated by health and education agency 2. Supported by health operational fund 3. Improve the frequency and coverage of monitoring 4. Improve reward for health workers to give motivation 5. Do monitoring three times per year 6. Utilise school health programme and other related programmes 7. Monitoring combined with socialisation activity
6. Improving accessibility to public facilities	1. Accessibility could improve the overall quality of life of young children with disabilities	1. Jakarta (capital city) has started accessibility development 2. Catholic church has started accessibility development 3. Need prototype and regulations for accessibility, started with government offices, general works, churches, BAPPEDA (Regional Planning Body) 4. Need to emphasize big population of people with disabilities (15%) to advocate government 5. Also emphasize improving accessibility for all vulnerable people 6. Start piloting in public facilities 7. Could use accessibility model from disability-friendly community health centre

6.6.2 Health theme

Participants commented on the fact that existing services are often quite fragmented and suggested a total of 8 activities, with several of these being relatively new to the West Timor community (Table 6.2). Specific suggestions included that of a comprehensive specialist disability clinic, which could also have the goal of improving the broader community's awareness of disability. Similarly, participants suggested that collaboration between health workers with shamans was important, given the absence of health services in remote areas, and the cultural importance of shamans in local areas. Finally, participants indicated that mental health services are not readily available outside of Kupang City, highlighting the need for regional and remote services. Participants also commented on the lack of budget and resourcing for such initiatives and the fact that other priorities such as malaria control were often given more attention. Exemplar extracts from this theme are listed below:

> DR (Sunday school teacher – focus group): *Working with shaman, like birth shaman, they must be trained, so, when health workers are not available, for example in an isolated village when health workers often not available, so when people need (health service), or when they are, dying, these trained shaman could help with giving first aid.*

> DP (UNICEF staff – interview): *I also agree, if we have like a, legitimate resource in psychology, at least they (government) should have psychologists and distribute them to every sub-district. Because in Indonesia we really need this, also we also still have, what is it called, a stigma of when you come to a psychologist, it means you are insane.*

Table 6.2: Final logic model: health theme

	Activities	**Assumptions**	**Implementation strategies**
1.	Collaboration between health workers (shaman and religious team)	1. Christian is the majority, collaboration with church prayer team is essential 2. Church ready to collaborate with shaman 3. Shaman and prayer team has important value in community 4. Shaman needs to be trained	1. Shaman is only to give support in medical intervention. 2. Should train shaman and prayer team first to give first aid 3. Initiated by health agency 4. Service location is in community health centres

	Activities	Assumptions	Implementation strategies
2.	Centred and home-based health training/class	1. Provide social interaction between parents 2. Feasible due to limited resources	1. Should be integrated in integrated service post, supported by ECED and below five guidance and church 2. Community health centre staff already trained to facilitate health class 3. Development class joined with parenting class 4. Early detection activities could be inserted in the class 5. Train parents about stimulation and disability detection 6. Target young mothers and fathers 7. Coverage per village or community health centre 8. Training in houses must focus in vulnerable population
3.	Special disability clinic	1. Existing clinics were not effective	1. Coverage per city/district hospital 2. Clinic could lead in awareness campaign 3. Need for clinic must be assessed first 4. Socialisation of special clinic's importance 5. Health agency or NGO initiate the clinic 6. Could add disability centre in child clinic 7. Empower physiotherapists
4.	Home visit to pregnant teenagers + reproduction education for teenagers	1. Community health centre rarely do home visit 2. Family planning agency is never offered	1. Use psychological approach in the service 2. Home visit must be careful in approaching teenagers 3. Should support parents of pregnant teenagers 4. Conducted by religious workers rather than government 5. Conducted by midwives, family planning cadres, social workers, community leaders, counselling teachers 6. Past programme existed in health agency and church 7. Similar programme runs in social ministry called child social prosperity programme

	Activities	Assumptions	Implementation strategies
5.	Empower parents to be able to serve nutritious local food	1. Healthy food needed for children's development	1. Available funds from health agency and other government programme (PNPM GSC) 2. Focus in indigenous resources
6.	Improving capacity and incentives of health cadres	1. Small incentives and poor knowledge of cadres in villages	1. Improve workload should cadres have more incentives 2. More important to improve capacity 3. Offer routine salary not just work-based incentives 4. Funding from national health operational fund and village fund. Some villages already started paying more incentives 5. Pay more attention to cadres in remote areas
7.	Disability-friendly community health centre and improved facilities	1. Promote inclusive health service 2. There is no special attention paid to special disability intervention	1. Health agency will initiate the programme 2. Health workers in the community health centres should be trained 3. Already initiated in Kupang City 4. Focus in providing more tools, especially screening in community health centre 5. Regional fund and national health operational fund could support financially 6. Focus on improving quality over quantity of health facilities
8.	Special mental health services	1. Mental health service lacking in Indonesia	1. Improve number of mental health workers first 2. Could implement in community health centre

6.6.2 Education theme

A total of five activities were identified in the education theme, with two related to creating a more inclusive environment for children with disabilities (Table 6.3), an idea in line with the main education agency's joint programme with Handicap International. Participants also suggested innovative approaches such as inclusive government or NGO run child forums (also referred to as child groups in some places in West Timor), which aim to bring together children with disabilities in village and urban communities to protect children's rights and to support inclusive education by providing a safe environment outside of formal education. Another innovation suggested in the interviews was that of social day care programmes for young children whose parents both do paid work. While such an approach has the potential to be quite practical given the increasing early childhood workforce, as well as the reported interest in the idea from social agencies, again respondents commented on budget constraints as well as lack of support from government executives and legislatives. Example of excerpts include:

> SS (NGO Project Coordinator – interview): *Yes inclusive child forum, because we would not discriminate, children, they have the potential, maybe they have some special needs in some (aspects), but they must have (strengths) in other (aspects), and they could complete with each other with children considered more normal.*

> YP (Kindergarten teacher – focus group): *Social day care maybe could be applied in our kindergarten I think. Maybe for people who, when they have a lot of work to do, for example when the father have to work, and maybe the mother have to go to market to do trading. Their child must be put in our kindergarten, so that we could take care of the child, so when they take their child here in the morning, they can pick up the child around 5pm.*

Table 6.3: Final logic model: education theme

	Activities	Assumptions	Implementation strategies
1.	Inclusive child forum	1. Help improve peer awareness of disability, avoid discrimination 2. Improve creativity and confidence	1. NGOs to support implementation 2. Universities could support community service programme 3. Prepare existing members of child forum first to be aware of disability 4. Child forum could join with inclusive school initiative
2.	Allocating special education teachers and/or psychologists in regular schools	1. Help improve inclusive education implementation 2. Teachers in regular school tend to be harsh on children with disabilities	1. Posting specialized teacher and psychologist in school permanently to support inclusive education 2. Teachers from special school and psychologist visit inclusive ECED posts 3. Must be regulated by government at ministry level 4. Special education teacher must be prepared not to teach with a vocational approach 5. Visits useful in early phase of inclusive school, won't be necessary in the later phase 6. Visit once or twice per month 7. One teacher responsible for teaching and supporting few number of schools 8. Post two teachers in an inclusive class
3.	Learning materials in ECED posts	1. Inadequate materials for young children with disabilities	1. Education agency already provided materials for a limited number of ECED posts 2. School operational fund only for general needs 3. Church, family prosperity agency could support materials 4. Materials could be produced from recyclable goods 5. Corporate social responsibility could be connected to ECED posts

	Activities	Assumptions	Implementation strategies
4.	Social day care	1. Fathers and mothers of young children with disabilities need to work	1. Social agency or family prosperity agency could start the initiative 2. Available at sub-district level or village level 3. Prioritise poor parents 4. Must train carer in social day care 5. Social day care should be discussed in *musrenbang* (policy making discussion) 6. Implementation must be watched closely, there are a lot of risks associated with day care 7. Social day care should focus on all aspects of development 8. Social day care could be integrated in existing services such as ECED post or special school
5.	Improving inclusive secondary and tertiary education	1. Some schools accepted children with disabilities in the past without inclusive education initiatives, although they might only accept selected students 2. Inclusive education must be applied from preschool to higher education levels	1. Inclusive province declaration momentum should be used to improve inclusive education 2. Every district must have a minimum of one inclusive school in each education stage 3. Improve inclusive education in vocational high school 4. Education agency at province level provides funding support 5. Must advocate for other education stakeholders to support the initiative 6. Must target all regular schools so they could become inclusive in the future

6.6.3 Economy theme

This theme included five suggested activities: tree saving programmes; disability-care national health insurance; allocating village funds for social protection of people with disabilities; disability job centres; and a productive economy group for mothers in the village (see Table 6.4). The idea of the tree saving programme is to encourage parents to plant incoming generating trees to fund their children’s future education. Such a programme may also help to create new water resources desperately needed in West Timor, which is dry and barren compared to the rest of Indonesia. Many participants also suggested alternative saving ideas, most notably livestock development programmes for cattle and pigs, which are communally owned and shepherded by Timorese. Another proposal was to develop earning capacities by economically empowering mothers in the village. Participants recommended the need for central and local governments to advocate for better social protection for children with disabilities. At the central government level this included the development of a more disability-friendly national health insurance programme, while the suggestion for local government was for greater allocation of village funds to people with disabilities. A final recommendation was for the establishment of a disability job centre for providing young people with vocational training and connection to employer groups. Related to this is the need to advocate on behalf of people with disabilities to encourage job providers to open employment opportunities to people with disabilities. Example of quotes are shown below:

> BP (kindergarten teacher – focus group): *I think if we want to do the tree saving, teachers could be involved in it. Teachers can help explain to children how to plant the tree and also in meetings with parents, we can also tell parents that, every child must plant at least one or two Cendana (local tree) threes for example.*

> BM (head of division in Timor Church Synod – interview): *I guess it is better if we have a specific fund allocated from village fund for children (with disabilities), in health, education and so on, so they should make a specific item (in regulation) for this.*

Table 6.4: Final logic model: economy theme

Activities	Assumptions	Implementation strategies
1. Tree saving programme	1. Programme is feasible, due to land in rural areas are yet to be utilised 2. Timor people used to planting trees 3. Children could learn responsibility by raising trees	1. Initiated by forestry or farming agency 2. Similar programme initiated by Kupang Regent in ECED posts 3. ChildFund has initiated flexible saving programme 4. Should consider several kinds of savings, and rotate savings to gain more benefits 5. Start the programme in school such as Kupang Regency 6. Choose trees like Cendana, utilised in another government programme 7. Emphasise conserving environment or saving behaviour 8. One child one tree programme
2. Disability-care national health insurance	1. National health insurance (BPJS) focus on poverty 2. National health insurance need to support large disabled population 3. Need to support therapy needs	1. People with disabilities are already a priority in national health insurance and regional health insurance programmes 2. National health insurance has covered assistive devices 3. National health insurance could easily cover children with disabilities in rehabilitation centre 4. Focus on improving payment system, especially in rural areas 5. National health insurance should cover therapy

Activities	Assumptions	Implementation strategies
3. Village fund allocation for social protection of people with disabilities	1. Scholarship as appreciation for young children with achievement 2. Social fund for disability has been started in other developing countries 3. Assistive devices from social agency is inadequate 4. Village fund still focussing on physical development	1. Social and education agency at district level should provide scholarship 2. Corporate social responsibility could provide scholarship 3. Scholarship focuses on providing special learning materials 4. Scholarship covers education needs, social fund covers the others 5. Advocate Kupang City government so they could allocate budget for urban communities 6. Improve parents and government awareness of ECED importance 7. The new disability law will help with advocacy, focus on derivative regulation in village level 8. Scholarship must target families with middle level of economy 9. Scholarship delivery must be monitored and improved 10. Work with Handicap International in persuading village leaders to allocate village funds 11. Should advocate government from top to regional levels to make village funds accessible 12. Utilise funds to improve general services in villages 13. Train cadres in village in inclusive service 14. Village funds must be allocated specifically for dealing with disability issues
4. Disability job centre on- and offline	1. Job centre could connect people with disabilities to jobs 2. Children with disabilities will have many friends through the online world 3. Online job centre necessary in urban areas	1. Conducted by International Labor Organisation (ILO) together with workforce, education and communication agencies 2. Could be initiated by universities 3. Need to collaborate with entrepreneur associations 4. Implemented at district level 5. Need a better database of persons with disabilities first 6. Job centre could also facilitate vocational training 7. Need derivative regulation to support the programme

Activities	Assumptions	Implementation strategies
5. Forming productive economy group for mothers in villages	1. No programme to support economy aspect of parents of children with disabilities	1. Economy programme existed but has not reached parents of children with disabilities yet 2. Conducted by community development agency, tourism agency, trade agency, and/or universities 3. Form economy group that works in local foods, recyclable goods, livestock, crafts, snacks, etc. 4. All families must be guided to have productive economy activities, according to potential and interest 5. Build centralised production so the profit won't be absorbed by middlemen 6. Productive group serves as an initiative to improve disability awareness and parenting 7. Focus on jobless mothers 8. Must provide economy group for fathers too 9. Could initiate in ECED post when parents are waiting for their children 10. Conduct Arisan (regular social gathering) to help gather mothers 11. Need initiatives that do not bother parenting process 12. Should only give incentives based on productivity

6.6.4 Social theme

This thematic area consists of five activities (see Table 6.5) including raising community awareness; improving general services; providing better personal assistance, and ensuring enactment of regional disability law. It was suggested that religious and cultural leaders, rather than government would have a greater role to play in creating new social attitudes and norms about disability, but they would at first have to be encouraged to undertake such a commitment. The majority of participants proposed providing more social assistants and social workers for young children with disabilities to support their development. They reported on the need to advocate to government to expedite the ratification and enactment of the regional derivation law of the National Disability Law so as to provide a legal basis for all other services. Additionally they argued for the importance of monitoring the implementation of such laws, in the form of a regional disability commission. Some quotes to represent the theme:

> TTY (NGO project officer – focus group): *Well, we should yes, not only (government) institutions' role, but this religion system is also important to start the change. People will hear more through religion, because, moreover if that person is Indonesian. Priests, clergymen, nuns, monks, they have, have the charisma, the authority, they are considered as figures. Figures whose talks, words must be listened. Maybe one way is in worships, they could advocate the community in worships.*

> FM (section head in Social agency of East Nusa Tenggara province – interview): *Well for social assistant, Ministry of Social Affairs have employees, kind of social assistant, but not for one-to-one service, their tasks including when there is person with severe disability who faces hard circumstances, such as neglected, we could provide needed service.*

Table 6.5: Final logic model: social theme

Activities	Assumptions	Implementation strategies
1. Socialisation by religious and culture leaders	1. Religious and cultural leaders have significant influence in West Timor	1. Government agencies, churches, and NGOs have started socialization 2. Socialization through Sunday services and nunneries, must advocate the synod first 3. Need to socialize disability from a theology perspective; disability happens not because of parents' fault but God wants to declare His honour 4. Better to use bottom-up approach 5. Focus more on religious leaders than cultural leaders. Improve awareness of religious and cultural leaders first

	Activities	Assumptions	Implementation strategies
2.	Providing social assistant and improve social worker	1. Social assistant necessary for severe disability cases 2. Social worker's effect is hardly felt by young children with disabilities	1. Social ministry has social assistant programme but not one assistant for one a person with a disability 2. Church should take part in providing social assistant, they have own system of social assistant 3. Campus provide volunteers to become social assistants 4. Social assistant only for severe disability cases 5. Social assistant focus in school activities, and focus on young children 6. Social assistant from social agency also gathers data 7. Better to have some sort of visiting nurse programme 8. Should also have a programme that gives the primary caregiver a break 9. Empower parents, or use rehabilitation centre instead of providing social assistant 10. Need social worker that works in the village, not in the office 11. Regional government could support social worker by giving more incentives
3.	Advocating and monitoring regional disability law	1. Kupang City and East Nusa Tenggara still have not finalised the regional law	1. Kupang City and Kupang Regency have related laws that consider disability issues such as child protection law and education law 2. NGOs should be involved in policy making and monitoring process 3. Need specific institution like disability committee to oversee law implementation 4. Disability committee should merge with existing committee such as child rights 5. Need a disability activist in house of representatives to oversee regional law making 6. Should focus on law socialization too 7. Advocate government in event such as children's day/disability day

	Activities	Assumptions	Implementation strategies
4.	Special disability card	1. Special disability card could improve access to necessary services	1. The new disability law already regulates disability card, need derivative regulations 2. Special card must be administered by central government 3. Special card could focus on severe disability cases 4. Need to have integrated system first between government agencies 5. Special card functions as identity card to get special priority
5.	Forming disability unit/ commission to improve coordination	1. Disability commission is already regulated in new disability law 2. Many NGO programmes were not successfully adapted/continued by government	1. Developed countries utilize working unit for multi-sectoral issues 2. Project like inclusive education shows cooperation between agencies 3. Need special unit in social, education and health agencies 4. Special unit only in one agency, to become coordinator 5. Agencies couldn't make new unit, except it is regulated at ministry level 6. Government doing best practice festival in order to promote collaboration with NGO

