

**MOTHER'S PERSPECTIVE ON SERVICE DELIVERY
FOR CHILDREN WITH AUTISM
IN A REGIONAL INDONESIAN CITY**

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ABSTRACT

The aim of this study is to investigate the experience of mothers of children with autism in Indonesia in raising the children and obtaining services for them. The present study seeks to contribute to the knowledge emerging from this study of user perspective on health and disability services area. There is silence in the Indonesian literature on this perspective, especially about the parents and/or mothers of children with autism that is the focus of this analysis. Therefore, in order to capture the points of view emerging from the mothers, a qualitative study design has been applied. The main data for this qualitative study was collected from interviews (semi-structured interviews and focus group discussion) with the mothers of children with autism who are member of parenting group in schools educating children with autism and rehabilitation centers in Barang¹, Indonesia.

The Indonesian government have formulated many policies in the areas of Education, Health and Social Affairs to assist and to help people with disability. Indonesia aims to empower them as community member as well as the citizens of Indonesia. However, the experiences of the mothers in this study suggest that the implementations of the policies are still not performing well, especially for the targeted population who are suffering with autism. This study reveals that the mothers' experience in raising a child who is diagnosed with autism is rooted in limited knowledge on autism, limited knowledge on availability of services and limited knowledge on service options. Compounding this is limited availability and accessibility of the services that are important to their child's development. An important contribution of this thesis is to show how tapping into the experience of mothers can provide much needed information to policy making and service planners and implementers that can improve the services for children with autism and their families.

Keywords: Mothers of Children with Autism, Autism, Services Delivery, Indonesia, Disability Policy, and Policy Implications.

¹ *Barang* is a pseudonym for the place where the research was conducted. Non-identification of the city where the research was conducted was required in order to obtain the consent of the participating organizations. It was intended to protect the identity of participants of the research including parents of children with autism and organizations.

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**THE THESIS IS LOVINGLY DEDICATED TO MY LATE PARENTS,
ALMARHUMAH IBU IIK AND ALMARHUM BAPAK RACHMAD BANGUN**

*They were my two lovely persons who had raised me to being an independent woman.
Using their intuition, they taught me how to do the right things.
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LIST OF ABBRIVIATIONS

- ABA – *Applied Behaviors Analysis*
- APBN – *Anggaran Pendapatan dan Belanja Negara*
- ASD – *Autistic Spectrum Disorder*
- ASKES – *Asuransi Kesehatan*
- ASKESKIN – *Asuransi Kesehatan bagi Masyarakat Miskin*
- BKIA – *Balai Kesehatan Ibu dan Anak*
- BOI – *Bantuan Operasional Institusi*
- BOS – *Bantuan Operasional Sekolah*
- BPS – *Biro Pusat Statistik*
- CSN – *Children with Special Needs*
- ECEC – *Early Childhood Education and Care*
- EETC - *Early Education and Training Centers*
- GAUN – *Gerakan Aksesibilitas Umum Nasional*
- GDP – *Gross Domestic Product*
- HDI – *Human Development Index*
- ICCC - *Integrated Child-Care Centers*
- JAMKESDA – *Jaminan Kesehatan Daerah*
- JAMKESMAS – *Jaminan Kesehatan Masyarakat*
- LD – *Learning Disabilities*
- MMR – *Measles Mumps Rubella*
- MONE – *The Ministry of National Education*
- MOSA – *The Ministry of Social Affairs*
- NGO – *Non-Government Organizations*
- OT – *Occupational Therapist*
- PAUD – *Pendidikan Anak Usia Dini*
- PKK – *Pembinaan Kesejahteraan Keluarga*
- Posyandu – *Pos Pelayanan Terpadu*
- PUSKESMAS – *Pusat Kesehatan Masyarakat*
- PWDs – *People With Disability*
- SCCC - *Special Child-Care Centers*
- SLB – *Sekolah Luar Biasa*

SMS – *Short Message Services*

SP2010 – *Sensus Penduduk tahun 2010*

SUSENAS – *Sensus Sosial dan Ekonomi Nasional*

TPQ – *Taman Pendidikan Al-Qur'an*

UN – *The United Nations*

UNCRPD – *United Nations Conventions on the Rights of Persons with Disabilities*

UNDP – *United Nations Development Programmers*

UNESCO – *The United Nations Educational, Scientific and Cultural Organization*

US – *The United States*

USAID – *United States Agency for International Development*

USCDC - *United States of Center for Disease Control*

WHO – *World Health Organizations*

YPAC – *Yayasan Pendidikan bagi Anak Cacat*

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Chapter One:

Introduction

1.1. Introduction

This study deals with mothers' view and experiences with autism and with services for their children with autism. It explores the mothers of children with autism's experience with the raising of their children and the delivery of services on autism in Indonesia. The views of mothers presented in this study are based on the narratives of their experiences once their child has been diagnosed with autism. It is also based on their experiences of interacting with their own child, both before the diagnosis of autism, and after it. Another element captured is their interactions with other family members about their child and the diagnosis, and with members of their community. The final element captured is their interactions with service providers about the delivery of services for their children with autism. Therefore, the aim of this study is to provide one side of a much larger dialogue occurring in Indonesia to improve the lives of people with disabilities. The research question considered in this thesis is "how do mothers of children with autism perceive the phenomenon of autism and how do they experience autism services in a regional Indonesian city"?

1.2. The Context of Research

What is autism, and what does it mean? When traced in history, the word autism comes from the Greek word 'Autos' meaning self (Sharpe & Baker 2007). There are two famous people who deal early with autism publicly, Kanner and Asperger. In 1943, Kanner was the first person to explain and give the name for a pattern of behavior he observed in a small group of young children, that he later termed autism.

He wrote the description of young children who were “socially aloof and indifferent, were intensely opposed to change in their own repetitive routines” (Cited in Wing 1997). Kanner considered his pattern of autism to be unique and different from the other disorder in childhood (Wing 1997). Autism has been puzzling researchers since and has prompted considerable research (Wolff 2004). The research outlined in this thesis can contribute to a better understanding of impacts of this disorder, as well as contributing to the creation on of the better care and treatment for people with the autism in developing countries.