6.6.5 Empowerment theme

Participants suggested six activities for the empowerment of the family and community (see Table 6.6), with a focus on social mobilisation for creating an inclusive community. Central to this idea is that of empowerment of parents of children with disabilities as well as the people in their immediate social sphere. Related to the concept is the suggestion of mobilising village members to create a more inclusive environment for vulnerable groups, including young children with disabilities. Other recommended activities include empowering West Timorese youth to become disability activists, and conducting more public events to promote knowledge of disability issues. Participants reported on the need to strengthen parents' groups (of children with disabilities); empower disabled people's organisations (DPO); encourage parents to participate in the policymaking process (*musrenbang*); and improve awareness of various media and parents. It was noted that most of these activities have been conducted previously in West Timor or are ongoing, and that such an approach would contribute to sustainability as well as encouraging improvements in other areas. Some quotes in relation to this theme:

> FL (community health centre worker – focus group): *So when there were malnutrition cases in Kupang, some newspaper articles also came up and then after that, government quickly took responsibility to deal with the issue. So I guess maybe we could publish in newspaper, latest research or data on disability, or maybe we could publish in social medias, so it could influence policy makers.*

> VH (Member of House of Representative Kupang City – interview): *Well for me, forum of family with disabilities, is one of the solution. Because when these families gather, talking to each other, be open to each other, I think it is important for them to learn and support each other.*

Table 6.6: Final logic model: empowerment theme

Activities	**Assumptions**	**Implementation strategies**
1. Parent group in village	1. Parent group necessary for exchanging information and experiences 2. Parent group good for mental health	1. Parent group facilitated by social or health or family planning agency, supported by church and DPOs 2. Ask for funds from villages to facilitate parent group meetings 3. There are vulnerable groups in some villages formed by NGOs 4. Similar programme of PKSA (Children Social Prosperity programme) that facilitates parents and children in general 5. The group of people with disabilities need to have an alliance in the village 6. Need to revive FKKADK (communication forum of family of children with disabilities) at village level

Activities	Assumptions	Implementation strategies
2. Advocating through media and model parents	1. Media socialization helps improve coverage 2. Model parents from similar backgrounds could motivate other parents	1. Government has started socialization in mass media like radio 2. Advocating through mass media should be soft to lobby the government 3. Should try to revitalize journalists first, change money orientation 4. Advocate government through their hotline centre 5. Socialization through open talks in social meeting 6. Model parents could also share their story in writing, or in church or parent groups
3. Empowering youth to be activists in disability issues	1. Youth community has more numbers, adapt to many media, use peer approach, and counted in village development	1. DPOs (e,g. Persani and Permata) have started youth initiative in the past, no longer active currently 2. Youth community must be trained first 3. Could empower youth community in churches 4. Government's youth community like Karang Taruna should be empowered too 5. Could also encourage youth community in campuses
4. Empowering disability organisations	1. Only few DPOs active in West Timor	1. Social agency and other agencies could support DPOs 2. NGO could support by providing training 3. Church could be involved with DPOs' programmes 4. DPOs must be legal by law first, some organisations were not legal 5. Fund support could be provided by corporate social responsibility 6. Giving members of DPOs jobs could support them
5. Inclusive public event	1. Could help improve community awareness	1. Need to improve accessibility and security in public facilities first 2. Community event in inclusive village pilot 3. Focus on follow-up activities after community event 4. Conduct one day with minister for government programme for children with disabilities

Activities	Assumptions	Implementation strategies
6. Encourage parents to be involved in policymaking process in villages	1. Parent involvement in policymaking process (*musrenbang*) is still low	1. Social agency has started pre-disability policymaking process programme before the actual policymaking process 2. There was a best practice pre- policymaking process for mothers and children 3. Kupang City to enact a law that invites people with disabilities to policymaking process 4. Successful policymaking process *g* must become a pilot 5. Head of RT/RW (community group) should be advocated first, and then they should encourage parents to attend policymaking process 6. Parents should be encouraged to join productive activities in villages 7. Consider enacting village law to regulate inclusive policymaking process 8. Children with disabilities must also be prioritized to attend policymaking process

6.6.6 Religious theme

The majority of West Timorese are Christian (almost all participants were either Protestant or Catholic) and the church plays a prominent role in shaping community behaviour and norms. Participants reported that the church has been working on various social issues in West Timor for some time, including disability issues. Three suggested activities (see Table 6.7) were: creating disability-care deaconships in the church; implementing inclusion principles for Sunday school; and inviting disabled people's organisations to attend church. Deaconship funds, mostly allocated for the elderly, were considered appropriate to be distributed to people with disabilities too, especially for young children. Some participants affiliated with the church admitted they did not even consider children with disabilities as a priority area for the deaconship programme, mostly due to lack of awareness. This could relate to the fact that, according to data from the focus groups, most young children with disabilities were absent from Sunday school activities. It was reported that to improve this situation, a more inclusive Sunday school movement is necessary, and that providing special transport would remove the barrier of poor accessibility. Lastly, an activity that is already ongoing is the attendance of disabled people's organisations or related groups of people with disabilities at church. Respondents considered that this could "open the eyes" of the Christian community and promote a more inclusive social environment. All three activities were considered positive by a leader in the Timor Church Synod, highlighting the potential for future application. Again however, the lack of budget was highlighted. Some examples of the quotes provided:

> SB (former Dean in a university - interview): *Well they should have, deaconship fund allocated for children with disabilities, because from what I know, most of the money usually goes to orphans. They really should begin helping children (with disabilities) too.*

> SR (Sunday school teacher – focus group): *When I do my role as Sunday school teacher, I teach them to read, these children with special needs. So that time I asked support from the priest, to ask other teachers so they could help to teach because I felt like, they also want to know God, but because of their limitations, so, they have the desire for that. I hope that, from church could facilitate us to make the Sunday school more facilitating for these children.*

Table 6.7: Final logic model: religious theme

Activities	Assumptions	Implementation strategies
1. Improving disability-care deaconship in church	1. Church has vital role in West Timor's community	1. Deaconship fund should be allocated to people with disabilities too, start from synod's initiative first 2. Prioritize children with disabilities in baptism and sacraments 3. Insert awareness improvement agenda for all activities 4. Providing transport for people with disabilities 5. Encourage parents to escort their children to church
2. Inclusive Sunday school	1. Many young children with disabilities are not active in Sunday school activities 2. Sunday school provides opportunity to mingle with peers	1. Inclusive teacher training for Sunday school teacher 2. Conduct socialization so parents would bring their children to church 3. Teacher could pick up children for the first couple of times, to encourage parents and children 4. Teacher could collect children with personal vehicles
3. Inviting disabled group to attend church	1. Community's exposure to people with disabilities could help improve awareness	1. Disability group has already attended and performed in churches 2. Social agency could help disability group by donating music instruments or offering transportation support 3. Must have activities that focus on children with disabilities

6.6.7 Data improving theme

This particular theme was repeatedly highlighted by participants as the most urgent of all activities, as data was considered essential for planning and evaluation of programmes. Respondents argued that past programmes had not worked well or had not been approved or funded by policymakers due to lack of available data. It was explained that when government and other agencies were not able to account for the number and needs of children with disabilities, policymakers hesitated to make disability issues a priority.

Three activities were considered essential for improving data collection in West Timor (see Table 6.8). Participants argued for the importance of data collection as part of screening activities and that this activity would aid in the formulation of early intervention programmes, especially those of children being hidden from the system. It was also emphasised that separate training for health and education workers in the area of screening was required. It was commented on that all screening activities are relatively new concepts in West Timor, and that several leading NGOs had not yet introduced the concept. A major challenge for implementation was thought to be the inadequate number of cadres on standby who would be available to undertake such roles. Some quotes from participants in regards of data improving:

> AD (medical doctor – focus group): *Health workers have to be trained, yes after trained, we have to search for them (children with disabilities), from house to house, or if there is indication, so we look for children with potential or risk of disabilities.*

> NH (head of division, People Prosperity Bureau of East Nusa Tenggara – interview): *I am a fond of participative approach. How this screening could be community-based, I think that is vital. We have to be kind to these people (parents of children with disabilities), so together we could raise these children with proper love and treatment. I think community-based screening is crucial for us here.*

Table 6.8: Final logic model: data improving theme

Activities	Assumptions	Implementation strategies
1. Improve data collection before all other programmes	1. A good database will improve implementation of all other programmes	1. Social ministries gather data through social workers, working with mobile social service units to input in their own databases 2. Data must be gathered by user agencies such as social and education agencies. Statistic Central Body (BPS) should only gather general population data 3. Churches could support data collection 4. Data gathering and updating at village level, conducted by village cadres and leaders, must also involve community members 5. Data gathering must be done by visiting the person 6. Data must be centralized and available online 7. BPS could begin to gather more specific data 8. Must have data verification system
2. Community-based screening	1. Programme could help improve coverage in rural areas	1. Community-based screening must involve churches, integrated service post, family prosperity agency, social agency, and legislative members 2. Empower undergraduate students so they could become cadres and function to screen for children with disabilities in community 3. Involve parent group as screener 4. Prefer head of RT or RW (community group) to become screener 5. Must train the cadres in psychological and social skills 6. Screener then refers to specialists 7. Need to prepare the procedure after screening 8. Could join programme with community-based domestic violence detection programme 9. Must focus in empowering family too 10. Make three RT as one community and have a cadre serve as the radar to screen for disability

Activities	Assumptions	Implementation strategies
3. Screening training for health and education workers	1. Screening will improve data collection and other programme's execution 2. Screening must be done in education setting too	1. Training conducted by health agency at district level, facilitated by children's specialist doctor, using standardized test 2. Training focus in development screening in general first, could focus in hearing, visual screening in the future 3. Screening training has been done in 2012 and 2013 by health ministry but the impact is yet to be felt 4. Screening conducted in community health centre or integrated service post or in ECED posts 5. Screening could be combined with immunization 6. Screening conducted by cadres such as ECED post cadres, integrated service post, below five guidance. 7. Early screening for learning disabilities needs different training 8. Prepare screening tools for educational setting

6.7 Discussion

This study demonstrates the utilization of an Implementation Science approach to build a best practice model from existing studies and additional qualitative data. The model aims to supply stakeholders (e.g. governmental and non-governmental institutions) with activities that can be applied to support young children with disabilities in Indonesia. Since evidence of interventions for young children with disabilities is lacking, this study could provide fresh insights for potential application in other developing countries.

The analysis of data obtained from the previous three studies plus focus groups and interviews resulted in 41 activities clustered in eight major thematic areas, namely multi-sectoral, health, education, economy, social, empowerment, religious and data improvement. The final version of the logic model briefly explains each activity along with assumptions and implementation strategies in order to provide a simple method to help stakeholders grasp and apply the suggested activities. Responses from interviews also indicated that the recommended implementation strategies helped stakeholders to better understand how to actualize activities listed in the model.

Two themes became very evident from the data analysis, religious and data improvement. The importance and urgency of both were repeatedly underlined by participants in this study as well as the previous studies (Kiling et al, 2018a; Kiling et al., 2018b; Kiling et al., 2018c). Religious institutions in West Timor were considered by respondents to be key stakeholders in motivating and setting examples to others about best practice regarding services for young children with disabilities. Participants in this research remarked that it is easier for community members to follow appeals from religious leaders than government leaders. Meanwhile, participants especially government leaders, stressed that improving the quality of data about young children with disabilities is a must, before devising and implementing programmes, as the data serves as justification for these programmes.

The range of activities listed in the model is comprehensive to support young children's personal development, increase family competencies, and strengthen social inclusion of children and families. These activities include targeted and general services such as rehabilitation, medical, family-centred services, special and inclusive education, and social, psychological and spiritual services. The services delivered in various settings include hospitals, rehabilitation centres, churches, schools and homes, involving multiple stakeholders from top-level government to community members. The utility of the model looks promising as it consisted of best practice evidence and community-defined evidence while closely following the agenda and framework suggested by the WHO and UNICEF (Johnson et al., 2015; WHO, 2012b).

However, even with a detailed framework, there is no guarantee that a best practice model will be actualized in West Timor. The model is designed to be implemented in a according to the preferences of policymakers and practitioners and there are issues in this regard. A recent report from Indonesia underlined the crucial problem of poor implementation of laws and programmes, and gaps in service coverage and law enforcement related to people with disabilities in Indonesia (Adioetomo et al., 2014). This issue was also raised by several participants in the focus group and interview sessions for this study, who expressed concerns about the low levels of awareness about disability issues amongst elites and that almost every government agency considered that disability issues are the sole responsibility of social agencies. This has the effect of weakening the elite's commitment to disability laws and programmes as well as also effecting programme coordination, resulting in poor implementation of many past programmes.

A complex issue like childhood disability might be termed as an example of a "wicked problem" (Carey, McLoughlin & Crammond, 2015) as it is characterized by no definitive solution, has many causes and involves many areas of life. Such issues have been dealt with using various approaches, including the stand out, 'joined-up government' (JUG). This approach was popularized by the Blair Government in the United Kingdom in addressing the problem of social exclusion, followed by the Australian Government in 2007 when dealing with the same issue (Carey et al., 2015). JUG has goals to improve the efficacy of policies by eliminating contradictions to improve cooperation and more integrated services (Pollitt, 2003). The implementation of JUG in Australia concentrated on two levels, the first targeted cultural and institutional change through policy narrative (a policy that sits 'above' policies), and the second targeted process and implementation through an interdepartmental working committee (Carey et al., 2015).

Based on the results of all four studies presented here, the model developed, and the aforementioned experience of JUG in developed countries, two recommendations for the government of West Timor are presented. The first recommendation is that every head of a region such as governor, mayor, or regent, should have a policy narrative like 'Nawa Cita', that of the current President of the Republic of Indonesia, which includes the vision of addressing disability issues. It is appreciated that this is a great challenge for elected regional leaders as they usually focus on programmes to boost their election chances for a second term of governing, or for an extended political career in the future. However, as the experience from developed countries suggests, a clear policy directive from top leaders would rally all stakeholders to work together on the same agenda.

When this is achieved, it should be easier to work on the second recommendation. In order to coordinate all stakeholders, a "disability hub project" could be considered. The idea would be to initiate a multi-agency advice centre with a one-stop shop that coordinates planning, implementing and monitoring processes and coordinates service provision for people with disabilities. Ideally, this disability hub would have its own building in every city/district, run by a special coordinating agency directly responsible to the head of cities/districts, and its officers would be stakeholders with special interests in disability issues. A special committee to work on issues for young children with disabilities could be established. A similar concept, the Bristol HUB project, has been implemented in the United Kingdom (Roche, 2004) to deal with the issue of homelessness with good results. The hub served as a centre that coordinated service provision and planning including many areas such as housing, employment, health, and social services. Even with current initiatives from the Coordinating Ministry for Human Development and Cultural Affairs to improve the coordination of disability programmes and laws (Badan Perencanaan Pembangunan Daerah Kabupaten Kulon Progo, 2017), there is much room for improvement, especially in rural and remote areas outside of the island of Java.

The recommended best practice model is not without limitations. The challenge of investigating a social issue in rural areas as an outsider is real. Some local leaders tend not to trust outsiders to help solve local problems. This cultural attitude impacts the process of data collection in the field. The interviewer met the challenge by making clear that the aim of the research was to help community members and local leaders solve their own problems. Also explaining that the interviewer had lived in the area for some time helped to improve ‘local/outsider’ tension.

In conclusion, inserting disability issues in the primary agenda of central and regional leaders would help improve infrastructure by providing a hub for stakeholders to work on future programmes. An integrated approach to service delivery would eventually help the adaptation process required for the best practice model to create a supportive environment for young children with disabilities in West Timor, and other rural areas of Indonesia.

CHAPTER SEVEN. DISCUSSION AND CONCLUSIONS

7.1 Preamble

This chapter presents a critical discussion of the findings and an overview of the strengths and limitations of the research, together with its contributions to knowledge. The chapter closes with a discussion of future research directions, and a postscript.

7.2 Strengths and contributions of the thesis

7.2.1 Statement of main findings and meta-inference

The aim of this thesis was to develop a best practice model to address the needs of young children with disabilities affected by environmental risk factors in West Timor, Indonesia. The thesis included a scoping review of extant literature (*study one*), a systematic review (*study two*), a qualitative interview and photovoice study (*study three*) and a qualitative interview and focus group study (*study four*). *Study one* found that interventions for young children with disabilities in Indonesia are scarce and limited in their methodology, but also have some potential as indicated by an emerging interest in employing indigenous resources in the interventions. *Study two* managed to conclude that promising interventions in developing countries included disability-screening, community-based rehabilitation, targeted services and inclusive general services. The systematic review also found that community-based rehabilitation needs more attention in the future, especially in terms of the evaluation of its effectiveness. *Study three* identified some crucial environmental risk factors including poverty, stigma and cultural beliefs, as well as some facilitators in religion, social support and early childhood education. *Study four* combined results from all studies resulting in the production of a best practice model consisting of 41 activities to support young children with disabilities in West Timor. The presentation of these activities was enriched with key information necessary to help stakeholders understand the context and process of implementation such as risk factors and available resources.

The overall results from all four studies reinforce the global report from WHO and UNICEF (WHO, 2012b), which stated that young children with disabilities in developing countries are threatened by environmental risk factors and are in need of best practice interventions to aid the developmental process. Collectively, the findings in this thesis indicate that there are some interventions that could and need to be implemented in order to support young children with disabilities in West Timor. Areas for action include inclusion of children with disabilities in all aspects of development, provision of services which specifically target young children with disabilities, improving public awareness of children with disabilities, and improved data collection and research. This thesis has produced a prototype best practice model. To confirm it as such now requires future research to determine if its application produces superior outcomes to those produced by usual approaches to service delivery. This holistic model should make a valuable contribution to current knowledge and serves as a trigger for future improvement, especially in public awareness raising and integration of disability services in West Timor and other rural areas with similar backgrounds.

7.2.2 Contributions to knowledge

7.2.2.1 Contribution 1: An investigation of complex issues within an ‘invisible‘ group

As mentioned in previous chapters, young children with disabilities in developing countries are often vulnerable and ‘invisible’ since they are frequently hidden by their parents (Trisnowati et al., 2013). Moreover, they can be threatened by various environmental risk factors, especially in rural and underdeveloped areas such as West Timor (Badan Pusat Statistik, 2017). Data from Indonesia, such as the Riskesdas survey and the national census, have also shown that young children with disabilities have been overlooked in the data collection process (Adioetomo et al., 2014). This thesis utilized a comprehensive research design to investigate interventions and environmental risk factors related to young children with disabilities in West Timor. As such, the findings make a valuable contribution to the current literature, especially in the field of disability studies and community psychology.

7.2.2.2 Contribution 2: Practice-oriented evidence that is easy for practitioners and policymakers to adapt

The best practice model arising from this thesis has been designed taking a practice-oriented and consumer-driven approach to content (i.e. available resources, risk and protective factors, activities and implementation strategies). This model was devised so that practitioners and policymakers can easily extract elements in the model and apply them to their own agencies and situations. While somewhat similar best practice models have been developed to address disability (McLaughlin, Barr, MaIlfatrick & McConkey, 2014; Wanaratwichit, Hills, Cruickshank & Newman, 2015), this is the first one that the author is aware of to specifically target young children. The list of activities in the model include implementation strategies for ease of adaptation. The activities are not prioritized specifically, as it is left to stakeholders to decide which elements can be utilised for their programmes. Future presentations (of this thesis) and research projects is currently being designed to ensure rapid uptake of the model for relevant stakeholders. Further, the author has been invited by several organisations in West Timor to disseminate the model.

7.2.2.3 Contribution 3: Highlighting the need for elite commitment and integrated services improvement

The findings from *studies three* and *four*, suggest a weak commitment from top-level or elite government leaders for reform in the disability sector, and poor integration of services by government and non-government agencies. The best practice model developed in this thesis provides many practical activities that need integration from executors, indicating the urgency of coordination between actors.

7.2.2.4 Contribution 4: Contribution to knowledge

Past reviews on interventions targeting young children with disabilities have mainly been carried out in developed countries in western settings such as the US, the UK and Australia (Lindo et al., 2016; Lindsay & Edwards, 2013; Skotarczak & Lee, 2015). Reviews undertaken in developing countries are scarce (Maulik & Darmstadt, 2007). *Study one* represents the first scoping review of interventions to support development of young children with disabilities in Indonesia, and likewise *study two* is the first systematic review of such interventions in developing countries.

Studies three and four contribute to knowledge about the application of indigenous psychology and participatory action research methods. Indigenous psychology emphasises the specific community within the context of familial, cultural, social and ecological factors (Kim et al., 2006). This approach has been increasingly popular in Indonesia with its significant cultural diversity (Narayansamy et al., 2014). Participatory action research methods improve community ownership of findings (Crane & O'Regan, 2010). Both studies also used thematic analysis (Braun & Clarke, 2006; Clarke & Braun, 2013) to analyse the textual data. This method is ideal for generating themes to represent overall data (Braun & Clarke, 2006) and was found to be particularly effective in the context of this thesis. The work presented here is a rare instance of application of these techniques, which were largely developed in western settings, with indigenous people in a developing country.

7.2.3 Strengths and limitations

A major strength of the research is the deliberately broad perspective adopted in each of the studies. The reviews not only considered interventions developed in Indonesia, but in other developing countries with similar development progress. The qualitative fieldwork involved many major actors in disability issues in West Timor, ranging from parents of young children with disabilities, to government, non-government, UN agencies and community leaders. The breadth of the literature reviews and extensive and holistic fieldwork enabled many perspectives to be documented for the research. The WHO (2011) has suggested in its *World Report on Disability* that the involvement of many stakeholders is indispensable in improving access to all mainstream policies in future.

Additionally, the thesis included a range of methods. The robust scoping review provided an overview of studies in an area where previous research is limited. The systematic review obtained rich, detailed information about interventions for tackling environmental risk factors in developing countries. The convergence of results from each review offered insights for the development of the best practice model. The employment of interview, photovoice and focus group techniques produced rich data for understanding the context of the topic. The use of Photovoice in particular, ensured better involvement of participants, especially those who were hesitant or unable to speak because of various circumstances (Plunkett et al., 2013). Employing a qualitative approach was also relevant in order to collect statements of community-defined evidence from participants (Johnson et al., 2015).

While the range of perspective is a strength, it is also possible that the lack of focus on specific disabilities may reduce the usefulness of findings in practical settings. Another potential limitation is that the review studies employed different criteria for inclusion, meaning that they are not entirely compatible. The scoping review excluded interventions if they involved a population more than eight years of age, perhaps inadvertently excluding useful studies. So as to avoid this, the subsequent systematic review did include interventions for those more than eight years as well as those 0 to 13 years of age. Another methodological limitation is that most interview sessions were conducted once, possibly limiting the amount of information obtained from each participant. At the same time, the number of interviewee participants for both *study three* and *study four* was higher when compared to other similar qualitative studies investigating young children with disabilities and their parents (Hamblin & Musa, 2006; Maloni et al., 2010; Morgan & Tan, 2011).

The translation of the transcripts of the qualitative data did not include a forward and back translation technique as recommended by the WHO (2018), meaning that the data may have some limitations in equivalence of meaning. A further limitation is that two of the three supervisors were not experienced researchers on Indonesian issues. Only one supervisor had deep knowledge, especially on the social and cultural life of the West Timorese community. When approached by the author to participate in the study, some parents were worried that their children might be taken away from them. Some considered that the author was a superior from a government agency whose objective was to encourage parents to put their children into school. Their preference was that their children should stay at home because they did not trust that teachers or other children would accept their children. As a result, there were two parents who politely refused to participate in the study. While others hesitated but eventually participated, their reservations would undoubtedly have impacted their accounts during the interviews.

At the outset of the fieldwork it became apparent that many of the local leader respondents were not overly familiar with disability issues, and the day-to-day life of parents with children with disabilities. After a discussion of this in the research team, it was decided to especially target participants with more experience of the topic, such as leaders of disability-focused NGOs and social agencies to gather more focussed and relevant data.

7.3 Future research directions and concluding statement

The findings of this thesis suggest several avenues for future research. As a starting point, more high quality research about interventions for childhood disability in developing countries is required. For example, while community based rehabilitation is frequently implemented, with results being promising, the research is often times of limited methodological quality. Similarly there is a need for Indonesian research to examine disability screening research and practice, especially given that many developing countries in Asia and Africa have been active in improving such services (Berg et al., 2006; Friderichs et al., 2012; Imam et al., 2013).

Studies from this thesis also identified key facilitators and barriers influencing interventions and services for young children with disabilities. Schools, kindergartens, peer groups, religion and religious activities are some examples of key facilitators. In contrast, key barriers included cultural beliefs, the use of traditional treatments, stigma and discrimination, and poor service access and integration. Future studies might examine how to best address barriers such as cultural beliefs and the associated social barriers.

Government agencies in Indonesia are still dominated by a patronage system, and the top leaders are key to future improvement with regards to all services. Stakeholders in *study four*, consistently pointed out that the blessings of their Mayors or Regents in the form of written law are indispensable if change is to be made. Therefore, in order to ensure that the best practice model developed in this thesis will improve and sustain early intervention in West Timor, securing policy narratives and work agendas for the top levels of national and regional government is necessary. This approach has worked before in developed and democratic countries (Pollitt, 2003), and has the potential to work in developing and democratic countries like Indonesia. A clear direction from leaders would also assist the process of coordination between different agencies. Elite leaders could initiate a whole of governance approach, and practically, establish a joint task force or committee consisting of related stakeholders (Carey et al., 2015). Another way of ensuring integration of services could be to provide a specific budget for disability services in every related government agency, in order to lock in commitment to providing services. So to conclude, in order to initiate comprehensive change, future efforts might focus on the development, implementation and evaluation of policies and integrated services within a best practice model like that proposed here.

7.4 Postscript

The findings and recommendation of this thesis will be presented to policymakers and practitioners based in West Timor, Indonesia, to assist with improving overall services for young children with disabilities. Research participants and other persons who have expressed an interest in this study will also be provided with research results. They include: UNICEF Indonesia – Kupang office; Social Agency – East Nusa Tenggara office; Disabled People's Organisations at West Timor; Christian Evangelical Church in Timor; Handicap International – Kupang office; ChildFund – Kupang office.

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APPENDICES

Appendix 1: Scoping review search terms

Disability	Intervention	Indonesia
Disabled persons[mh] OR Mental disorders[mh] OR Mobility limitation[mh:noexp] OR Paraplegia[mh] OR Quadriplegia[mh:noexp] OR Hearing Disorders[mh] OR Vision disorders[mh] OR Disabled person*[tw] OR Disab*[tw] OR Disabled people[tw] OR Amputee*[tw] OR Hearing impaired person*[tw] OR Hearing impaired people[tw] OR Mentally disabled person*[tw] OR Mentally disabled people[tw] OR Mentally ill person*[tw] OR Mentally ill people[tw] OR Visually impaired person*[tw] OR Visually impaired people[tw] OR Developmental disabilit*[tw] OR Mental retardation[tw] OR Mentally retarded[tw] OR Mobility limitation*[tw] OR paraplegia[tw] OR quadriplegia[tw] OR	Therapeutics[mh] OR Community Health Services[mh] OR Rehabilitation[sh] OR Intervention Studies[mh:noexp] OR Evidence-Based Practice[mh] OR Prevention and control[sh] OR Health Services for Persons with Disabilities[mh:noexp] OR Nursing process[mh] OR Social Welfare[mh] OR Education, Special[mh] OR Social Work[mh] OR Social Control Policies[mh] OR Early Intervention[tw] OR Early Interventions[tw] OR Intervention, Early[tw] OR Interventions, Early[tw] OR Early Medical Interventions[tw] OR Intervention, Early Medical[tw] OR Interventions, Early Medical[tw] OR Medical Intervention, Early[tw] OR Medical Interventions, Early[tw] OR Health Services for the Disabled[tw] OR Health Services for Disabled Persons[tw] OR Health Services for People with Disabilities[tw] OR Therap*[tw] OR Treat*[tw] OR Rehab*[tw] OR Interven*[tw] OR Program*[tw]	Indonesia[mh:noexp] OR Indonesia[tw] OR Timor[tw] OR Java[tw] OR Sumatra[tw] OR Celebes[tw] OR Sulawesi[tw] OR West Irian[tw] OR New Guinea, Indonesian[tw] OR New Guinea, West[tw] OR Indonesian New Guinea[tw] OR Irian Jaya[tw] OR Madoera[tw] OR Madura[tw] OR Borneo[tw] OR Kalimantan[tw] OR West Papua[tw] OR Bali[tw] OR Nusa Tenggara[tw] OR Lesser Sunda Islands[tw] OR Mollucas[tw] OR Maluku[tw] OR West Timor[tw]

Disability	Intervention	Indonesia
Hearing loss[tw] OR blindness[tw] OR Vision disorder*[tw] OR Mental disorder*[tw] OR Psychiatric disabilit*[tw] OR Mental health disabilit*[tw] OR Mental health impairment*[tw] OR Functional limitation*[tw] OR Activity limitation*[tw] OR Mobility impairment*[tw]		

- Search terms formatted for PubMed. Terms were modified in accordance with each databases search requirements

Appendix 2: List of Indonesian journals searched in scoping review

	Journal's name	Journal's field
1.	Indonesian Journal of Disability Studies	Disability
2.	Psikologia USU	Psychology
3.	Media Penelitian dan Pengembangan Kesehatan	Health
4.	Health Science Journal of Indonesia	Health
5.	Buletin Penelitian Kesehatan	Health
6.	Buletin Penelitian Sistem Kesehatan	Health system
7.	Jurnal Penelitian Gizi dan Makanan	Food and nutrition
8.	Jurnal Ekologi Kesehatan	Health Ecology
9.	Jurnal Kesehatan Reproduksi	Reproduction health
10.	Media Gizi Mikro Indonesia	Nutrition
11.	Jurnal Kefarmasian Indonesia	Pharmacy
12.	Health Research and Development Body Indonesia Library Catalogue	Health
13.	Pusat Penelitian dan Pengembangan Kesejahteraan Sosial	Social welfare
14.	Jurnal Informasi	Social and information
15.	Jurnal Sosioinforma	Social and information
16.	Jurnal Sosiokonsepsia	Social welfare
17.	Jurnal Kesejahteraan Sosial	Social welfare
18.	Puslitbangbud	Social and culture
19.	E-jupekhu	Special education
20.	Jurnal Pendidikan Khusus UNY	Special education
21.	Jurnal Pendidikan Khusus UNESA	Special education
22.	Jurnal Psikologi UGM	Psychology
23.	Jurnal Psikologi Undip	Psychology
24.	Jurnal Psikologi Esa Unggul	Psychology
25.	Portal Garuda	General Sciences
26.	Jurnal Psikologi Indonesia	Psychology
27.	Humanitas	Psychology
28.	MANASA	Psychology
29.	Jurnal Psikologi Pendidikan dan Perkembangan Unair	Psychology

	Journal’s name	Journal’s field
30.	Jurnal Ilmiah Psikologi Gunadarma	Psychology
31.	Jurnal Penelitian Psikologi UIN Sunan Ampel	Psychology
32.	Jurnal Psikologi PITUTUR	Psychology
33.	Jurnal Online Psikologi UMM	Psychology
34.	Jurnal Ilmiah Psikologi Terapan UMM	Psychology
35.	Procedia Studi Kasus dan Intervensi Psikologi UMM	Psychology
36.	Jurnal Sains dan Praktik Psikologi UMM	Psychology
37.	Jurnal Psikologi UIN Suska Riau	Psychology
38.	Jurnal Ilmiah Psikologi Candrajiwa	Psychology
39.	Psikologika	Psychology
40.	Jurnal Psikologi Undayana	Psychology
41.	Jurnal Psikologi Teori dan Terapan Unesa	Psychology
42.	Psikobuana	Psychology
43.	Experientia: Jurnal Psikologi Indonesia	Psychology
44.	Jurnal Psikologi Tabularasa	Psychology
45.	Psikostudia	Psychology
46.	Jurnal Disabilitas Sosial	Social Disability

Appendix 3: Systematic review search terms

Disability	Intervention	Developing countries
Disabled persons[mh] OR Mental disorders[mh] OR Mobility limitation[mh:noexp] OR Paraplegia[mh] OR Quadriplegia[mh:noexp] OR Hearing Disorders[mh] OR Vision disorders[mh] OR Disabled person*[tw] OR Disab*[tw] OR Disabled people[tw] OR Amputee*[tw] OR Hearing impaired person*[tw] OR Hearing impaired people[tw] OR Mentally disabled person*[tw] OR Mentally disabled people[tw] OR Mentally ill person*[tw] OR Mentally ill people[tw] OR Visually impaired person*[tw] OR Visually impaired people[tw] OR Developmental disabilit*[tw] OR Mental retardation[tw] OR Mentally retarded[tw] OR Mobility limitation*[tw] OR	Therapeutics[mh] OR Community Health Services[mh] OR Rehabilitation[sh] OR Intervention Studies[mh:noexp] OR Evidence-Based Practice[mh] OR Prevention and control[sh] OR Health Services for Persons with Disabilities[mh:noexp] OR Nursing process[mh] OR Social Welfare[mh] OR Education, Special[mh] OR Social Work[mh] OR Social Control Policies[mh] OR Early Intervention[tw] OR Early Interventions[tw] OR Intervention, Early[tw] OR Interventions, Early[tw] OR Early Medical Interventions[tw] OR Intervention, Early Medical[tw] OR Interventions, Early Medical[tw] OR Medical Intervention, Early[tw] OR Medical Interventions, Early[tw] OR Health Services for the Disabled[tw] OR Health Services for Disabled Persons[tw] OR Health Services for People with	Developing countries[mh:noexp] OR Countries, Developing[tw] OR Country, Developing[tw] OR Developing Countr*[tw] OR Developing Nation*[tw] OR Nations, Developing[tw] OR Nation, Developing[tw] OR Countries, Less-Developed[tw] OR Country, Less-Developed[tw] OR Nation, Less-Developed[tw] OR Nations, Less-Developed[tw] OR Less Developed Countr*[tw] OR Less-Developed Countr*[tw] OR Less Developed Nation*[tw] OR Less-Developed Nation*[tw] OR Nation, Under-Developed[tw] OR Nations, Under-Developed[tw] OR Country, Under-Developed[tw] OR Countries, Under-Developed[tw] OR Under Developed Nation*[tw] OR Under-Developed Nation*[tw] OR Under-Developed Countr*[tw] OR Under Developed

Disability	Intervention	Developing countries
paraplegia[tw] OR quadriplegia[tw] OR Hearing loss[tw] OR blindness[tw] OR Vision disorder*[tw] OR Mental disorder*[tw] OR Psychiatric disabilit*[tw] OR Mental health disabilit*[tw] OR Mental health impairment*[tw] OR Functional limitation*[tw] OR Activity limitation*[tw] OR Mobility impairment*[tw]	Disabilities[tw] OR Therap*[tw] OR Treat*[tw] OR Rehab*[tw] OR Interven*[tw] OR Program*[tw] OR Randomized Controlled Trials as Topic[mh]	Countr*[tw]

- Search terms formatted for PubMed. Terms were modified in accordance with each databases search requirements

Appendix 4: Approval from The University of Adelaide HREC

THE UNIVERSITY of ADELAIDE

RESEARCH BRANCH
OFFICE OF RESEARCH ETHICS, COMPLIANCE AND INTEGRITY

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CRICOS Provider Number 00123M

1 September 2015

Professor D Turnbull
Psychology

Dear Professor Turnbull

PROJECT NO: H-2015-165
The development of a best practice model to support young children with disabilities in West Timor, Indonesia

I write to advise you that the Human Research Ethics Committee has approved the above project. Please refer to the enclosed endorsement sheet for further details and conditions that may be applicable to this approval. Ethics approval is granted for a period of three years subject to satisfactory annual progress reporting. Ethics approval may be extended subject to submission of a satisfactory ethics renewal report prior to expiry.