The National Research Council in United States (2001) stated that autism affects children throughout the world and of every racial, ethnic and socioeconomic background. Autism can be found in every country and region of the world. Autism is a lifelong developmental disability resulting from abnormal brain function. Autism is a childhood behavioural syndrome defined by the presence of marked social deficits, specific language impairment, stereotyped repetitive behaviours and a characteristic course (Rutter and Schopler 1988, cited in Shu 2009). Children with autism have difficulties with interaction and communication with others as well as severe deficits in reciprocal social interactions and imagination (Bilgin & Kucuk 2010), usually evident before the age of 3, which adversely affects a child’s educational performance (Lal 2005).

It is widely acknowledged that the number of children identified with Autistic Spectrum Disorder (ASDs) is increasing (Dymon & Gilson 2007). This can create problems, particularly in the provision of services. For example, The Centres for Disease Control in United States estimated that one in 150 children in the US have an

autism spectrum disorder (Bryson et al. 2008). The estimated prevalence of autism ranges from two to six per 1,000 children in western society; In Turkey, the prevalence of children with autistic disorder is approximately 12/1,000 (Bilgin & Kucuk 2010). Autism has been described as a major health problem, which imposes great costs on the individual, family and community (Gordon et al. 1993). Even though there is little information about the cost of health and social services for children with autism, the cost of those services tends to be quite high when compared with other children with disability. For example, one study discovered that the average lifetime cost of supporting a person with autism in United Kingdom was £ 2.94 million, with the cost for a person with high functioning autism being £ 875,000 (Bebbington & Beecham 2007). Consequently, the issue of the increasing number of children with autism combined with the high cost of treatments and the need for expanded availability of services for children with autism is attracting the public's attention and has made it onto the public agenda in some countries. There is considerable literature concerned on with this issue, particularly in the developed countries. However, there is still only limited documentation capturing the realities of autism in developing countries, including Indonesia.

There is some literature that goes beyond individual accounts of the parents of children with autism struggling with raising their children with autism. The parents of children with autism encounter barriers regarding the provision of services such as medical treatment and education facilities (Bromley et al. 2004, Bryson et al. 2008, Dymon & Gilson 2007, Hare et al. 2004). For children with disabilities, those services are critical ingredients in promoting successful child development and life chances in adulthood. Parents are trying to figure out the most appropriate services for their

children, and sometimes find it hard to access them due to the financial hardship. Parents are often forced to rely on their own resources for the provision of service for their affected children. As a result of this situation, this sometimes creates delays in treatment. A literature review for this thesis found that the financial impact of autism on families is one of the problems in terms of raising a child with autism. Jarbink et al (2003, cited in Sharpe & Baker 2007) established that the parents in their study had weekly out-of-pocket cost equivalent to US\$120 that was related to the education and treatments services of the affected child with autism in United States. They needed treatment and therapy as well as a special schooling for their children.

The increasing number of children with autism diagnosed means that these issues are very real, not just for the parents, but also for the community. Autism has a pervasive impact on each family member. Research has shown that there is a higher level of stress among the parents, particularly mothers (Benson 2006, Gupta 2007). According to Bilgin & Kucuk (2010), parents of children with autism tend to report a greater family burden, and are at a greater risk of experiencing physical and psychological stress than parents without children with autism.

Parenting a child with a disability may require more complex and more intensive care giving than parenting a child without special needs (Leiter et al. 2004); parenting children with special needs is also associated with increased time needed for parental and/or maternal care giving (Harris & McHalle 1989). Additionally, caring for children with special needs often requires specialized knowledge and collaboration activities between parents and professionals of health and education services (Hill &

Zimmerman 1995). As a result, parenting (and particularly mothering) a child with special needs can be seriously challenging.

Mothers of children with disability (including children with autism) are greatly affected by the problems and challenges both at home and in their community (Bilgin & Kucuk 2010, Bromley et al. 2004, Hare et al. 2004). Children with autism physically look like any other normal child. This is causing many parents and mothers to initially have difficulties accepting their child's disability even after knowing the health condition officially. They feel that their child is not a child with disability because they do not see the impairment marking their child's body. However, a child with autism has been categorized as a child with disability. This is a disability caused by brain damage creating a disorder in young child in terms of how they behave and communicate.

Raising a child with a disability can be a source of stress for parents, particularly for mothers (Hodapp et al. 2003, Sharpley 1997). Johnston et al (2003) found that the degree of stress is higher among mothers than fathers due to the comparative closeness of a child to its mother. Some researchers have found that mothers of children with Autistic Spectrum Disorder are more likely to experience serious psychological distress than are parents (or mothers) of children with other developmental disabilities (Abbeduto et al. 2004, White & Hasting 2004, Weiss 2002, Pisula 2007). Sources of stress include learning to cope with the unexpected event of having child with disability, the varying physical and psychological demands of childcare, and the lifelong dependency. In summary, it appears that the level of hardship either emotional or financial is very high compared to parents of non-

children with disability. The literature of hardship in parenting a child with autism has demonstrated that the parenting burden falls more heavily on mothers than fathers (Moes et al. 1992, Kingston 2007, Gill & Harris 1991, Lamb & Tamis-Lemonda 2004) and mothers might suffer the emotional consequences of that burden (Gray 1993, 2002).

In some developing countries including most areas of Indonesia, there is a culture of family functioning shaping the relationship between mother and father in the household where the father is the primary breadwinner and the mother is responsible for the children. In terms of having a child with disability, the mother is given the most important role to look after the child with disability while father is responsible for earning money to support the care of the child financially. Therefore, mother is often the main caretaker of the child with disability in family, whereas fathers tend to assume financial responsibilities.

In terms of the prevalence of autism in Indonesia, the number of children with autism in Indonesia has not been estimated until recently. According to a USAID funded census study of Indonesia conducted by the US Bureau Census in 2005 (cited in Sari 2006), the numbers of children with autism in Indonesia is approximately 475,000 children. The *Yayasan Autisma Indonesia* (2007) estimates that there are 140 organizations, clinics and therapy centres which handle the children with autism in Indonesia. However, the services for people with autism provided by either Indonesian government or by non-government organizations are insufficient to adequately serve the needs of the population. There is no specific provision for children with autism such as special schools or therapy centres for children with

autism provided by the Indonesian government (Budiman 2009). Without public provision, parents of children with autism are forced to rely on themselves or private services. The Indonesian popular news magazine, Tempo (Aziz 2010) stated that some families are tying their autistic child with a chain in their legs² or laying their child in a locked room because they do not know how to deal with autism. This is happening in families who live in the rural and remote area who also experience financial hardship.