The ethics expiry date for this project is: 30 September 2018

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

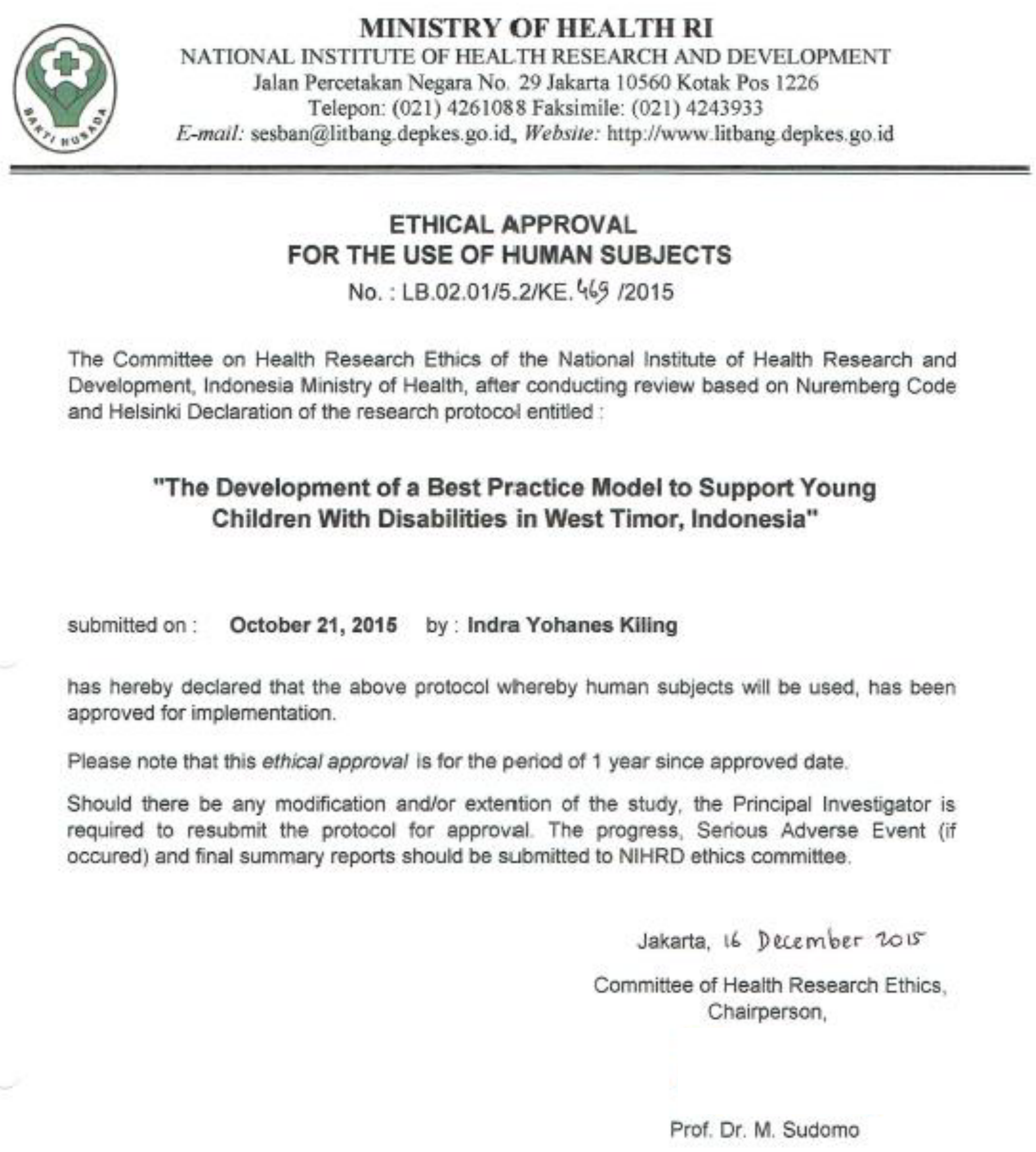
Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form for the annual progress report, project completion and ethics renewal report is available from the website at http://www.adelaide.edu.au/ethics/human/guidelines/reporting/

Yours sincerely

Professor P Delfabbro
Acting Convenor
Human Research Ethics Committee

Appendix 5: Approval from Ministry of Health, Republic of Indonesia



MINISTRY OF HEALTH RI
NATIONAL INSTITUTE OF HEALTH RESEARCH AND DEVELOPMENT
Jalan Percetakan Negara No. 29 Jakarta 10560 Kotak Pos 1226
Telepon: (021) 4261088 Faksimile: (021) 4243933
E-mail: sesban@litbang.depkes.go.id, *Website:* http://www.litbang.depkes.go.id

ETHICAL APPROVAL
FOR THE USE OF HUMAN SUBJECTS

No. : LB.02.01/5.2/KE.469 /2015

The Committee on Health Research Ethics of the National Institute of Health Research and Development, Indonesia Ministry of Health, after conducting review based on Nuremberg Code and Helsinki Declaration of the research protocol entitled :

"The Development of a Best Practice Model to Support Young Children With Disabilities in West Timor, Indonesia"

submitted on : **October 21, 2015** by : **Indra Yohanes Kiling**

has hereby declared that the above protocol whereby human subjects will be used, has been approved for implementation.

Please note that this *ethical approval* is for the period of 1 year since approved date.

Should there be any modification and/or extention of the study, the Principal Investigator is required to resubmit the protocol for approval. The progress, Serious Adverse Event (if occured) and final summary reports should be submitted to NIHRD ethics committee.

Jakarta, 16 December 2015

Committee of Health Research Ethics,
Chairperson,

Prof. Dr. M. Sudomo

Appendix 6: Approval from Ministry of Home Affairs, Republic of Indonesia

KEMENTERIAN DALAM NEGERI
REPUBLIK INDONESIA
DIREKTORAT JENDERAL POLITIK DAN PEMERINTAHAN UMUM
JALAN MEDAN MERDEKA UTARA NO. 7 JAKARTA PUSAT 10110, Telp. 3454270

REKOMENDASI PENELITIAN
NOMOR 460.02/4137/Polpum

a. Dasar : 1. Peraturan Menteri Dalam Negeri Nomor 41 Tahun 2010 tentang Organisasi dan Tata Kerja Kementerian Dalam Negeri (Berita Negara Republik Indonesia Tahun 2010 Nomor 316), sebagaimana telah diubah dengan Peraturan Menteri Dalam Negeri Nomor 14 Tahun 2011 tentang Perubahan Atas Peraturan Menteri Dalam Negeri Nomor 41 Tahun 2010 tentang Organisasi dan Tata Kerja Kementerian Dalam Negeri (Berita Negara Republik Indonesia Tahun 2011 Nomor 168);

2. Peraturan Menteri Dalam Negeri Nomor 7 Tahun 2014 tentang Perubahan Atas Peraturan Menteri Dalam Negeri Nomor 64 Tahun 2011 tentang Pedoman Penerbitan Rekomendasi Penelitian;

b. Menimbang : Surat Mahasiswa The University of Adelaide Australia Perihal Surat Permohonan Izin Penelitian.

MEMBERITAHUKAN BAHWA :

a Nama/ Obyek : Indra Yohanes Kiling.

b Jabatan/Tempat/ Identitas : Peneliti Utama / Wanea Lingkungan V No. 106 Manado Telp. 081252525144 / No. KTP 7171071908870004.

c Untuk : 1) Melakukan penelitian, dengan proposal berjudul Pengembangan Model Praktik Untuk Mendukung Anak Usia Dini dengan Disabilitas di Timor;
2) Lokasi penelitian : Provinsi Nusa Tenggara Timur (1 provinsi);
3) Waktu/lama penelitian : Desember 2015 s.d. Juni 2016;
4) Anggota tim peneliti : -
5) Bidang penelitian : Sosial;
6) Status penelitian : Perpanjangan.

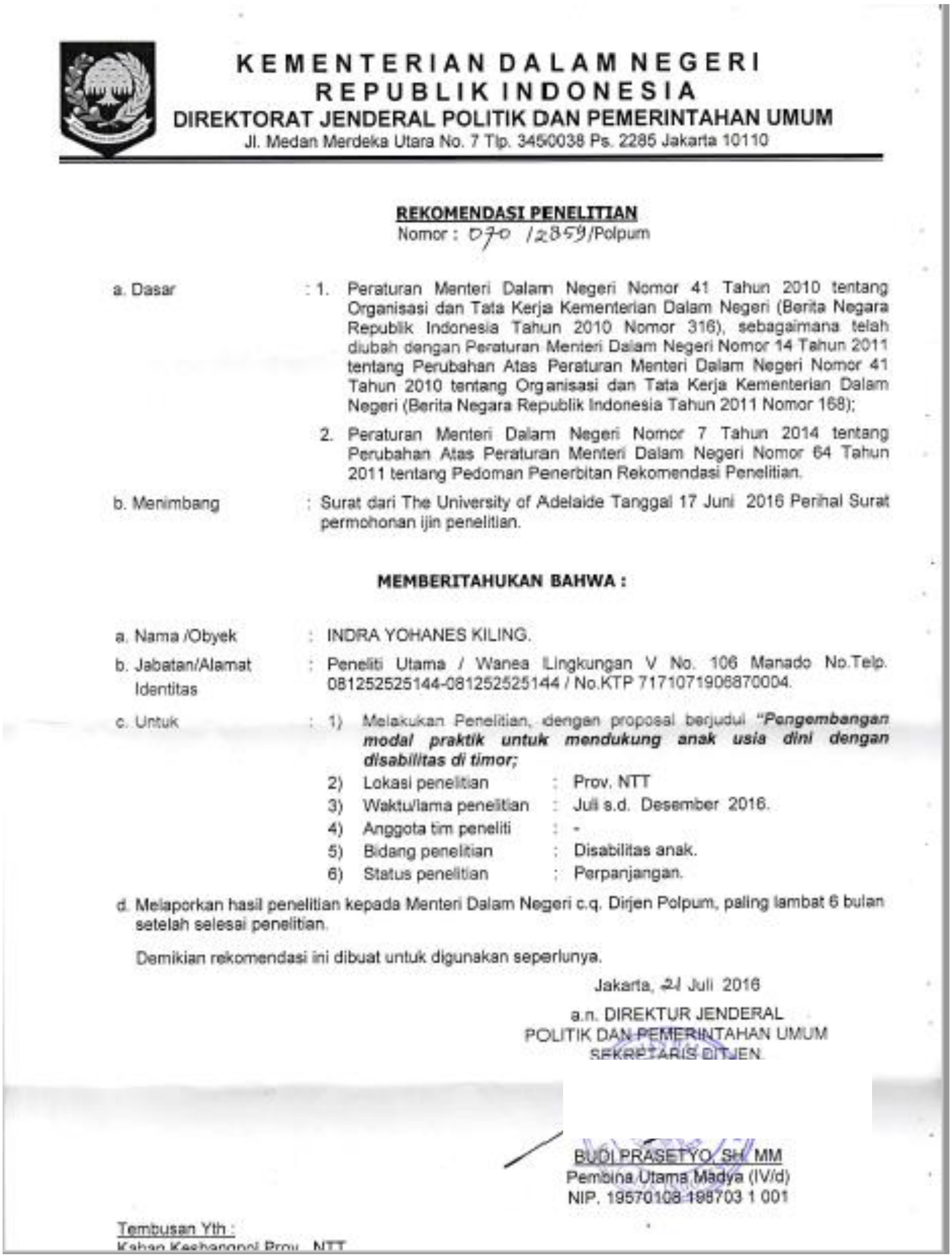
d Melaporkan hasil penelitian kepada Menteri Dalam Negeri c.q. Dirjen Polpum, paling lambat 6 bulan setelah selesai penelitian.

Demikian rekomendasi ini dibuat untuk digunakan seperlunya.

Jakarta, 7 Desember 2015
a.n. DIREKTUR JENDERAL
POLITIK DAN PEMERINTAHAN UMUM
SEKRETARIS DITJEN.

BUDI PRASETYO, SH, MM
Pembina Utama Madya (IV/d)
NIP. 19570108 198703 1 001

Tembusan:
Yth. Gubernur Nusa Tenggara Timur;
up. Kaban Kesbang dan Linmas Prov.



KEMENTERIAN DALAM NEGERI
REPUBLIK INDONESIA
DIREKTORAT JENDERAL POLITIK DAN PEMERINTAHAN UMUM
Jl. Medan Merdeka Utara No. 7 Tlp. 3450038 Ps. 2285 Jakarta 10110

REKOMENDASI PENELITIAN
Nomor : 070 /2859/Polpum

a. Dasar : 1. Peraturan Menteri Dalam Negeri Nomor 41 Tahun 2010 tentang Organisasi dan Tata Kerja Kementerian Dalam Negeri (Berita Negara Republik Indonesia Tahun 2010 Nomor 316), sebagaimana telah diubah dengan Peraturan Menteri Dalam Negeri Nomor 14 Tahun 2011 tentang Perubahan Atas Peraturan Menteri Dalam Negeri Nomor 41 Tahun 2010 tentang Organisasi dan Tata Kerja Kementerian Dalam Negeri (Berita Negara Republik Indonesia Tahun 2011 Nomor 168);

2. Peraturan Menteri Dalam Negeri Nomor 7 Tahun 2014 tentang Perubahan Atas Peraturan Menteri Dalam Negeri Nomor 64 Tahun 2011 tentang Pedoman Penerbitan Rekomendasi Penelitian.

b. Menimbang : Surat dari The University of Adelaide Tanggal 17 Juni 2016 Perihal Surat permohonan ijin penelitian.

MEMBERITAHUKAN BAHWA :

a. Nama /Obyek : INDRA YOHANES KILING.

b. Jabatan/Alamat Identitas : Peneliti Utama / Wanea Lingkungan V No. 106 Manado No.Telp. 081252525144-081252525144 / No.KTP 7171071906870004.

c. Untuk : 1) Melakukan Penelitian, dengan proposal berjudul ***"Pengembangan modal praktik untuk mendukung anak usia dini dengan disabilitas di timor;***
2) Lokasi penelitian : Prov. NTT
3) Waktu/lama penelitian : Juli s.d. Desember 2016.
4) Anggota tim peneliti : -
5) Bidang penelitian : Disabilitas anak.
6) Status penelitian : Perpanjangan.

d. Melaporkan hasil penelitian kepada Menteri Dalam Negeri c.q. Dirjen Polpum, paling lambat 6 bulan setelah selesai penelitian.

Demikian rekomendasi ini dibuat untuk digunakan seperlunya.

Jakarta, 21 Juli 2016

a.n. DIREKTUR JENDERAL
POLITIK DAN PEMERINTAHAN UMUM
SEKRETARIS DITJEN

[redacted]

BUDI PRASETYO, SH, MM
Pembina Utama Madya (IV/d)
NIP. 19570108 198703 1 001

Tembusan Yth :
Kaban Kesbangpol Prov. NTT

Appendix 7: Participant information sheet

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: The development of a strategy to support young children with disabilities in West Timor
HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2015-165
PRINCIPAL INVESTIGATOR: Professor Deborah Turnbull
STUDENT RESEARCHER: Indra Yohanes Kiling
STUDENT'S DEGREE: PhD

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

This project aims to develop a strategy to help support the development of young children with disabilities in West Timor.

The activities developed in the strategy may help increase participation of young children with disabilities in health, education and other basic services.

Who is undertaking the project?

This project is carried out by Professor Deborah Turnbull, Indra Yohanes Kiling, Dr Clemence Due and Dr Dominggus Elcid Li. This research is funded by Indonesia Endowment Fund For Education.

Why am I being invited to participate?

You're invited because you fulfil the criteria as a family member of a young child living with disability.

What will I be asked to do?

You will be participating in the activities below:

- Group Discussion → You will be participating in a group discussion with other participants. The group discussion will be recorded with a sound and video recorder with permission from all the participants. Questions will be asked about the experiences of families with young children with disabilities, including the problems that they face. You will also be asked about what might be done to improve the lives of these young children and their families.
- Photovoice → You will be asked to take photos using a digital camera and to talk about the photos you have taken. The type of photos you will be taking might include household furniture, kitchen utensils, medicines, learning materials, gardens, religious buildings, vehicles, schools, community health centres, etc.
- Interview → You will be involved in discussions with investigator and the activity will be recorded with a sound and video recorder with your permission

The location of the activities will be decided by you and Mr Indra. It is hoped that you would participate.

How much time will the project take?

- One group discussion session will take around two hours.
- You will be lent a camera free of charge, and then you will be asked to take approximately 20 pictures in about two weeks time using the camera.
- One interview session requires about one hour.

Are there any risks associated with participating in this project?

You may lose some time from your other activities while you are participating in the group discussions and the photograph sessions. You might also feel uncomfortable when you are sharing the situation of young children with disabilities in your environment.

If you have this uncomfortable feeling, you will be given the chance to take a break from the project activity. If it is necessary, you can also withdraw from the whole project.

What are the benefits of the research project?

You will have increased knowledge and understanding about young children with disabilities. You will also have the chance to show your opinion about the topic.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw yourself and your information from the study at any time up to the publication of the results.

Your withdrawal will not affect your relationships in the village or any basic services you may receive.

What will happen to my information?

All information regarding the participant will be stored on a secure personal laptop and University computing system and a safe cupboard in the principal investigator's office. Data will be used for academic publications and for the thesis for a PhD programme. Only combined data will be published and the summary of results will be made available by presentations. You and the other participants will not be identified in any reporting of the results.

Who do I contact if I have questions about the project?

You can contact all investigators below, it is better that you contact the primary investigator:

1. Professor Deborah Turnbull (primary investigator), +61 8 3131 229 (Australian phone number); deborah.turnbull@adelaide.edu.au
2. Indra Yohanes Kiling, 081 25 25 25 144 (Indonesian phone number)
3. Dr. Clemence Due, +61 8 8313 5693 (Australian phone number)
4. Dr. Dominggus Elcid Li, +185 7777 9021 (United States phone number)

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2015-165). This study has also gain approval from Committee of Health Research Ethics, Ministry of Health Republic of Indonesia (No: LB.02.01/5.2/KE.469/2015). If you have questions or problems related to the practical aspects of your participation in the project, or wish to state a concern or complaint about the project, then you should talk with the Principal Investigator.

Contact the Human Research Ethics Committee's Secretariat on phone +61 8 8313 6028 or by email at hrec@adelaide.edu.au if you wish to speak with an independent person about concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant. You can also talk with Beatriks Bunga in Kupang on 0852 5309 7800 if you want to talk with an independent fellow West Timor. Any complaint or concern will be treated in confidence and will be fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

You will be asked to read and/or listen about the information sheet, the adverse events procedure and complaints procedure. You will also be asked to complete a standard consent form.

Child protection statement

According to Child Protection Law No. 23 Year 2002 in Indonesia, the investigator is obliged to report to authorities (police department, child protection body) any act of child abuse (e.g. sexual assault).

Yours sincerely,
Professor Deborah Turnbull, Indra Yohanes Kiling, Dr Clemence Due and Dr Dominggus Elcid Li

LEMBAR INFORMASI PESERTA

JUDUL PENELITIAN: Cara mendukung perkembangan anak umur di bawah delapan tahun dengan disabilitas di Timor
NOMOR PERSETUJUAN KOMISI ETIK: H-2015-165
PENELITI UTAMA: Professor Deborah Turnbull
PENELITI MAHASISWA: Indra Yohanes Kiling
GELAR MAHASISWA: PhD (Doktor)

Peserta yang terhormat,
Anda diundang untuk ikut dalam penelitian yang dijelaskan di bawah ini.

Apa maksud penelitian ini?

Penelitian ini bertujuan untuk menciptakan cara yang nanti akan digunakan untuk membantu proses perkembangan anak usia di bawah delapan tahun dengan disabilitas (kecacatan) di Timor.

Program dan/atau kegiatan dalam model ini diharap bisa meningkatkan partisipasi anak usia di bawah delapan tahun dengan disabilitas dalam pelayanan kesehatan, pendidikan dan layanan masyarakat lainnya.

Keterbatasan dari penelitian ini adalah ketika cara ini tidak digunakan oleh pelayanan masyarakat, hal ini akan dijawab dengan penelitian/program lain di masa depan untuk memastikan cara ini dilakukan.

Siapa penelitinya?

Penelitian ini dilakukan oleh Indra Yohanes Kiling, mahasiswa program PhD (doktor) Psikologi di The University of Adelaide, Australia.

Penelitian ini akan menjadi dasar gelar PhD di University of Adelaide di bawah bimbingan dari Profesor Deborah Turnbull, Dr. Clemence Due dan Dr. Dominggus Elcid Li.

Peneliti melaksanakan studinya dengan dukungan beasiswa dari Lembaga Pengelola Dana Pendidikan (LPDP) Indonesia.

Kenapa saya diundang untuk ikut serta dalam penelitian ini?

Anda diundang karena anda merupakan anggota keluarga dari anak usia di bawah delapan tahun dengan disabilitas.

Apa yang akan saya lakukan dalam penelitian ini?

Anda akan ikut serta dalam salah satu/beberapa dari kegiatan di bawah ini:

- Foto cerita → Anda akan diminta mengambil foto menggunakan kamera digital dan menceritakan foto yang anda ambil tersebut. Jenis foto yang akan anda ambil seperti perabot rumah tangga, peralatan memasak, obat-obatan, alat belajar, kebun/sawah, hewan ternak, bangunan ibadah, kendaraan, sekolah, posyandu/puskesmas dan yang lainnya
- Diskusi Kelompok → Anda akan ikut dalam diskusi kelompok bersama peserta penelitian lainnya, kegiatan akan direkam menggunakan perekam suara dan gambar. Pertanyaan yang akan ditanyakan terkait foto yang anda ambil

Lokasi dari kegiatan akan ditentukan bersama antara pak Indra dan anda. Anda diharap untuk ikut dalam penelitian ini.

Berapa lama waktu penelitian ini?

- Anda akan dipinjami sebuah kamera digital tanpa dimintai biaya, setelah itu anda akan diminta untuk mengambil kurang lebih 20 foto dalam kurun waktu dua minggu menggunakan kamera tersebut.
- Satu sesi diskusi kelompok membutuhkan waktu dua jam.

Apakah ada risiko atau ketidaknyamanan dalam mengikuti penelitian ini?

Ketidaknyamanan yang akan anda alami adalah kehilangan waktu anda ketika ikut serta dalam diskusi kelompok dan foto cerita.

Anda juga berisiko untuk merasa tidak nyaman secara emosional (sedih, tertekan) ketika menceritakan keadaan dari anak usia di bawah delapan tahun dengan disabilitas di lingkungan anda.

Ketika anda mengalami rasa yang tidak menyenangkan saat mengikuti penelitian ini, anda akan diberikan kesempatan untuk beristirahat dari kegiatan penelitian. Jika diharuskan, anda juga diperbolehkan untuk berhenti mengikuti rangkaian kegiatan penelitian.

Apa keuntungan dari penelitian ini?

Pengetahuan dan wawasan anda tentang anak usia di bawah delapan tahun dengan disabilitas akan meningkat, anda juga akan memiliki kesempatan untuk memberikan pendapat anda terkait topik ini.

Apakah saya bisa berhenti mengikuti penelitian ini?

Partisipasi di penelitian ini bersifat sukarela. Jika anda setuju untuk berpartisipasi, anda dapat mengundurkan diri anda dan semua informasi dari anda dari penelitian ini kapan saja anda mau sampai dengan waktu publikasi/penerbitan hasil penelitian (untuk informasi/data). Pengunduran diri anda tidak akan mempengaruhi status anda di desa/tempat kerja dan layanan apapun yang anda terima.

Apa yang terjadi dengan informasi tentang saya?

Segala informasi tentang partisipan penelitian akan disimpan dalam laptop pribadi, lemari pribadi di kantor Profesor Deborah dan sistem komputer Universitas serta hanya dapat diakses oleh peneliti. Data akan digunakan untuk publikasi ilmiah seperti jurnal ilmiah dan tentunya untuk penyusunan disertasi. Segala informasi mengenai anda tidak akan disebarluaskan tanpa seizin anda. Presentasi akan dilakukan agar anda bisa mengetahui hasil dari penelitian ini.

Siapa yang bisa saya hubungi untuk bertanya mengenai penelitian ini?

Silahkan bertanya kepada daftar peneliti di bawah ini, dianjurkan untuk menghubungi Profesor Deborah:

5. Profesor Deborah Turnbull (bahasa Inggris), +61 8 3131 229 (Nomor telepon Australia)
6. Indra Yohanes Kiling (bahasa Indonesia), 081252525144 (Nomor telepon Indonesia)
7. Dr. Clemence Due (bahasa Inggris), +61 8 8313 5693 (Nomor telepon Australia)
8. Dr. Dominggus Elcid Li (bahasa Indonesia), +185 7777 9021 (Nomor telepon Amerika Serikat)

Bagaimana jika saya mempunyai keluhan?

Studi ini telah disetujui oleh Komite Etik Penelitian Manusia di University of Adelaide (nomor persetujuan H-2015-165). Jika anda memiliki keluhan terkait aspek teknis penelitian, maka disarankan anda menghubungi peneliti.

Jika anda ingin mengajukan keluhan terkait penelitian ini, silakan hubungi Sekretariat Komite Etik Penelitian Manusia di The University of Adelaide melalui nomor telepon +61 8 8313 6028 atau melalui email ke alamat hrec@adelaide.edu.au. Jika anda ingin berbicara dengan pihak independen terkait keluhan anda silakan menghubungi Beatriks Bunga di Kupang melalui nomor 0852 5309 7800. Segala keluhan anda dijamin kerahasiaannya dan akan segera ditindaklanjuti. Anda kemudian akan diinformasikan hasil tindak lanjut tersebut.

Jika saya ingin berpartisipasi, apa yang harus saya lakukan?

Anda akan diminta untuk membaca dan/atau mendengar informasi terkait penelitian, prosedur jika ada kejadian tidak menyenangkan dan prosedur untuk mengajukan keluhan. Anda juga diminta untuk mengembalikan formulir persetujuan keikutsertaan.

Pernyataan perlindungan anak

Berdasarkan Undang-Undang Perlindungan Anak No. 23 Tahun 2002 di Indonesia, peneliti diharuskan untuk melaporkan kepada pihak berwajib jika menemukan tindakan kekerasan terhadap anak (contoh: kekerasan seksual, memukul)

Salam hangat,
Indra Yohanes Kiling, Profesor Deborah Turnbull, Dr. Clemence Due dan Dr. Dominggus Elcid Li.

Appendix 8: Participant consent form

CONSENT FORM

1. I have read the attached Information Sheet and agree to take part in the following research project:

Title:	**The development of a best practice model to support young children with disabilities affected by environmental risk factors in West Timor, Indonesia.**
Ethics Approval Number:	**Researcher to insert this number (allocated once the project has been approved.**

2. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.
3. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.
4. Although I understand the purpose of the research project it has also been explained that involvement may not be of any benefit to me.
5. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.
6. I understand that I am free to withdraw from the project at any time.
7. I agree to the interview being audio/video recorded. Yes ☐ No ☐
8. I am aware that I should keep a copy of this Consent Form, when completed, and the attached Information Sheet.

Participant to complete:

Name: ________________________ Signature:___________________________ Date: ____________

Researcher/Witness to complete:

I have described the nature of the research to____

(print name of participant)

and in my opinion she/he understood the explanation.

Signature: _____________________ Position:____________________________ Date: ____________

LEMBAR PERSETUJUAN

1. Saya sudah membaca Lembar Informasi Peserta dan setuju untuk ikut dalam penelitian di bawah ini:

Judul:	Cara mendukung perkembangan anak umur di bawah delapan tahun dengan disabilitas/kecacatan di Timor
Nomor persetujuan Komisi Etik:	H-2015-165

2. Semua informasi tentang penelitian sudah dijelaskan kepada saya oleh peneliti (pak Indra). Saya setuju untuk ikut dengan sukarela.
3. Saya sudah ditemani anggota keluarga atau teman waktu mendengar penjelasan penelitian.
4. Saya sudah tahu tujuan penelitian ini dan saya tahu bahwa tidak ada keuntungan langsung yang akan saya dapat. Untung yang akan saya dapat adalah pengetahuan bertambah dan bisa kasih pendapat.
5. Saya tahu kalau kegiatan di penelitian ini adalah diskusi dengan peneliti, diskusi dalam kelompok, dan mengambil foto serta menceritakan foto itu.
6. Saya mengerti kalau risiko dalam penelitian ini adalah rasa tidak nyaman atau senang waktu berdiskusi.
7. Saya tahu kalau nama dan informasi lain tentang saya tidak akan diketahui orang lain lewat penelitian ini, walau penelitian ini akan diterbitkan nanti.
8. Saya mengerti kalau saya punya hak untuk mundur dari penelitian ini kapan pun saya mau.
9. Saya tidak akan mengambil foto muka orang lain waktu diminta mengambil foto.
10. Saya mau untuk direkam waktu berdiskusi Ya ☐ Tidak ☐
11. Saya mengerti kalau saya harus menyimpan fotokopi/salinan Lembar Persetujuan dan Lembar Informasi Peserta setelah saya mengisinya.

Peserta Penelitian:

Nama: _________________________ Tanda tangan:_________________________ Tanggal: __________

Saksi/Peneliti:

Saya sudah mendengar penjelasan/menjelaskan penelitian kepada____________________________________

(nama peserta)

dan menurut pendapat saya beliau mengerti dengan baik penelitian ini.
Tanda tangan: ______________________Jabatan:__________________________________ Tanggal: ___________

Appendix 9: Fieldwork research timeline

	Familiarisation with community	Interview with family (Study three)	Interview with local leaders (study three)	Focus group (study four)	Interview (study four)
SEP 2015	▨				
OCT 2015	▨				
NOV 2015	▨				
DEC 2015	▨				
JAN 2016		▨	▨		
FEB 2016			▨		
MAR 2016					
APR 2016				▨	
MAY 2016				▨	
JUN 2016					
JUL 2016					
AUG 2016					▨
SEP 2016					▨
OCT 2016					▨

Appendix 10: Interview schedule study three

Questions guide for Interview and Photovoice in study three:

a. What is the story behind this picture you took?
b. What is disability according to you?
c. Who is young child with disability according to you?
d. How is the current situation of young children with disabilities in your surrounding environment?
e. Why do children with disabilities experience their situation right now?
f. Where is the ideal place of children with disabilities?
g. What is the current health situation of young children with disabilities in your environment?
h. What is the current education situation of young children with disabilities in your environment?
i. What is the current economy situation of young children with disabilities in your environment?
j. What is the current social situation of young children with disabilities in your environment?
k. Do you have comments you would like to add?

Panduan Wawancara dan Photovoice untuk studi tiga: (*Indonesian version was refined after first interview)

a. Apa makna dari foto yang anda ambil ini? → Apa yang terjadi di foto? → Apa hubungannya dengan kehidupan anak? → Kenapa masalah/keuntungan ada? → Apa yang bisa dilakukan?
b. Apa itu disabilitas/kecacatan menurut anda?
c. Apa keadaan anak anda menurut anda?
d. Mengapa anak usia dini disabilitas mengalami apa yang mereka alami? Apa saja penyebabnya? → Apa ada penjelasan lain tentang penyebab disabilitas?
e. Apa yang dilakukan waktu pertama kali tahu berbeda atau sakit?
f. Apa pernah melakukan pengobatan tradisional? → Apa ada pengaruh budaya terhadap pengambilan keputusan pengobatan?
g. Bagaimana cara mengasuh anak? → Bagaimana peran ayah dan ibu?
h. Apa saja yang memperparah keadaan disabilitas anak usia dini itu?
i. Apa tantangan dalam membesarkan anak? → Apa pengaruh anak ke kehidupan orangtua?

j. Bagaimana keadaan pelayanan masyarakat di bidang kesehatan, pendidikan, sosial? → Apa ada dukungan atau program khusus? → Apa ada harapan atau saran untuk pelayanan masyarakat?
k. Apa ada harapan atau cita-cita untuk anak?
l. Apa dukungan yang mereka butuhkan? (Pertanyaan untuk pemimpin masyarakat)
m. Apa yang sudah dilakukan di masyarakat/institusi anda? (Pertanyaan untuk pemimpin masyarakat)
n. Apa yang bisa anda/institusi anda berikan? (Pertanyaan untuk pemimpin masyarakat)

Appendix 11: Focus group schedule study four

Field staff:

1. Moderator/Facilitator: Indra Yohanes Kiling

   Role:

   a) Directing the discussion and not taking over the group;
   b) Encouraging participants to express their feelings and opinions and communicate among themselves during the discussion;
   c) Building rapport to gain the confidence and trust of the participants and thereby probe beneath the surface of comments and responses;
   d) Maintaining flexibility and being as neutral as possible: if the discussion wanders away from the topic, subtly directs it back without offending participants;
   e) Controlling the time allotted to each topic and to the entire discussion.
2. Observer/recorder: Dea Boeky (bachelor of science graduate, experienced in focus group)

   Role:

   a) Operates the voice recorder and or video recorder, make sure it captures clear voices
   b) Take some notes on the non-verbal expressions
   c) Take some notes on the overall activities in focus group, strengths, weaknesses, etc.
   d) Can speak in discussion if the moderator overlooks a useful point raised by a participant, or to suggest a new question or topic relevant to the study, or if the moderator has missed an important topic in guide
3. Video recorder: Chipset team

   Role: operates video recorder all the time in the focus group.
4. 2nd observer: Berti Malingara (bachelor of sociology, experienced in focus group)

   Role: Similar to Dea.