According to Mudjito (the Director for special Education at The Ministry of National Education), Indonesia lacks facilities for children with special needs (Jakarta Post 2013). For children with autism, the education sector needs to foster acquisition of academic skill, adaptive skill, language and communication, and reduction of problem behaviour (Lal 2005). The government of Indonesia has some policies and regulations targeting children with disability. However, there is still a huge lack of facilities to implement the policies.

1.3. Statement of Problem

Indonesia is the largest archipelago in the world and inhabited by a population of 235 million. From the total population there are about 1.48 millions people who are categorized as disabled persons. According to Act of the Republic of Indonesia No. 4 of 1997, the definition of persons with disabilities is:

Disabled person is someone who has physical and/or mental abnormality, which could disturb or be seen as obstacle and constraint in performing normal activities, and consists of i) physically disabled, ii) mentally disabled, iii) physically and mentally disabled.

² Pemasungan.

Disability classification and definitions are according to national standards that were developed by the Ministry of Social Affairs. In Indonesia, people with disabilities are an integral part of society, and they have the same rights and obligations as other Indonesian. There are programs to promote the welfare and total integration of people with disabilities is implemented both by the government and by non-governmental organizations (NGOs). The welfare development program covers areas such as prevention, rehabilitation, social assistance and care. In fact however, there are still many who have not been able to get the most out of these rights, particularly in getting services in the area of health and education. A barrier to obtain access to the system occurs due to there being a lack of services aiming to assist people with disability.

Currently, there are 12 separate statutes that can be used as the basis to advance the welfare of people with disabilities in Indonesia. All governmental agencies and institutions are required to formulate policies, strategies and programs to improve and promote the welfare of persons with disability. Legislative acts such as the following support the human rights and dignity of Indonesian citizen with disabilities:

1. Government Regulation Number 72 of 1997 focused on special education for person with disability including disabled school pupils.
2. Presidential Decree number 83 of 1999 created an agency to coordinate and to control social welfare for people with a disability.

Such policies will be further discussed in Chapter 4.

Every society has people who are vulnerable because of disability. Persons with disabilities are probably the most marginalized group in society (Howell 2001). The Indonesian government has committed to assist the people with disabilities through assistance schemes. These schemes comprise programs that include all forms of public action, government and non-government. In terms of disability programs, the Indonesian government has focused mainly on three different areas, namely education, health and social services.

The Indonesian government has targeted early detection, early intervention and education programs, especially for children and youth with disabilities aiming by 2015 for all boys and girls to complete a full course of primary schooling. By 2010, target is at least 75% of children and youth with disabilities to complete a full course of primary schooling.

Indonesia has many policies for children with disabilities in the areas of health, education and social services; however, there is poor implementation of policies, particularly at the regional and district level. As a result, Indonesia is facing many problems in the provision of services for children with autism and/or children with disability in general. The problems range from a lack of facilities for supporting children with disability and children with autism in particular to a limitation of the availability of skilled personnel able to provide services for children with autism.

1.4. Research Aim and Objectives

The aim of this study is to investigate the experience of mothers of children with autism in a regional Indonesian city in raising their children and obtaining services for them. In order to do so, a numbers of factors will be considered, including:

1. Identifying government policies supporting the delivery of services to children with autism in Indonesia.
2. Identifying the actuality of services available for children with autism.
3. Analyzing the role of government and the non-government organizations in service delivery for children with autism.
4. Identifying the perspectives of mothers of children with autism on the provision of supporting services for children with autism in Indonesia.
5. Identifying the needs and perspective of mothers of children with autism on their support needs.
6. Analyzing the impacts of service delivery for mothers with children with autism.

This study focuses on the individuals who are the mothers of children with autism, their experience with raising their children, their perceptions of their needs at various times and how services could be improved to better meet those needs. Most of the mothers in this study are members of a parenting group at schools for children with autism and rehabilitation centre in a regional town in the east of Java Island, Indonesia.

1.5. Research Question

The research question for this study: “How do mothers of children with autism perceive the phenomenon of autism and how do they experience services for children with autism in a regional Indonesian city?” There are some sub research question including:

1. How do participants understand autism?
2. How do participants think about support needs for children with autism?
3. What do participants think the existing of service delivery for children with autism?
4. What are participants’ perspectives on the role of government and non-government organizations in the delivery of services for children with autism?
5. What do participants think as mothers of children with autism about the impact of service delivery for them?

1.6. Significance of the Study

This study is expected to provide information that might be used to help policy makers and implementers in the area of health and education as well as human services. It also can assist service providers to improve the services for children with disability including children with autism.

The context of this study can improve the understanding in Indonesia of the phenomenon of autism from the viewpoints of mothers who have children diagnosed with autism. As well, it can improve the understanding of how parents deal with problems that arise both before and after diagnoses particularly helping services

provide training for their staff. In this way, the present study seeks to contribute to the international knowledge emerging on this area. At present, the research literature is silent on this aspect of the Indonesian experience of parents – particularly mothers – of children with autism; here, they are the focus of the analysis. So this study will reduce an important gap by providing their perspective.

1.7. Locating the Researcher

This study is shaped by personal experience that observed some mothers who have a child with autism in my neighbourhood as well as amongst my relatives. From this personal observation of the daily lives of the mothers I was familiar with in their daily lives, I know how difficult it is for them to raise their children with autism, and how difficult it is for them when dealing with the system of services for their children. Even when services do exist, they as mother still struggle to find out about and get access to services as they struggle for the good of their children. I was determined to understand their lives and the difficulties they face and overcome in the raising of their special child.