Format of Contents of Observer's Notes

The recorder's notes would include the following:

1. <u>Group:</u> (Identification of participating group)
2. <u>Date:</u> (of group discussion)
3. <u>Time:</u> (group began and ended, time the whole session)
4. <u>Name of Community/Group of Professionals</u>: (brief description of it and any other information that may bear on the activities of the participants (e.g. Alak = rural sub-district compared to other sub-district, full in-house mother, any side jobs etc.)
5. <u>Meeting Place:</u> (location and brief description (i.e., big, convenient) and how this could affect the discussion)

6. Participants: (including number, personal characteristics, impression and observations result of **EACH participant** and other kinds of relevant information such as presence of children) (**specific per person**)
7. Group Dynamics: (general description, level of participation, dormant participants, interest level, boredom, anxiety, etc.) (**general in group**)
8. Interruptions: (occurring during the session)
9. Seating Diagram of the group. (It is best to have the group seated in a circle.)
10. Running Notes on discussion of various topics. Please Dea list any important notes related to the discussion of topics

Focus Group Moderator's Guide

1. **Introduction (10 minutes)**

[Before begins, make sure all participants have completed informed consent and have all of their demographic data, write names on metaplan]

[Narrative welcoming participants, describing reasons for discussion, explain a little about Indra and Indra's previous research;

tell about the **purpose** of the research and what will I do with it, ask if they wish to get a copy of findings, ask details;

and setting up the general ground rules for the session]

Ground Rules

1. 60-90 minutes (voice and video recorded -- observer and note taker)
2. Give candies—Everyone must speak in the discussion (at least twice until the end)
3. No right/wrong answers
4. Assurance of anonymity and confidentiality

2. **Disability and young children definition (5 minutes)**

Definition of a person with a disability according to United Nations is "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

What does it mean? *or* do you agree with it?

United Nations define young children as child in a period from pre-natal to eight years of age.

What does it mean? *or* do you agree with it?

3. **Problems (5 minutes)**

Please take a look at the second flipchart. We have a goal, that is to help development of young children with disabilities

You can see the problems based in West Timor identified on my previous research. They are divided on **family, community and services** level.

Do you have comments on it?

Do you see something inappropriate?

Do you want to add another problems?

4. **Activities & Outcomes: Health (10 minutes)**

Please take a look at the flipchart. Now please see the list of potential of activities that could be done in health sector. I formulated in based on previous research. These activities I predicted are not exist yet in West Timor. (Explain a bit both activities & outcomes)

What do you think of the activities?

What more can be done in the future in health sector considering the resources we have access to?

What are the changes in the children/family/community that you expect from this activity when it is done?

5. **Activities & Outcomes: Education (10 minutes)**

Please take a look at the flipchart. Now please see the list of potential of activities that could be done in education sector. I formulated in based on previous research. These activities I predicted are not exist yet in West Timor. (Explain a bit, especially **inclusive concept**)

What do you think of the activities?

What more can be done in the future in education sector considering the resources we have access to?

What are the changes in the children/family/community that you expect from this activity when it is done?

6. **Activities & Outcomes: Economy (10 minutes)**

Please take a look at the flipchart. Now please see the list of potential of activities that could be done in economy sector. I formulated in based on previous research. These activities I predicted are not exist yet in West Timor. (Explain a bit)

What do you think of the activities?

What more can be done in the future in economy sector considering the resources we have access to?

What are the changes in the children/family/community that you expect from this activity when it is done?

7. **Activities & Outcomes: Social (10 minutes)**

Please take a look at the flipchart. Now please see the list of potential of activities that could be done in social sector. I formulated in based on previous research. These activities I predicted are not exist yet in West Timor. (Explain a bit)

What do you think of the activities?

What more can be done in the future in social sector considering the resources we have access to?

What are the changes in the children/family/community that you expect from this activity when it is done?

8. **Activities & Outcomes: Parent and People Empowerment (10 minutes)**

Please take a look at the flipchart. Now please see the list of potential of activities that could be done in parents empowerment sector. I formulated in based on previous research. These activities I predicted are not exist yet in West Timor. (Explain a bit)

What do you think of the activities?

What more can be done in the future in the sector considering the resources we have access to?

What are the changes in the children/family/community that you expect from this activity when it is done?

9. **Closing (5 minutes)**

Now please see the overall chart, do you have something that you want to add? Thank you for participating! Now enjoy the refreshments! Listen to additional comments as the group breaks up

Focus Group Checklist

(a) Arrange	(b) Bring to the Field
Transport Chairs, Mats, etc. Refreshments (snack, candies, aqua) Souvenirs	Voice Recorder + Video recorder (in case) Microphone (if needed) Batteries (plus extra) Moderator's guide Format of observer’s notes Souvenir absence list Flipchart + markers Metaplan + paper tape Notebook + ballpoint Scissor & rubber band Plastic bag

Appendix 12: Interview schedule study four

Bahan bacaan sebelum wawancara—*Printed reading material before interview (*English available in initial best practice model table)*

Indra Yohanes Kiling

Berikut ini adalah daftar kegiatan yang diusulkan oleh pemerintah, LSM dan elemen masyarakat lain di Kota Kupang dan Kabupaten Kupang untuk dilakukan di Timor.

Daftar kegiatan ini mempunyai tujuan untuk mendukung tumbuh kembang anak usia dini (bawah delapan tahun) dengan disabilitas (kecacatan) di Timor.

Silakan baca terlebih dahulu sebelum wawancara dimulai, karena pertanyaan wawancara akan berhubungan dengan aktivitas-aktivitas di bawah ini:

Kesehatan

1. Pelatihan deteksi (skrining) disabilitas untuk petugas kesehatan di Puskesmas dan Posyandu.
2. Meningkatkan kerjasama dari dukun, tim doa institusi agama (gereja, dll.) dan tenaga kesehatan.
3. Pelatihan kesehatan di rumah-rumah warga tentang perkembangan anak.
4. Membuat poli khusus tumbuh kembang anak di rumah sakit atau fasilitas kesehatan lain.
5. Program kunjungan rumah (*home-visit*) untuk remaja yang hamil di luar nikah.
6. Kelas kesehatan dan perkembangan untuk anak usia dini dan orangtua
7. Mengadvokasi perguruan tinggi untuk memasukkan topik pelayanan inklusif di program studi-program studi kesehatan.
8. Meningkatkan kualitas dan kuantitas perlengkapan medis untuk memperbaiki pelayanan kesehatan.
9. LSM, Puskesmas dan Posyandu menyediakan suplemen dan makanan pendamping untuk anak usia dini dengan disabilitas.
10. Sosialisasi pentingnya makanan bernutrisi.
11. Program deteksi dini disabilitas berbasis komunitas.
12. Meningkatkan insentif yang diterima kader kesehatan.
13. Pelatihan untuk meningkatkan kapasitas dukun terutama dalam menangani hela step.
14. Mentoring untuk pasangan suami istri terkait perencanaan kehamilan.

Pendidikan

15. Program forum anak inklusif – melibatkan anak usia dini dengan disabilitas.
16. Mengadvokasi perguruan tinggi untuk memasukkan topik pendidikan inklusif di program studi-program studi pendidikan guru.
17. Pelatihan implementasi pendidikan inklusif di sekolah-sekolah terutama sekolah inklusif.
18. Pemerintah menyediakan beasiswa untuk anak usia dini dengan disabilitas.
19. Menempatkan guru pendidikan luar biasa di sekolah/PAUD reguler atau inklusif.
20. Pemerintah menyediakan buku, alat permainan edukatif dan fasilitas lain di PAUD.
21. Sosialisasi dan kunjungan rumah tentang pentingnya PAUD di komunitas.
22. Puskesmas memonitor perkembangan anak di Sekolah Dasar (SD).
23. Memperkuat komite sekolah—lebih melibatkan orangtua dari anak disabilitas di sekolah.
24. Pemerintah mendukung sekolah inklusif yang ada dengan berbagai cara.
25. Menyediakan bantuan penitipan anak seperti Taman Anak Sejahtera untuk keluarga tidak mampu, terutama orangtua dari anak usia dini dengan disabilitas.
26. Mendirikan dan memperkuat (pelatihan, fasilitas) kelompok belajar anak disabilitas (eksklusif).
27. Menyediakan pusat yang mampu menyediakan atau menghubungkan anak disabilitas dengan pekerjaan setelah lulus dari SMA.
28. Mengadvokasi pemerintah untuk menyiapkan lebih banyak SMP dan SMA inklusif.

Ekonomi

29. Mengenalkan dan sosialisasi tabungan pohon dan tanaman hias sebagai tabungan anak di sekolah, lembaga agama dll.
30. Mengadvokasi BPJS untuk menyediakan kebijakan khusus bagi penyandang disabilitas.
31. Mengadvokasi pemerintah agar menggunakan dana desa untuk subsidi transportasi anak usia dini disabilitas ke SLB dan untuk mengunjungi fasilitas kesehatan.
32. Menyediakan dana bantuan untuk operasi medis.
33. Memperbaiki implementasi Kartu Indonesia Sehat terutama untuk anak usia dini disabilitas.

34. Memberdayakan ibu dari anak usia dini disabilitas di PAUD untuk membuat kelompok tenun ikat, keuntungan ditabung untuk pendidikan anak.

Sosial

35. Mengadvokasi pemimpin agama dan budaya didukung orangtua dan pihak lainnya untuk melakukan kampanye kesadaran demi mengurangi stigma terhadap/memiliki anak disabilitas.
36. Pemerintah melalui dinas sosial dan pemerintah desa menyediakan alat bantu untuk anak disabilitas.
37. Meningkatkan aksesibilitas di semua infrastruktur publik (ram, dll.).
38. Memperbaiki pengumpulan data di masyarakat untuk meningkatkan kualitas pelayanan masyarakat.
39. Mengadvokasi Gereja dan lembaga agama lain untuk melakukan aktivitas ramah disabilitas seperti kompetisi, kelompok spiritual untuk anak, dana diakonia dsb.
40. Menyediakan asisten sosial untuk anak usia dini disabilitas.
41. Guru Sekolah Minggu menjemput anak usia dini disabilitas untuk ikut sekolah Minggu.
42. Membuat/mengawal Peraturan Daerah untuk melindungi hak anak, terutama anak disabilitas.
43. Meningkatkan kemampuan pemerintah untuk mengambil alih program LSM begitu LSM selesai.
44. Kartu pelayanan umum yang dibuat spesial untuk anak/penyandang disabilitas.
45. Merekrut dan mempekerjakan lebih banyak pekerja sosial.
46. Meningkatkan pelayanan publik dengan cara mengetatkan sistem hadiah dan hukuman.
47. Membuat unit disabilitas di SKPD pemerintah terkait untuk meningkatkan kolaborasi antar SKPD.
48. Mengundang kelompok penyandang disabilitas untuk hadir di gereja/lembaga agama lain demi membuka mata masyarakat terhadap keberadaan mereka.
49. Program ojek khusus untuk menjemput anak disabilitas untuk pergi ke gereja.
50. Meningkatkan kerjasama program dari pemerintah dan LSM.

Pemberdayaan

51. Mengadvokasi pemerintah (biro kesejahteraan masyarakat) untuk mengadakan desa inklusif.
52. Mendirikan dan memperkuat (pelatihan, dll.) kelompok orangtua dari anak disabilitas.
53. Membentuk Pelayanan Anak Usia Dini Inklusif dan Terintegrasi yakni—PAUD inklusif, Posyandu inklusif, SD Inklusif, Bina Keluarga Balita inklusif, dan Sekolah Minggu inklusif, kemudian memperkuat kolaborasi dari semua layanan tersebut.
54. Mengadvokasi pemerintah melalui media massa seperti koran.
55. Mendorong komunitas anak muda untuk menjadi advokator dalam meningkatkan kesadaran masyarakat terhadap isu disabilitas.
56. Melakukan sosialisasi tentang isu disabilitas melalui media seperti televisi, radio, kunjungan rumah.
57. Memperkuat organisasi penyandang disabilitas dalam melakukan aktivitasnya.
58. Memperkuat keterikatan dari komunitas aktivis disabilitas.
59. Merekrut sarjana dari kota Kupang untuk bekerja di pelayanan usia dini inklusif dan terintegrasi di daerah tertinggal.
60. Sosialisasi dan pemberian motivasi dari orangtua anak disabilitas yang sukses membesarkan anak terhadap orangtua anak disabilitas lainnya.
61. Melakukan aktivitas dengan anak disabilitas (seni dan olahraga) pada *car free day*.
62. Mendorong orangtua dari anak disabilitas untuk terlibat dalam pemerintahan desa melalui kelompok orangtua anak disabilitas.
63. Membuat peraturan desa yang mengharuskan minimal sekian penyandang disabilitas hadir dalam Musrenbangdes.
64. Mendorong pengelola PAUD untuk menginisiasi program pelayanan anak usia dini inklusif dan terintegrasi.

Terima kasih sudah membaca!

Interview Checklist

(a) Arrange
- Transport
- Incentives

(b) Bring to the Field
- Voice Recorder + Video recorder (in case)
- Batteries (plus extra)
- Interview guide
- Reading material
- Permit letters
- Extra informed consent

Main interview questions:

a. Apa pendapat anda mengenai kegiatan pada nomor 1, 2, 3, dst.?

   Kemungkinan pertanyaan tambahan:

   Apa memungkinkan?

   Siapa aktornya?

   Ada saran/mau dilengkapi?

   Apa kelebihannya?

   Apa kekurangannya?

   Bagaimana cara memperbaikinya?

   Apa ukuran efektivitas program tersebut?

   Ada ide lain di bidang kesehatan dll?

b. Mana yang paling menarik untuk anda (baik positif atau negatif)? Bisa satu aktivitas, bisa banyak!

c. Mana yang bisa dilakukan institusi/lingkungan anda? → Program utama yang bisa diadopsi? → Bagaimana cara melakukannya?

d. Ada yang mau ditambahkan sebagai penutup?

Appendix 13: Demographic table of study four participant

Table 19. Demographic table of parent discussion participants

No	Name	Relationship	Age & Sex	Occupation	Ethnic	Religion	Education level	Child's name	Age & sex	Disability	Total child	Sibling's age & sex
1.	YS	Mother	32 & F	Entrepreneurship	Timor	Christian	Junior high school	VS	7 & F	Can't walk, low vision	1	-
2.	NWL	Mother	36 & F	Housemother	Sabu	Christian	Elementary school	AWL	1 & M	Glued legs and hands	4	1. 13 & F 2. 9 & F 3. 6 & M 4. AWL
3.	VM	Grandmother	50 & F	Housemother	Sabu	Christian	Junior high school	VIM & VAM	4 & M 3 & F	Walk and talk delays (VIM); can't stand, folded hand	2	-
4.	IL	Mother	36 & F	Housemother	Sabu	Catholic	Junior high school	EL	4 & F	Low vision, walk and talk delays	4	1. 11 & F 2. 10 & F 3. EL 4. 1 & F
5.	RL	Aunt	30 & F	Housemother	Sabu	Catholic	Senior high school	EL	Idem	Idem	Idem	Idem
6.	YM	Mother	30 & F	Domestic worker	Timor	Christian	Senior high school	RMM	7 & M	Talk delays, mild intellectual disability	2	1. 13 & M 2. RMM
7.	DT	Aunt	34 & F	College student	Sumba	Christian	Diploma 3	RMM	Idem	Idem	Idem	Idem
8.	VN	Mother	36 & F	Farmer	Timor	Christian	Elementary school	AN	7 & M	Emotional disorder	4	1. 9 & F 2. AN 3. 5 & F 4. 1 & M
9.	DS	Mother	40 & F	Teacher	Batak	Christian	Senior high school	MA	7 & F	Gifted child	3	1. 9 & M 2. MA 3. 3 & F
10.	ER	Mother	33 & f	Housemother	Sabu	Christian	Elementary school	MD	6 & F	Intellectual disability, talk delays	3	1. MD 2. 3 & F 3. 1 & M
11.	JSM	Mother	32 & F	Housemother	Timor	Christian	Elementary school	EM	7 & M	Hearing impairment	3	1. 10 & M 2. EM 3. 6 & M
12.	SL	Aunt	36 & F	Store attendant	Timor	Catholic	Senior high school	TL	5 & F	Communication delays	2	1. 6 & F 2. TL

No	Name	Relationship	Age & Sex	Occupation	Ethnic	Religion	Education level	Child's name	Age & sex	Disability	Total child	Sibling's age & sex
13.	SB	Mother	42 & F	Housemother	Timor	Christian	Junior high school	RB	7 & M	Talk and walk delays	3	1. 15 & F 2. 13 & M 3. RB
14.	IA	Mother	27 & F	Housemother	Flores Ende	Christian	Senior high school	RA	7 & M	Can't walk	3	1. RA 2. 1 & M 3. 2 months & F
15.	YS	Mother	40 & F	Entrepreneur	Timor	Christian	Elementary school	KS	4 & F	Walk and talk delays	2	1. 12 & M 2. KS
16.	RF	Mother	33 & F	Housemother	Rote	Christian	Junior high school	BMF	7 & F	Intellectual disability, walk and talk delays	3	1. 8 & F 2. BMF 3. 2 & M
17.	AL	Aunt	36 & F	Housemother	Rote	Christian	Elementary school	Idem	Idem	Idem	Idem	Idem
18.	SF	Aunt	40 & F	Housemother	Rote	Christian	Elementary school	Idem	Idem	Idem	Idem	Idem
19.	AF	Aunt	38 & F	Housemother	Rote	Christian	Elementary school	Idem	Idem	Idem	Idem	Idem
20.	RF	Aunt	46 & F	Housemother	Rote	Christian	Elementary school	Idem	Idem	Idem	Idem	Idem
21.	JRL	Mother	29 & F	Store employee	Sabu	Christian	Senior high school	Idem	Idem	Idem	Idem	Idem