In addition, as stated above there being increased numbers of children with autism over recent years, it crossed in my mind to investigate the situation in Indonesia. With the number of children with autism in Indonesia in year 2006 approaching to 475,000 (Sari 2006)³, the questions of what is the role of state and the community in helping

³ No official recent reports stating the numbers of children with autism exist. An estimate can be based, instead on Wignyo Sumarto et al. (1992) who reported the prevalence of children with autism in Indonesia was 12 per 10,000. There are two newspapers (Melissa 2009, Sutriyanto 2013) that reported the numbers of children with autism in Indonesia currently as approximately 112,000 children. However, Sari (2006) stated that the numbers of children with autism was 475,000. There are disparate information sources, but there is still no clear picture of the exact number of affected children currently in Indonesia. I have contacted the Office of Social Services and the *YPAC* (a non-for-profit organization) both institutions at Kota Barang

families who have children with autism arises. The increasing prevalence of autism, my personal observations of mothers of children with autism and the difficulties they faced, and recent public interest in Indonesia to address the democratic rights of its disabled citizens encouraged me as the researcher to conduct this study and to bring personal observation into academic work by contributing to the efforts of providing information from the points of view of mothers of children with autism through this thesis.

1.8. Contribution of the Knowledge

The current study contributes to the literature in some of the following ways:

1. This study makes a conceptual contribution to the development of an evaluative framework to examine service delivery for children with disabilities in general and particularly for children with autism through the points of view of mother of children with autism. If, in fact, services are being provided, the parents as consumers of services have an ability to contribute to the evaluation of services. This study fills a research gap in the literature review regarding how the government and community agencies can include the views of service consumers in designing and monitoring the services for children with disabilities including children with autism. This research aims to enrich the knowledge on the adequacy of the service delivery system for children with autism in Indonesia, improving the directions for national policy implementation at regional level and informing policy planning for children with autism as targeted populations at the district level. This thesis is not an evaluation of services, however it has implications for Indonesia but also for other developing countries by encouraging

concerning to provide services for children with disabilities but have not been able find any updated figures regarding the numbers of children with autism in Indonesia.

research providing mothers' perspectives on current services and mothers' perspective on their needs and their views on service improvement and using this knowledge to plan and improve services.

2. From the standpoints of mothers of children with autism, the research may provide a point of reference for the experience of other mothers. This also can lead to improved services through the contribution of individual mothers of children with disabilities who have personal experience of the services. The standpoints of mothers can provide information that will help both government and community service providers improve their efforts to help children with a disability, and their caregivers. This is a qualitative research study that sought in depth information from a small group of mothers in a regional Indonesian city. The experience of these mothers is not representative of all mothers of children with autism in Indonesia. It is hoped that this study will prompt further research with mothers in different circumstances, such as those in rural or more remote areas, but that this research will demonstrate the value and contribution that can be made to policy development and services quality by involving mothers in their design and monitoring.
3. There is another point regarding the choosing of Indonesia as a location of the study. Since the study was conducted in Indonesia, it contributes to new knowledge useful to Indonesia. Indonesia like other developing countries is showing an increased recognition of the number of children with intellectual disabilities, however there is still lack of adequacy of services to meet their basic needs or to be clear about the extent and rate of various disabilities across the

population. Therefore, the purpose of this study is also to recognize the existence of services for children with disability particularly children with autism in Indonesia and to explore any gaps in services. This study can contribute new knowledge to improve the services and the quality of life for children with disabilities in Indonesia. The new knowledge will, it is hoped, help policy makers in Indonesia to design appropriate services that can meet the affected children's needs and the needs of their families. This is also a very interesting time to contribute knowledge to Indonesia's policy-making concerning disability. Indonesia has embarked on a journey of democratization since the end of the Suharto regime in 1998 and this has embraced the extension of human rights to all of its citizens, with an emphasis in the past decade or so on the rights of the disabled.

4. This study recognizes the involvement of the service users who are mothers of children with autism. It is hoped that the thesis can thereby encourage mothers of children with disabilities to create themselves as active members of civil society, to form and join be an active civil society groups to contribute to designing future disability policy in Indonesia and engage in monitoring and working to improve the quality of services. The voice of Indonesian mothers of children with autism in this study has proven that they can contribute and have a valuable voice that needs to hear alongside experts. This study has contributed new knowledge on Indonesia and autism to the academic literature, and makes a contribution in terms of both the process of design and the content of reform for future services and policies in the disability area.

1.9. The Structure of the Thesis

This study contains eight chapters starting with Chapter 1, which has presented an introduction to the study concerning the phenomenon of autism and its services from the points of view of Indonesian mothers of children with autism. It covers the background of this study as well as the research aims and question. It continues to discuss the locating of researcher on this study and ends with the structure of the thesis.

The structure of the thesis builds the foundation of this study from the review of literature in Chapter 2. The first section of this chapter demonstrate that parenting and/or mothering of children with disabilities such as children with autism is more stressful and more difficult than parenting other children due to the typically lifelong disability conferred by autism, the stigma of autism and the high cost of acquiring services for the child with autism. The second point outlines the literature on autism service systems including their barriers in terms of delivery of services for the child with autism. The literature review moves from international studies to studies of the situation in Indonesia. The last section of Chapter 2 explains the position of the present study in relation to the existing literature.

Chapter 3 explains the methodological approach used in this study. In adopting a qualitative study as this study used there is a pivotal approach that Creswell (1998) states involves the researcher building a complex, holistic picture; analyzing the words and reports and detailed views of participants. In the field of disability research, qualitative methodologies have become known as important tools in understanding the complexity of disability in the social context (Benderix et al. 2006,

Bumiller 2008). This qualitative study can help readers to understand better the life of the people with disability – and those who support them - through understanding the complexity of their every day lives experiences in their own voice. The process of interviews with selected mothers who have a child with autism can gather data on perceptions and life experiences of people with disability. Therefore, this chapter also contains the justification of the research methods used including document analysis, semi-structured interview and focus group discussion.

Chapter 4 details the policy and the implementation of policy on disabilities in Indonesia. The result of document analysis process is presented in this chapter. The information analyzed was obtained from the document analysis process using multiple sources including non-government organizations annual reports, government regulations on disability as well as articles from journals.

Chapter 5 demonstrates the life journey of mothers raising and caring for children with autism. The journey mothers experienced is traced from the beginning of their understanding on the initial conditions of their children and extended to their recent situation. This is a journey that includes mothers' struggles with caring for their children and a journey that brings them into a network of health and educational specialists that can provide support but also presents its own challenges.

Chapter 6 portrays the experiences of mothers of child with autism as they interact with service providers and other people when they seek help for their children. This portrait starts from how they seek information on the Internet and from other sources to gain better understanding of the meaning of autism, and continues to follow the

mothers as they interact and communicate with General Practitioners, Paediatricians, Therapists, school principals and teachers. This chapter will be grouped into a number of sections: understanding of autism, interacting with medical professionals, and delivering of services for children with autism including affordability of services, type of services, partnering with services, schooling and funding of services.

Chapter 7 presents an analysis and discussion of the key findings of this study. These key policy analysis findings highlight some areas of possible policy action including addressing parents' needs for information including by designing an official website to help parents, changing cultural understanding of disability, and possible ways to enhance education services and therapeutic treatments. This chapter applies the insights presented in chapters 5 and 6 to see how to improve Indonesia's policy implementation for children with disability specifically in the area of autism. This chapter continues to draw on analysis of the empirical data collected from the interviews with mothers of children with autism and combines this with the policy document analysis.

Chapter Two:

Literature Review

2.1. Introduction

This chapter provides a review of the literature pertinent to the context of this study. The review is divided into three sections. The first section provides contextual information on the mothering of special children and children with autism. The experience of mothering children with a disability, and how they struggle to raise their children is the focus of this section, as well as the impacts of this on the mother. The second section explains autism and services for children with autism. Here, the history of the concept of autism, and the understanding of autism is reviewed and the debate over the causes of autism, along with research on intervention services for children with autism and other disabilities. The last section of this chapter reviews the studies of mothers' perspectives on autism and services for children with autism more generally and then in Indonesia. The discussion in the last section develops the framework of this study. The chapter concludes by arguing that mothering of children with autism is difficult and attention should be paid to the role of mothering and the services for children with autism, which still do not accommodate the needs of affected children.

2.2. Mothering of Special Children.

The first section presents a literature review on mothering of special children including children with autism. The aim of this section is to contextualize the research inquiry. The issue of mothering a child with special needs has been a central focus of the literature for the last few years and has received considerable attention in the

literature on the experience of parenting children with disabilities. Most of the research is focused on how the research subjects as mothers struggle to raise a child with a disability. There is some research focused on autism, and some research that emphasizes the negative impact of the experience on caregivers' emotional lives and maternal employment patterns. Research involving parents and families of children with disabilities is becoming more important for people who are concerned with child and family welfare. The study of mothering of special children has become a major focus of public attention and research. However, there is still a lack of research focusing on mothers who have children with autism, particularly in the context of Indonesia. Therefore, this section aims to explore literature on parenting and/or mothering a child with autism.

2.2.1. The Experiences of Mothering of Children with Disabilities

Parental involvement has been identified as of key importance for building strong and effective development of children with disabilities in their daily routines. Parents and other family members experience disability profoundly and intimately; the lives of family members are altered or affected for better or worse by living with a child with a disability. The most affected by the experience of having a disabled child in their family are the parents of the child. Parenting a child with special needs may involve unusual caregiving requirements that differ from normal caregiving due to the complexity and the intensity of the needed care (Leiter et al. 2004), and children with special needs are associated with increased time needed for maternal caregiving (Harris & McHalle 1989). In addition, caring for children with special needs often requires specialized knowledge and collaboration activities between parents and professionals from both health and education (Hill & Zimmerman 1995). As a result,

parenting (or mothering) of special needs children is a serious challenge, to develop the lives of children with disabilities.

Raising a child with a disability can be a source of stress for parents (Hodapp et al. 2003, Sharpley 1997). The degree of stress is higher among mothers, due to the closeness of a child to the mother (Johnston et al. 2003). A child has a major level of closeness physically and emotionally while the child is still in the womb, and this contributes to closeness with the mother as he or she grows up. There are some stressful factors associated with parenting a child with autism, including concern over the permanency of the condition, poor acceptance of autistic behavior by society and often by other family members, and the very low levels of social support received by parents (Sharpley et al. 1997) and, as Gray (2002) adds, the stigmatization of autism is another burden. Sanders and Morgan (1997), among others, reported higher levels of stress in mothers of children with autism when compared with other developmental disabilities. Some sources of stress include learning to cope with the unexpected event of having a child with a disability, the varying physical and psychological demands of childcare, and the lifelong dependency (Abbeduto et al. 2004, White & Hasting 2004, Weiss 2002, Pisula 2007). A majority of mothers feel distress and this is associated with low levels of family support and with bringing up a child with higher levels of challenging behavior. The level of hardship, either emotional or financial, is very high compared to parents of non-children with disabilities. Several studies show that parents experienced psychological distresses, which were affected by levels of social support (Dunn et al. 2001, Gill and Harris 1991). Parenting a child with a disability can produce great stress and a sense of imbalance in the family (Burrell et al. 1994). So it is important that parents have a means to cope with such a stress, and one factor

that has been shown to alleviate parental stress is social support (Bristol 1984, Dyson 1997). However, the ability of social support to serve as stress mediator has been found to relate to the parents' gender. Krauss (1993) found that social support contributed to lower maternal stress among mothers of children with disabilities. Such findings may reflect the fact that typically the majority of caregiver demands are placed on mothers of children with disabilities. As a group, mothers of children with autism appear to be most adversely affected by the stress-related factors that result from rearing a child with a disability but also to be more likely than fathers to access social support. Several studies have demonstrated that the parenting burden falls more heavily on mothers than fathers (Moes et al. 1992), and mothers may suffer the emotional consequences of that burden (Gray 1993, 2002). Parents also have an emotional burden if they get involved with the broader community or lay people with no knowledge of disabilities or autism. Gray (1995, 2002) adds that many parents have said that lay people view children with autism as unintelligent, undisciplined and rude. Gray (1993) has also stated that some parents felt that they are stigmatized by their child's autism because of the lack of knowledge lay people have about autism.