Note. M = male, F = female

Table 20. Demographic table of local leaders discussion participants

No.	Name	Age & Sex	Occupation	Length of work in the current job	Ethnicity	Religion	Education level
1.	JAL	38 & F	Kindergarten Teacher (Tarus)	6 years	Sabu	Christian	Senior high school
2.	RFL	46 & F	Kindergarten Teacher	20 years	Sabu	Christian	Bachelor degree
3.	EMS	29 & F	Kindergarten Teacher	2 years	Rote	Christian	Senior high school
4.	SHD	56 & F	Kindergarten Teacher	38 years	Rote	Christian	Teacher education course
5.	DP	23 & F	Kindergarten Teacher	2 years	Sabu	Christian	Senior high school
6.	KM	22 & F	Kindergarten Teacher	1 year	Sumba	Christian	Senior high school

No.	Name	Age & Sex	Occupation	Length of work in the current job	Ethnicity	Religion	Education level
7.	BP	48 & F	Kindergarten Teacher	3 years	Sabu	Christian	Bachelor degree
8.	NDD	32 & F	Kindergarten Teacher	1 year	Sabu	Christian	Bachelor degree
9.	MEN	38 & F	Kindergarten Teacher (Manutapen)	9 years	Timor	Christian	Senior high school
10.	YM	18 & F	Kindergarten Teacher	1 year	Java	Christian	Junior high school
11.	EAN	29 & F	Kindergarten teacher	9 years	Timor	Christian	Senior high school
12.	SYR	34 & F	Kindergarten teacher	1 year	Sabu	Christian	Senior high school
13.	SHT	31 & F	Kindergarten teacher	1 year	Sabu	Christian	Senior high school
14.	MMS	45 & F	Kindergarten teacher	9 years	Alor	Christian	Senior high school
15.	YP	63 & F	Kindergarten teacher	9 years	Timor	Christian	Senior high school
16.	EB	21 & F	Sunday school teacher (Manutapen)	7 years	Sabu	Christian	Senior high school
17.	SL	23 & F	Sunday school teacher	5 years	Timor	Christian	Senior high school
18.	DT	31 & F	Sunday school teacher	3 years	Timor	Christian	Bachelor degree
19.	NS	26 & F	Sunday school teacher	4 years	Timor	Christian	Bachelor degree
20.	OYF	20 & F	Sunday school teacher	4 years	Timor	Christian	Senior high school
21.	CT	19 & F	Sunday school teacher	3 years	Timor	Christian	Senior high school
22.	HSS	26 & F	Sunday school teacher	3 years	Timor	Christian	Bachelor degree
23.	APB	19 & F	Sunday school teacher	2 years	Timor	Christian	Senior high school
24.	PM	27 & F	Community health centre (Manutapen)	2 years	Bali	Hindu	Dentist
25.	AD	25 & F	Community health centre	6 months	Java	Islam	Medical doctor
26.	FB	42 & F	Community health centre	16 years	Timor	Christian	Diploma
27.	LEM	39 & F	Community health centre	5 years	Rote	Islam	Diploma
28.	SI	47 & F	Community health centre	21 years	Flores	Catholic	Diploma
29.	YED	33 & F	Community health centre	9 years	Flores	Catholic	Bachelor degree
30.	FL	31 & F	Community health centre	6 years	Sabu	Christian	Bachelor degree
31.	WA	34 & F	Community health centre	6 months	Timor	Christian	Senior high school
32.	KB	24 & F	Sunday school teacher (Tarus)	6 years	Timor	Christian	Bachelor degree
33.	SAB	35 & F	Sunday school teacher	2 years	Timor	Christian	Senior high school

No.	Name	Age & Sex	Occupation	Length of work in the current job	Ethnicity	Religion	Education level
34.	DR	27 & F	Sunday school teacher	7 years	Sabu	Christian	Bachelor degree
35.	SR	22 & F	Sunday school teacher	4 years	Sumba	Christian	Senior high school
36.	IM	40 & F	Community health centre (Tarus)	16 years	Rote	Christian	Senior high school
37.	LL	42 & F	Community health centre	5 years	Timor	Christian	Diploma
38.	MG	40 & F	Community health centre	17 years	Timor	Catholic	Diploma
39.	YLW	42 & F	Community health centre	5 years	Sabu	Christian	Diploma
40.	MN	36 & F	Community health centre	2 years	Flores	Catholic	Diploma
41.	MWM	30 & F	Community health centre	4 years	Alor	Christian	Diploma
42.	RL	30 & F	Community health centre	2 years	Rote	Christian	Diploma
43.	KW	35 & F	Community health centre	5 years	Flores	Catholic	Diploma
44.	PD	24 & F	NGO workers (woman)	2 years	Batak	Christian	Bachelor degree
45.	BPS	24 & F	NGO workers	2 years	Palembang	Islam	Bachelor degree
46.	SRLS	26 & F	NGO workers	6 years	Alor	Christian	Bachelor degree
47.	TTY	42 & F	NGO workers	6 years	Flores	Catholic	Bachelor degree
48.	YH	43 & F	NGO workers	4 years	Rote	Christian	Junior high school
49.	RL	35 & M	NGO workers (man)	15 years	Timor	Christian	Senior high school
50.	PM	35 & M	NGO workers	9 years	Timor Belu	Catholic	Bachelor degree
51.	LJ	47 & M	NGO workers	5 years	Flores	Catholic	Bachelor degree
52.	YAD	27 & M	NGO workers	2 years	Flores	Catholic	Senior high school
53.	YAL	29 & M	NGO workers	5 years	Sabu	Christian	Senior high school
54.	WF	32 & M	NGO workers	4 years	Rote	Chrsitian	Bachelor degree
55.	DL	52 & M	NGO workers	19 years	Alor	Christian	Senior high school

Note. M = male, F = female

Table 21. Demographic table of interview participant

No.	Name	Age & Sex	Occupation	Length of work in the current job	Ethnicity	Religion	Education level	Personal disability	Family with disability – age	Type of family member's disability	Involvement in disability related programme	Type of project involved	Having young children
1.	JK	54 & F	Head of Social Agency Kupang City	2 years	Minahasa-Sangir	Christian	Bachelor medicine	Pain in the leg and using glasses	Yes, nephew	Physical disability	Yes—with Handicap International; Disability person organisations	Inclusive education	None
2.	SS	48 & M	Project coordinator ChildFund	7 years	Flores Ngada	Catholic	Bachelor sociology	None	Yes, sponsor boy in Oebelo – 11 years old	Communication disability	Yes—involved in discussions with Handicap	Inclusive education	None
3.	RJ	42 & F	Head of Tarus urban community	5 years	Rote	Christian	Master in public administration	None	None	N/A	None	-	None
4.	AU	48 & F	Household mother	12 years	Flores	Catholic	Senior high school	None	Yes, daughter 8 years old	Down syndrome	Yes—Persani	Parents group, children exclusive learning group	One boy, 6 years old
5.	SL	53 & M	Secretary of Education Agency Kupang City	9 months	Rote	Christian	Bachelor in education	None	Yes, far relative, niece of his wife	Small legs—can't walk	Yes—Handicap International, Australian Aid, UNICEF	Inclusive education	None
6.	FM	52 & M	Head of section of social rehabilitation in Social Agency Province	2 years	Rote	Christian	Bachelor in public administration	None	None	N/A	Yes—Handicap International (capacity improvement of parents of children with disabilities),	Socialization, empowerment, capacity improvement	None
7.	YS	32 & F	Staff of child, teenager and elderly health in Health Agency Kupang City	6 years	Jawa – Rote	Christian	Bachelor in public health	None	Yes – younger male cousin, live in the same house – 21 years old	Hearing and communication impairment	Yes—Handicap International, Persani	Persani—Reproduction health Handicap International—Advocacy, inclusion meeting	None
8.	YY	51 & M	Rector of Catholic	7 years	Manggarai	Catholic	Master in sociology,	None	None	N/A	None	-	None

No.	Name	Age & Sex	Occupation	Length of work in the current job	Ethnicity	Religion	Education level	Personal disability	Family with disability – age	Type of family member's disability	Involvement in disability related programme	Type of project involved	Having young children
			University of Widya Mandira				master in social policy						
9.	ECT	33 & F	Head of social aid sub-division in Social Division, Region Secretary of Kupang City	10 months	Jawa – Toraja	Christian	Bachelor in government system	None	Yes – 2 persons, nephew 5 years old – autism; husband's nephew 21 years old – ASD	Autism	Yes – CIS Timor (coordination meeting)	Inclusive education	None
10.	LM	54 & M	Former Dean in Teachers Training Faculty of Artha Wacana Christian University	24 years	Timor	Christian	Master in social education	None (has slight hearing difficulty in left ear but don't serve as barrier)	Yes – one person, younger brother	Emotional difficulties	None	-	None (passed early age)
11.	BM	50 & M	Head of service support unit, Timor Church Synod	2 months	Savu	Christian	Bachelor in theology	None	None	-	None	-	None (passed early age)
12.	VH	40 & M	Member of IV Commission in House of People Representative Kupang City	3 years	Rote	Christian	Diploma III in civil engineering	Polio – difficulty in walking, need to be assisted with crutch	Mother 78 years old; also far nephew 14 years old	Mother caused by accident, can't walk; nephew – hearing difficulty	Yes— as facilitator and speaker; Handicap International, Bengkel Appek, DPOs; also head of disability sports committee	Sports, inclusive education etc.	Two – 5 years old girl, 2 years old boy
13.	MT	38 & M	Head of sub-division social, culture and pariwisata; in BAPPEDA (Regional Planning Body) Kupang City	3 years	Timor – Dawan	Christian	Bachelor in Economy	None	Far aunt from mother 60 years of age;	Mental disability	Yes—involved as participant in workshop with Handicap International	Inclusive education, regulation concerning disability	None

No.	Name	Age & Sex	Occupation	Length of work in the current job	Ethnicity	Religion	Education level	Personal disability	Family with disability – age	Type of family member's disability	Involvement in disability related programme	Type of project involved	Having young children
14.	DPH	47 & F	Data coordinator in Health agency Province	9 years	Batak Toba	Christian	Master in Epidemiology—public health	None	None	-	None	-	None (passed early age)
15.	DT	30 & F	Head of sub-division in National Population and Family Planning Board Provice	2 years	Timor	Christian	Bachelor in Economy Accounting	None	None	-	Yes—inclusive education meeting with Handicap International and CIS Timor	Inclusive education	None
16.	GB	48 & M	Head of ECED section in Education Agency province	5 years	Flores	Catholic	Bachelor in nation administrative	None	Close nephew	Physical disability—hand	None	-	None (passed early age)
17.	DB	45 & M	Head of division of social culture, BAPPEDA Province	3 years	Kemak—Tetun	Catholic	Master of natural resources and environment management	None	Yes—far cousin, far nephew.	Autism and physical disability—legs	Yes—his division handles matters about disability	Inclusive education, rehabilitation	None (passed early age)
18.	YA	45 & M	Head of sub-division human resources and development, BAPPEDA Province	3 years	Flores	Catholic	Bachelor of Geography	None	Yes—far cousin 13 years of age male	Autism	Yes—planning programmes	Inclusive education, rehabilitation	Yes, two children, 7 years of age boy, 3 months old boy
19.	YB	45 & M	Deputy Project Manager in Handicap International project	1 year	Flores	Catholic	Bachelor in Philosophy	None	Yes— close niece 16 years of age	Communication disability	Yes—deputy project manager and several other roles in the past	Project advocacy for change, inclusive education	Yes, one child, 5 years old girl
20.	AA	39 & F	Nun in Alma nunnery. Head of an orphanage and ECED	3 years	Flores (Bajawa)	Catholic	Bachelor in religion	None	Yes—two far cousins; male and female.	Communication and hearing difficulties & krutinisme	Yes—daily services	Inclusive education & rehabilitation	None (not married)

No.	Name	Age & Sex	Occupation	Length of work in the current job	Ethnicity	Religion	Education level	Personal disability	Family with disability – age	Type of family member's disability	Involvement in disability related programme	Type of project involved	Having young children
21.	KK	37 & F	Field Education Specialist in Save The Children	7 months	Tetun	Christian	Master in International community development	None	None	-	Yes—only once helped an inclusive ECED in Kuanino area for a year	Inclusive education	Yes—one child, female, 4.5 years old
22.	FB	51 & M	Rector of Universitas Nusa Cendana	3 years	Timor	Christian	PhD in Agribusiness (Curtin Uni)	None	Yes—close cousin; 20 years old; female	Hearing disability	None	-	-
23.	SB	38 & F	Private sector employee; Head of Persani. (Christian DPO)	Private = 15 years; Persani 6 years	Flores	Catholic	Vocational high school	Physical disabiity; can't walk because of polio	Yes—far family; 17 years old nephew (male);	Multiple disabilities epilepsy, experience seizure a lot	Yes—with Handicap and own project	Inclusive education and advocacy for change (Handicap International); Educational guidance and socialisation	Yes—two children : 7 years old girl and 3 years old boy
24.	AP	41 & F	Head of sub-division in Planned Family and Prosperous Family Body Kupang City	1 year	Toraja	Christian	Master in Public Health	None	None	-	None	-	None (passed early age)
25.	PD	24 & F	Wahana Visi Indonesia as Sponsorship Implementation Monitoring Officer	2 years	Batak	Christian	Bachelor in International Relationship	None	None	-	None	-	None (not yet married)
26.	GR	40 & F	Staff in CIS Timor. Program officer in sanitation program, also a teacher (private teacher)	8 years	Rote	Christian	Bachelor in Theology	None (uses glasses)	None	-	Inclusive education with Handicap International	Inclusive education	None (not yet married)

No.	Name	Age & Sex	Occupation	Length of work in the current job	Ethnicity	Religion	Education level	Personal disability	Family with disability – age	Type of family member's disability	Involvement in disability related programme	Type of project involved	Having young children
27.	EM	28 & F	Staff in People Prosperity Bureau Province	2 years	Flores	Catholic	Bachelor in Public Health	None	None; has a close friend with disability. between 10-20 years old.	Down syndrome	None	-	None
28.	MKT	58 & F	Head of sub division Kesejahteraan in People Prosperity Bureau	2 years 10 months	Flores	Catholic	Bachelor Arts (Sarjana Muda) in Religion	None	None	-	As a college student, in Bakti Luhur orphanage	Centre-based	None (passed early age)
29.	MN	39 & F	Staff in People Prosperity Bureau Province	6 years	Timor	Catholic	Bachelor in Government study	None	Yes—far family aunt, in Kefa. Already passed away in 16 years old	Krutinism, autism	None	-	Yes; 5 years of age girl
30.	NH	39 & M	Head of sub division in People Prosperity Bureau Province	6 months	Sabu	Christian	Master in public policy, specialised in policy analysis	None	Yes—far family, wife's cousin's son. 8 years old boy	Intellectual disability, hyperactive	None	-	None (already married)
31.	MP	23 & M	Staff in People Prosperity Bureau Province	2 months old	Java	Islam	Diploma 4 in government study	None	Yes—step-brother	Can't walk, parts of brain missing	None	-	None (not yet married)
32.	WR	40 & M	Head of commission V (people prosperity) in House of Representatives Province	2 years of age	Rote	Christian	Bachelor in peternakan	Believed he has but not know about it yet	Yes—close cousin—12 years of age female	Low vision	Yes—in House of Representatives and in CIS Timor	Together with Handicap International promoting mainstreaming disability in every programmes	None (passed early age)

No.	Name	Age & Sex	Occupation	Length of work in the current job	Ethnicity	Religion	Education level	Personal disability	Family with disability – age	Type of family member's disability	Involvement in disability related programme	Type of project involved	Having young children
33.	PM	35 & M	Head of Permata (DPO)	7 years	Tetun Timor	Catholic	Bachelor in religion teacher	Yes—ex-leprosy, can't move hand very well	Yes—two close uncle around 45 years of age, one aunt 40 years of age, one cousin 18 years of age	Uncles and aunt—leprosy; cousin—physical disability	Yes—in Permata with Handicap International and Bengkel APPEK	Advocacy for change, inclusive education, socialisation	Yes two children —first 7 years old boy; second 1 year old girl
34.	WO	? & F	Early Childhood Development Specialist working in UNICEF Kupang. previously 4,5 years in UNICEF Pacific.	5 weeks	American	Neutral	Bachelor in special education, master in international training and education	No	Yes—mother has multiple sclerosis	Multiple sclerosis; almost quadriplegic; 72 years of age	Yes—classroom teacher	Early childhood special education	No
35.	DP	38 & F	Early Childhood Development Officer in UNICEF Kupang;	2,5 months	Java	Islam	Master of education	No	No	-	Yes—was in special school; back in kindergarten	Kindergarten	No