Bromley (2004) shows that families have a range of needs relating to caring for their children with autism and that high levels of psychological distress were particularly associated with low levels of support from within their family, and with bringing up children with higher levels of challenging behavior. This study also found that, for families of children with intellectual disabilities, the association between child behavior problems and maternal distress might be moderated by the family's social and economic situation (Emerson 2003). This still needs to be investigated further in the case of families of children with autism spectrum disorder. Mothers who

experience distress in bringing up their children are more likely to be associated with low levels of informal support within the family.

Stigma is a difficult aspect of public encounters experienced by families with a disabled member. The reaction from the public is often negative for them. Gray (1993) added that most parents perceived themselves to be stigmatized by their child's disorder. He said that there was a strong tendency for mothers to feel more stigmatized than fathers in the case of autism. In addition, parents of a child with a disability must raise their child within the context of a powerful discourse that devalues adults with disabilities and holds low expectations for the success of parenting children with disabilities (Green 2007). It can be understood how a difficult raising child with a disability is, especially with the emergence of a heavy load associated with the emotional and financial burden.

The literature on diagnosing children with a disability and/or autism discusses the need for ongoing post-diagnostic support and counseling for mothers. Goin-Kochel et al. (2006) have reported that the process of diagnosis is part of the source of stress among parents of a child with a disability, including how they deal with obtaining a diagnosis and treatment for their children. Any form of chronic illness or disruptive antisocial behavior (autism) embodies a serious challenge, not only to the affected individual, but also to their family members. The challenges range from the process of finding out how to get an accurate diagnosis to accessing appropriate forms of treatment. The provision of special services for autism, particular in developing countries, is limited (Gray 1993). Although the situation has improved in the case of autism in recent years, the public has little knowledge of autism. As a result, the parents of children with

autism frequently encounter hostile or insensitive reactions from the public when their children behave inappropriately. However, the literature also states that diagnosis has sometimes been seen to serve the interests of parents (Avdi et al. 2000). The diagnosis of autism or any other disability means for parents that their children's condition is recognized as a medical problem.

From the perspective of this research and some of the literature, there is one single question often raised and that is, "why mothers?" If the research focuses on mothers and excludes fathers, this is not done in order to undermine the role the fathers play in families with special needs children (Kingston 2007). The reason is that it is the mothers who are given the primary responsibility for caring for their child, particular for the daily management of the child. Seltzer (cited at Bromley et al. 2004) stated that the vast majority of carers of children with autism are their mothers. Given this, mothers are more likely to present more extensive accounts of their child's autism. Parents and/or families are often described as needing to accept the disability of their children. They sometimes go through a process of adjustment to the reality of the condition of their children who have impairments either physical or mental. It seems that it is easier for mothers rather than fathers to accept their children. The majority of studies about autism focuses on the mother-child relationship and typically do not include an analysis of the father (Gill & Harris 1991, Gray 2002). Gray (2003) conducted a study that looked deeper into gender roles and found that mothers have a major role in terms of caregiver requirements and spend more time with the child (e.g. doctor's appointments; social activities), mothers therefore have to deal with the day-to-day behavioral issues on more frequent and intensive basis. Moreover, mothers are more likely to be held responsible for the behavior of their children.

The experience and behavior of fathers in families with a child with autism are of interest but have not been assessed consistently. An assessment of fathers is important for understanding family functioning (Lamb and Tamis-Lemonda 2004) and could be the focus of a future Indonesian study. The functions of a family are traditionally divided into gender roles, as fathers earn money for supporting family life and mothers are commonly the most important individual in the early life of the child and look after the household. In Indonesia, there is still the presence of a clear division of gender roles in the household, between husband and wife, particularly in the Javanese middle class household. There is an understanding of the role of a father, revealing that they are embodied as the breadwinner for the family. One of their roles is to give most of their monthly⁴ income to the wife to be managed. They will feel successful running their roles and duties as breadwinners if they are able to meet the financial needs of the family (Wike 2000).

2.2.2. Mothers Struggle to Raise Children with Autism

Mothering children with disabilities can present multiple challenges and stressors; therefore, mothers are perceived as having more need for social support from family and friends. Dunst, Trivette and Cross (1986) defined social support as a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resources and information sharing, and emotional and psychological support. Social support may also refer to formal services one receives from professional-based organizations, and/or services from more loosely structured organizations (social clubs, religious organizations). In terms of social support, it is focused on helping the parents to raise their child, such as by reducing

⁴ Salary is a form of periodic payment from an employer to the employee stated in an employment contract. In Indonesia, the salary is calculated for a fixed month.

parents/maternal stress and practically assisting them to cope with the problems of raising a disabled child. Kazak and Marvin (1985) and Kazak and Wilcox (1984) stress the importance of examining the social support network, the degree of isolation, and the adequacy of informal and formal support services. Honig and Winger (1997) found that professional support services made a measureable difference in maternal perceptions of stress. Support services can help parents of children with disability to raise their special needs children.

Previous research suggests that moderate levels of family cohesion and adaptability are associated with higher levels of positive coping, and that the more coping strategies a family implements, the greater their satisfaction with family functioning. A child with autism presents unique challenges and stressors for the family because of the ambiguity of diagnosis, the severity and duration of the disorder, and problems with the child's lack of adherence to social norms (Bristol 1984). A family with a child with autism must make significant adjustments to cope and function adequately. The family system is an important part of the environment and plays a central role in the developmental outcome of children (Sameroff 1990). Most studies of families with a child with autism have traditionally examined this interaction by focusing on the effects parents have on the child, not vice versa (Kanner 1943). More recently, research has focused on the difficulties that parents face related to caring for a child with autism, and the strategies employed to cope with the stress associated with raising these children (Gray 1994, Schall 2000). Although families typically establish functional styles early, it is likely that these rules change significantly upon discovery that their child has autism.

Sometimes, the family functioning style is adaptive, with the capacity to adopt new rules, or sometime they are resistant to change. Most parents feel that their experiences are uniquely and inherently different from those of their family and friends (Marsh 1993), and this is reflected in a sense of isolation (Seligman & Darling 1997). Parents of children with disabilities may experience fatigue, depression, lowered self-esteem, and interpersonal dissatisfaction (Bristol 1984, Dyson & Fewell 1986, Sobotor 1989). Mothers of children with disabilities also experience increased moodiness, are prone to illness (Holroyd 1974), are acutely affected by the degree to which their child is accepted or rejected by the community (Bristol 1984, Holroyd 1974), and report considerable family disharmony. More specifically, mothers describe themselves as unable to pursue personal goals and as having little free time (Holroyd 1974).

Additionally, in terms of the role of extended relatives in the family of children with autism, Seligman and Darling (1997) found that extended family; particular grandparents play a central role in the family's adaptation and can be a source of practical help and emotional support. Emotional support or emotional empathy and understanding can be provided through intimate relationships. Bristol's (1984) study of a group of 40 mothers of children with autism reported that the highest stressed group and the lowest stressed group differed with reference to support networks and availability of services. The lowest stressed mothers reported greater perceived support from partner, family, friends and other parents of children with disability.

In terms of obtaining the appropriate diagnosis of autism, there are some studies, which focus on this. These studies can range from the hardship of getting a diagnosis

to the acceptance of diagnosis among parents of children with autism and children with disability in general. The difficulties of obtaining a diagnosis are common (Birenbaum & Cohen 1993, Howlin & Moore 1997), causing uncertainty for parents and delaying appropriate early interventions or educational programs. Having a child with autism can severely disrupt family life. Parents may experience emotional stress, anxiety, fear and guilt (Gray 1994). They may have to rearrange their way of life to accommodate their child. Due to the complexity of autism, the process of obtaining an accurate diagnosis and treatment is often a long process and results in frustration for the parents. Moes (1996) stated that the stress includes issues such as the disorder's cause and prognosis often remaining unclear. Thus parenting a child with a developmental disability is more stressful compared with some other disability types. The nature of the child's disability affects family stress. Thus mothers of children with autism experience more stress than mothers of children with other disabilities. Instrumental strategies and coping strategies such as parent training and information programs focus on implementing change directly in the person and their environment (Bristol & Schopler 1983, Harris 1984). Coping strategies refer to conscious cognitive and behavioral efforts to alleviate distress associated with, and emanating from, an event (Cohen & Lazarus 1979, Lazarus & Folkman 1984). For parents of children with disability, including children with autism, learning coping strategies is important both to understand the problems coming up in the child and the impacts of the family's responses.

2.3. Services for Children with Autism

This section presents a review of literature about autism and service delivery for children with autism. The aim of this chapter is to contextualize the research inquiry.

In terms of autism, this literature review offers a brief of history of autism, what autism is and autism in some countries, including Indonesia.

2.3.1. Autism: History, Concept and its Cause

The term ‘autism’ comes from the Greek word ‘Autos’ meaning self (Sharpe & Baker 2007). Historical records suggest that autism has existed throughout history. Any treatment of the topic of childhood autism must start with the pioneers Leo Kanner and Hans Asperger who independently of each other published accounts of this disorder. In 1943, American psychiatrist Leo Kanner, who was working in Baltimore, was the first person to explain and give a name for a pattern of behavior he observed in a small group of young children; later he termed it autism (Wing 1997). He wrote a description of young children who were socially aloof and indifferent and were intensely opposing change in their own repetitive routines. He called this “early infantile autism”. Kanner considered his pattern of autism to be unique and different from the other disorders of childhood. Hans Asperger was studying a group of children in Vienna, Austria, at around the same time that Kanner was conducting his research in the United States. However, there is a slight difference between Kanner’s and Asperger’s studies. The children in Asperger’s study had better language skills, and they could tell about their experiences and inner feelings, whereas those with classical autism cannot. Because Asperger’s work was not published in English, his contribution was not widely recognized until 1981, when psychiatrist Wing adopted the term Asperger’s syndrome.

Historically, the existence of autism can be traced back long before Kanner and Asperger found the pattern of autism among young children. Autism, as it is

recognized today, was identified as a disorder in the middle of the 20th century, but evidence has suggested that there have always been people with autism. Some versions have described it, for instance, as a child who was left in place of a real human baby who had been stolen by fairies. Kanner (1964, cited in Wing 1997) quoted Martin Luther's report about a child whose behavior was similar to his children with autism. Luther described the child as possessed by the Devil, and as having no soul (Wing 1997). Wing also describes figures in legends, such as Brother Juniper, who was known for his innocence and naivety but who would be diagnosed with autism today. Evidence of the disorder pattern that is now known as autism disorder, preceding Kanner and Asperger, is in John Haslam's book. He published his book 'Observations on Madness and Melancholy' in 1809 (Wolff 2004). The book explained about cases of insane children, and he described a boy of 7 years old who was slow to walk and very late to talk, but curious (or not curious) about his environment. So Haslam was the first person to publish a book recording some detailed cases of children who may have had autism syndrome.

The causes of autism among young children are still disputed among some scholars in this field. Many parents of children with autism and lay people believe autism to be caused by brain abnormalities (Huws & Jones 2010). Although autism is the result of a neurologic abnormality, the cause of the problem within the nervous system was unknown until recently. Most likely, genetics, environmental and immunological factors influence the development of the autism disorder. Environmental factors and exposures may interact with genetic factors to cause an increased risk of autism in some families. It has been found that first-degree relatives of children with autism have an increased risk of autism spectrum disorders. There are a number of different

genes that, when combined together, increase the risk of autism. In families with one child with autism, the risk of having another child with autism is 3% to 8% (O'Reilly & Wicks 2008). It can be said that a family with one child with autism has a greater chance of having another child with autism. Mercer et al. (2006) found that most parents believed that autism was caused by a variety of factors. The most frequently cited was a genetic cause and this belief affected the parents' decision about having additional children. As a result, parents frequently question the role of genes in autism if a child is diagnosed with autism, and they look at themselves and their partner. Parents blame themselves or their partner, and in Gray's (1995) study it was found that parents expressed a sense of guilt for possibly having passed on genes that caused their child's disability.

A poor quality environment is also blamed as a cause of autism. Many people worry whether exposure to environmental pollutants such as heavy metals and organic solvents might increase the risk of autism. Another concern is focused on pregnancy and early infancy as crucial periods where brain is developing. During pregnancy, maternal infections and fever, extreme maternal stress, use of some epilepsy medicines, maternal obesity and gestational diabetes appear to increase the risk of having a child with autism. The last concern is the vaccine controversy. The vaccines Thiomersal and Measles Mumps Rubella (MMR) have been blamed for causing an increase in autism (O'Reilly & Wicks 2008). However, this is still contentious and is rejected by most scholars (Madsen et al. 2002, Stehr-Green et al. 2003, Price et al. 2010, DeStefano et al. 2013).