Note. M = male, F = female

Appendix 14: Chapter 6 initial logic models

Table 22: Initial logic model pre focus group

Strategies	Assumptions	Risk & protective factors	Resources	Activities	Outcomes	Impact
Multi-sectoral • Strengthen CBR implementation by inclusive village; focus on participation, data and transportation • Make inclusive holistic integrative young children's services: conduct combined home-visit and centre-based programmes • Involve universities in the inclusive village pilot and inclusive education Health • Train community health centre and ECED workers for disability screening • Improve collaboration between psychic and primary health workers Education • Create an inclusive child forum programme • Improve inclusive education implementation Economy • Plant cendana and jati trees to save for children's education, tree seeds provided by governments & NGOs • Special arrangements for children by national social security provider Social • Awareness campaign by religious and cultural leaders to reduce stigma Empowerment • Establish and empower self-help groups for parents	• Inclusive village will help improve rehabilitation and awareness of children • Young children's services are available in every village • Universities have expertise in psychology, ECED, medicine etc. • Disability screening existed but needs improvements in actuation • Psychics were more trusted • Inclusive child forum will help with discrimination from peers • Some teachers were already trained but there is a need for more teachers as trainers • Tree planting/saving programme has been done in East Sumba • Simple administrative help connects children to services • Religion and cultural leaders prove vital in reducing stigma • Self-help parents' group exists but needs improvement	Family **Risk:** Poverty, religion beliefs, cultural beliefs, poor time management, poor first aid, home set-up, poor interaction, malnutrition, injuries, sanitation, low compliance, father and mother's relationship, harsh parenting, formula milk dependence, low awareness, low education, child neglect, confinement in animal stall, want aid without effort, focus more on children without disabilities **Protective:** Trust in God, concern for health & education, stimulate development, ideal breastfeeding, parents' acceptance Community **Risk:** Discrimination, poor interaction with peers, disease vectors, stigma, exploitation, access to public facilities **Protective:** Social support, up-to-date data Programme/service **Risk:** Distance to services, complex administration, lack of information, low number of facilities, limited resources, no special attention, poor inclusive execution, institutionalization, psychic's low ability, lack of professionalism from workers, harmful therapy, corruption **Protective:** ECED's stimulation, nutritious food from IHP	West Timor resources-village/sub-district level • Integrated service post • Community Health Centre • Psychic • ECED post • Elementary school • Child forum • Sunday School and similar activities • Church • Cultural leaders West Timor resources-city level • Nunneries • Hospitals • Inclusive schools • Special schools • Universities • Government health, education and social agency • People prosperity bureau and child protection body • Child protection institute • International disability NGOs • International children NGOs • Local NGOs • DPOs	Health • Training about disability screening for community health centre and integrated service post workers • Improve collaboration between psychic and primary health workers Education • Inclusive child forum • Advocates universities to insert inclusive education topic in teacher training faculties Economy • Introduce tree as children's saving • Advocate social security provider for special arrangements • Advocate government to subsidize transportation for special schools' student Social • Advocate religious and cultural leaders to begin awareness campaign to reduce stigma Empowerment • Advocate inclusive village to people prosperity bureau • Establish and empower parents self-help groups • Inclusive integrated service post, ECED, below five guidance, elementary school, Sunday school, and strengthen collaboration	Health • # of children screened increases • # of children get appropriate first aid increases Education • Children with and without disabilities mingle together • # of inclusive school increases Economy • # of children with savings for future education increases • # of therapies given to children increases • # children from rural in special schools increases Social • # of foster children decreases Empowerment • # of inclusive sub-district increases • # of parents attended village policy making meetings increases • # of activities conducted together by provider of holistic-integrative young children services in sub-district level increases	Young children with disabilities developing their full potential

Table 23: Logic model after focus group

Strategies	Assumptions	Risk & protective factors	Resources	Activities	Outcome
Multi-sectoral • Strengthen CBR implementation by inclusive village; focus on participation, data and transportation • Make inclusive holistic integrative young children's services: ECED, elementary school, integrated service post, below five guidance and Sunday school. Conduct combined home visit and centre-based programmes • Involve universities in the inclusive village pilot and inclusive education	Multi-sectoral: • Simple administrative help connects children to services • Young children's services are available in every village • Universities have expertise in psychology, ECED, medicine etc. • Importance of environmental factors • Consider regulations and policies as important and should be top priorities • Everything and every place in the community needs to be inclusive • PNPM (national development) programme will be over in 2017 • Prefer programme from government instead of NGO to be more sustainable • Easier to recruit available cadres into disability activities because of their familiarity with children • Taking care of children with disabilities in services needs more skills and patience • Health workers should inform ECED teachers about children with disabilities so they can take the initiative to invite children to attend ECED • NGO has focused partners and scope • Consider training in how to take care of children and region law as priority	Family **Risk:** • Poverty • Religion beliefs • Cultural beliefs • Poor time management • Poor first aid • Home set-up • Poor interaction • Malnutrition • Injuries • Sanitation • Low compliance • Father and mother's relationship • Harsh parenting • Formula milk dependence • Low awareness • Low education • Child neglect • Confinement in animal stall • Want aid without effort (lazy) • Focus more on children without disabilities • Problem in dental health • Parent's feel disgrace • Parents' disappointment • Family pride and prestige • Seizure and high fever • Parents don't trust children to enter ECED • Parents don't have time to take care of children	West Timor resources-village/sub-district level • Integrated service post • Community Health Centre • Psychic • ECED post • Elementary school • Child forum • Sunday School and similar activities • Church • Cultural leaders	-	-

Strategies	Assumptions	Risk & protective factors	Resources	Activities	Outcome
		• Parents losing hope about their children **Protective:** • Trust in God • Concern for health & education • Stimulate development • Ideal breastfeeding • Parents’ acceptance			
Health • Train community health centre and ECED workers for disability screening • Improve collaboration between psychic and primary health workers	Health: • Disability screening existed but needs improvement in actuation • Psychics were more trusted • Health operational support is available for primitive and preventive effort • Consider young children with disabilities have a good chance of recovering from their condition • Health workers need knowledge concerning treatment and how to interact with children • Disability friendly community health centre programme is already on health agency’s agenda • Psychics are available in remote areas • Importance of immunisation and development monitoring (weight, height) • Formula milk doesn’t guarantee smart children • Some parents don’t trust psychics • Majority of parents have not received routine visit from health workers • Collaboration between psychics and health workers existed in Timor in the past • Delivery by psychics could cause	Community **Risk:** • Discrimination • Poor interaction with peers • Disease vectors • Stigma • Exploitation • Access to public facilities • Ineffective positive deviance • Children are disabled by community • Lacking information • Porn sites causing teenager pregnancy • Problems have complex cause and effect relationships • NGO dependency • Unfulfilled promises from institutions break hearts **Protective:** • Social support • Up-to-date data	West Timor resources-city level • Nunneries • Hospitals • Inclusive schools • Special schools • Universities • Government health, education and social agency • People prosperity bureau and child protection body • Child protection institute • International disability NGOs • International children NGOs • Local NGOs • DPOs	Health 1. Training of disability screening (content focusing on disability) for community health centre and integrated service post workers 2. Improve collaboration between psychics, prayer team and primary health workers 3. Simple training in family houses concerning development and preventing delays 4. Add special disability or child growth and development polyclinic in the hospital 5. Home-visit programme for pregnant teenagers 6. Health class for young children and parents 7. Advocates universities to insert inclusive service topic in health faculties/programmes 8. Improved technology (tools) and other facilities for detection and other services 9. NGOs, integrated service post and community health centre providing needed supplements and food for children 10. Socialisation of importance of nutritious food 11. Community-based detection programme 12. Improve cadres’ incentives 13. Training for psychics 14. Mentoring for parents concerning pregnancy planning	Health 1. # of children screened increases 2. # of children get appropriate first aid increases 3. Improvement in healthy behaviour 4. # of children medically rehabilitated increases 5. # of children delivered healthily increases 6. # of children develops properly increases 7. # of inclusive services increases 8. # of service improved efficiency increases 9. # of children develops properly increases 10. # of children getting nutritious food daily increases 11. # of children detected increases

Strategies	Assumptions	Risk & protective factors	Resources	Activities	Outcome
	disability • Integrated service post cadres have been doing socialization to improve health awareness • Home visit once a month and focus on guiding the parents in improving awareness • Psychics should have a smaller role in collaboration with health workers • Add cadres and psychologists in collaboration between psychics and health workers to improve efficiency • Add home visit services and screening to improve number of children screened				12. # of programme (esp. home visit) done by cadres increases 13. # of psychics collaborating with health workers increases 14. # of planned pregnancy increases
Education • Create inclusive child forum programme • Improve inclusive education implementation	Education: • Inclusive child forum will help discrimination from peers • Some teachers were already trained but need more teachers as trainers • ECED could stimulate children with disabilities' development • Children with intellectual disability have many friends in special schools and treated well by the teachers • Children with intellectual disability do not want to go to regular high school, but choose a special school • Many parents struggled to train their children to be independent • Consider supporting children to attend special school is a contra-movement to inclusive education programmes • Special schools will support inclusive schools in the future • Consider special school important • Consider parenting important • Parents begin to realise the	Programme/service **Risk:** • Distance to services • Complex administration • Lack of information • Low number and poor facilities • Limited resources • No special attention/programmes • Poor inclusive execution • Institutionalization • Psychic's low ability • Lack of professionalism from workers • Harmful therapy and other services (vacuum) • Corruption and nepotism • Lack of awareness and commitment from government and workers • Bullying in school from other students • Low collaboration between government agencies and		Education 1. Inclusive child forum (train the facilitators, teach reading and writing for drop-out children) 2. Advocates universities to insert inclusive education topic in teacher training faculties 3. Training for inclusive implementation in inclusive schools 4. Government provide scholarships for children 5. Putting special education teachers in inclusive and regular schools/ECED 6. Government provide books, learning materials and facilities to ECED 7. Socialization and home visit of importance of ECED to the community 8. Community health centre should monitor children's development in elementary school 9. Strengthen school committee, involving parents of children with disabilities (activities example: involve parents in class) 10. Government must support available	Education 1. Children with and without disabilities mingle together 2. # of inclusive school increases 3. # of inclusive school truly implementing inclusive environment increases 4. # of children attend school increases 5. # of school with inclusive environment increases 6. # of well-equipped ECED increases 7. Increase in ECED pure participation rate 8. # of children monitored increases

Strategies	Assumptions	Risk & protective factors	Resources	Activities	Outcome
	importance of special teachers and educated parents • Child forum hasn't paid attention to children with disabilities yet • Parents want their children to attend special school • Young children copies their close persons' behaviours • Mother communicating with fetus could help development • Special needs school scholarship from programmes in the past unsuccessful because of parents don't want to let children attend school • Existing children's group could be absorbed in child forum to make it formal • Inclusive ECED existed even though they don't realise the term inclusive yet • ECED could help improve confidence	service workers • Problems of data accuracy and collection • Low number of workers • Ineffective NGO programmes • Insufficient number of scholarships • School operational support fund not designated for disability issues • Low wage for workers • Low social access • Harsh teaching, different disciplining style between schools and parents • Unsupervised delivery **Protective:** • ECED's stimulation, • Nutritious food from integrated service post		inclusive schools 11. Providing day care support for poor families 12. Found and strengthen (training, facilities) exclusive children with disabilities learning group 13. Provide centre that could provide jobs for children (almost graduate) from senior high school 14. Advocating government to prepare more inclusive junior and senior high schools	9. # of school with inclusive environment increases 10. # of inclusive school truly implementing inclusive environment increases 11. # of children in day care increases 12. # of children involved in learning group increases 13. # of current young children connected to jobs in the future increases 14. # of young children complete high schools in the future increases
Economy • Plant cendana and jati trees as children's saving, tree seeds provided by governments & NGOs • Special arrangements for children in national social security provider	Economy: • Tree saving programme has been done in East Sumba • Put advocating national health insurance (BPJS) for special policy as priority • Tree as saving might not appropriate to be applied in urban area • Poor family could provide nutritious food too to support children's development, especially intelligence • ECED posts have started saving programmes for children • Saving programmes should be continued to elementary school and			Economy 1. Introduce (through socialization) tree and decorative plant (in urban area) as children's saving in schools, other services community, etc. 2. Advocate social security provider for special arrangements 3. Advocates government (village's fund) to subsidize transportation for special schools' student and for visiting health facilities (money should be managed carefully) 4. Support fund for surgery 5. Improve implementation of Kartu Indonesia Sehat (KIS) 6. Empower mothers of children in ECED to	Economy 1. # of children with savings for future education increases 2. # of therapies given to children increases 3. # children from rural in special schools increases 4. # of children improved condition increases 5. # of children receiving services increases

Strategies	Assumptions	Risk & protective factors	Resources	Activities	Outcome
	higher stages of school too • Many parents tends to neglect their social security's premium • Transition between government programmes (Jamkesmas → BPJS) was not successfully socialized to poor parents • Medicinal plants programme unsuccessful in the past • Giving cash programme is often be misuse by parents • BPJS don't cover growth and development issues			make ikat weave group which profit is saved for education	6. # of children with education savings increases
Social • Awareness campaign by religious and cultural leaders to reduce stigma	Social: • Religion and cultural leaders prove vital in reducing stigma • God, faith and religion plays as important factors in parents' acceptance and development supporting behaviours • Consider data is very important and should be top priority • Data should be collected by villagers not statistics centre body • Education could help reduce people believing in harmful cultural customs • Sunday school is needed to help spiritual development • The mentor programmes are not fully supported by church (contradicting priest's statement) • Good programmes need to be adopted in church's agenda to be sustainable • Teenager mentor programmes successful in improving teenagers' confidence to teach and self-efficacy			Social 1. Advocate religious and cultural leaders (supported by parents and other stakeholders) to begin awareness campaign to reduce stigma 2. Providing assisting devices by social agency and village's fund 3. Improve accessibility to all public infrastructures 4. Improve data collection activities to improve overall services 5. Advocated the Church Synod to push church to insert disability-inclusive activities (like competition, spiritual learning group, deaconship fund, etc.) in their agenda 6. Providing care assistant for children to help them in school 7. Sunday school teachers picking up children to attend the school 8. Region law to protect children rights 9. Improve government takeover on NGO's initiated programmes when NGO has finished them 10. Special card to provide needed services for children/people with disabilities 11. Recruit more social workers	Social 1. # of foster children increases 2. # of children improved in daily activities increases 3. # of sub-districts with inclusive infrastructures increases 4. Social agency has a comprehensive and complete database 5. # of other religion institutions with inclusive activities increases 6. # of children helped in school and daily activities increases 7. # of children involved in Sunday school increases 8. # of child's rights violation decreases 9. # of children benefitted from the

Strategies	Assumptions	Risk & protective factors	Resources	Activities	Outcome
				12. Monitor law and implementation by improving punishment and reward system 13. Disability unit in related government agencies to improve collaboration 14. Best practice of inviting people with disabilities in church worship to open community eyes to people with disabilities 15. Best practice in church of specialized "ojek" (motorcycle taxi) that picks up persons with disabilities to go to church 16. Best practice of a child who survived blood cancer due to support from government and NGO programmes	programmes increases 10. # of children who benefitted from the card increases 11. # of social programmes well executed increases 12. # of law well executed increases 13. # of collaboration programme increases 14. # of people and children with disabilities attended church increases 15. # of children attended church increases 16. # of children in emergency helped increases
Empowerment • Establish and empower self-help groups for parents	Empowerment: • Inclusive village will help improve rehabilitation and awareness to children • Self-help parents group existed but needs improvement • Parent benefitted from meetings with other parents and in disability organisations • Socialization should be repeated over and over • Consider socialization and awareness increasing is the foundation and top priority in activities • Socialization should concentrate on family • Inclusive village had been planned by East Nusa Tenggara governor			Empowerment 1. Advocate inclusive village to people prosperity bureau 2. Establish and empower parents self help groups (trainings) 3. Inclusive integrated service post, ECED, elementary school, below five guidance, sunday school, and strengthen the collaboration (e.g. watch transition from ECED to elementary school) 4. Advocating government officials through newspaper 5. Pushing youth community to become advocator to increase community's awareness 6. Do socialization using media (television and radio, home visit) 7. Empowering DPO in doing socialization	Empowerment 1. # of inclusive sub-district increases 2. # of parents attended village policy making meetings increases 3. # of activities conducted together by provider of holistic-integrative young children services in sub-district level increases 4. # of disability programmes increases

Strategies	Assumptions	Risk & protective factors	Resources	Activities	Outcome
	supported by AIPJ (Australia Indonesia Partnership for Justice) • Consider inclusive village is not necessary, the more important one is people are included • Disability-care journalist forum had formed in East Nusa Tenggara and had become stagnant without any activities • Parents began to change their mindset that disability is caused by past sins because of support from disability workers • Parents had difficult in managing time to attend parent group meetings • Weak collaboration with below five guidance and Sunday school. Strong relation between ECED and community health centre and integrated service post			and other activities 8. Strengthen disability activist community 9. Recruit young bachelors in city to work in inclusive and integrated young children's services in rural areas 10. Fellow parents of children with disabilities who are successful in nurturing their children motivates other parents 11. Best practice of flash mob and dance with children in car free day 12. Best practice of parent groups could support internal political movements in villages 13. Best practice of regulation that regulates a minimum of five people with disabilities attend the village development plan meeting 14. Best practice of ECED manager successful in networking, involved in many young children's programmes from government	5. # of youth community committed in the issue increases 6. # of media committed in promoting awareness increases 7. # of programmes led by DPO increases 8. # of joint activities increases 9. # of services ran by young bachelors increases 10. # of parents persuaded to support their children increases 11. # of people who watched the activities increases 12. # of members participated/elected as leaders increases 13. # of persons with disabilities or parents who attended meetings regularly increases 14. # of successful integrated inclusive young children's services increases