Medical experts define autism as a neurological (brain) disorder that disrupts normal child development in the first few years of life. Symptoms will be evident in early childhood although sometimes these can be subtle and diagnosis may not occur until some years later. Children with autism usually do not look physically different from other children and, as yet, the experts cannot detect it with a blood test or brain scan. Autism can be diagnosed only by observing behavior (O'Reilly & Wicks 2008). O'Reilly and Wicks (2008) explain the details of autism and Autism Spectrum Disorder as follows:

Autism is characterized by differences and delays in: communication, social interactions, routines and repetitive (or stereotyped) behaviors, interests and activities. Meanwhile, what is an autism spectrum disorder or ASD? This is because, while all individuals with autism share in common social and communication delays as well as restricted and repetitive interests, the severity of these problems and their impact on a person's life can vary considerably. It is a spectrum, as the name implies. Some children will avoid eye contact while others will smile and hug. Some will have learning difficulties; others will be top of their class. Some children will never speak, whereas others will display impressive vocabularies. The following signs for a possible ASD are: lack of babbling, pointing or other gesture (e.g. waving) by 12 months; no sharing of interest in objects or activities with another person; no single words by 16 months, or no two-word (non-echoed) phrases by 24 months; any loss of language or social skills at any age. If children show any of these signs described, parents of the child should go to visit a doctor and seek a referral for a developmental assessment immediately (p. 58-59).

Autism has its roots in early brain development and abnormal brain function and is a complex developmental disability in which there is a dysfunction of some parts of the brain and central nervous system. Autism Spectrum Disorder can be associated with intellectual disability, difficulties in motor coordination, and attention and physical health issues such as sleep and behavioral disturbances. Therefore, autism is best described as a group of disorders with similar patterns of behavior in the area of social interaction, communication and imaginative thoughts. The signs of autism and

symptoms of autism tend to emerge between 12 and 18 months of age. Some infants and toddlers begin to develop normally until the second year of life, when they lose skills and develop autism. They will show a pattern called 'regression'. Parents are usually the first to notice unusual behavior in their child. In some cases, the baby reveals differences from birth. Meanwhile, in other cases symptoms are not revealed until after the first one or two years of a child's life. Parents notice the loss of words, and, for some children, that they stop pointing and waving and begin to avoid eye contact. The term Autism Spectrum Disorder (ASD) is used to describe a group of childhood neuro-developmental disorders whose onset is usually before three years old and can be diagnosed at two years of age in most children. According to the United States Centre for Disease Control (2014), the prevalence of autism in 2010 is four to five times more common among boys than girls.

Autism is a typical childhood behavioral syndrome defined by the presence of marked social deficits, specific language impairment, stereotyped repetitive behaviors, and a characteristic course (Rutter & Schopler 1988 cited in Shu 2009). These have certain effects that are characterized by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. In terms of communicating, children with autism vary as some individuals have only slight language impairments while others are not able to speak (Doktor et al. 2010), which adversely affects the educational performance of the child (Lal 2005).

While the research work for this thesis was being conducted a new version of the Diagnostic and Statistical Manual of Mental Disorders, DSM-V (Jaarsma & Wellin 2012), was issued. This was developed by the American Psychiatric Association but is

used throughout the world. It can impact on access to services, insurance, diagnosis and how people and professionals understand autism. The DSM-V defines people with Autism Spectrum Disorder as having problems in ‘social communication’ and/or with ‘restrictive and repetitive behaviors’. People with autism are generally healthy but have difficulties functioning in social situations. The DSM-V brings Aspergers and Autism together under the diagnosis of Autism Spectrum Disorder but provides a scale of severity of functional impairment. It points out that the onset of symptoms occurs in the early developmental period and provides diagnostic criteria such as ‘failure to initiate or respond to social interactions’, ‘abnormalities in eye contact’, ‘lack of facial expressions’, ‘absence of interest in peers’, ‘repetitive movements’ and ‘extreme distress at small changes’. At the higher end of severity a person with autism will require substantial support, may have ‘few words of intelligible speech’ and ‘rarely initiates interaction with others’. At lower severity levels people with autism are likely to have trouble functioning in some contexts due to ‘difficulties switching between activities’, ‘problems of organization and planning’, and difficulties in social interactions such as attempts at making friends or engaging in to-and-fro conversation being typically unsuccessful.

Internationally, there is some debate about whether people with autism, particularly at the higher functioning end of the Autism Spectrum Disorder, should be considered disabled. The ‘neurodiversity movement’ has opposed such labeling under a bio-medical model that sees the different styles of communication and neurological functioning of people with autism as disorders. According to this movement, which has attracted considerable support from people with autism who are able to live autonomously, such labeling creates stigma. They argue that atypical neurological

functioning is not in itself a deficit; rather the response of society to people with autism is what creates subjective distress and impairment (Singer 1999, Fenton & Krahn 2007). The neurodiversity movement thus argued against Aspergers Syndrome being folded into the Autism Spectrum Disorder, at the same time opposing the medicalisation of Aspergers altogether. This movement is calling for a social rather than a medical model of disability where it is the environment of people with autism that is the problem. It is not the person with autism's way of being in the world that is pathological; it is the social world that they inhabit that needs to be made 'autism-compatible'. According to this social conception of disability it is not a matter of changing the individual with autism but of changing the society so that people with the neuro-atypical modes of communication and social interaction associated with autism can be accommodated and supported to live positive lives (Jaarsma & Welin 2012). Consideration of the debate about how autism should be defined by the DSM, and of debates about the relative risks and benefits of the medical categorization of autism as a disorder are beyond the scope of this thesis. For children and adults with autism who do need special care and support, being diagnosable under the DSM can have real benefits. At the same time, this thesis is mindful of the social model of disability and seeks to make a contribution to understanding how Indonesian society can become truly democratic by ensuring true equality for all its citizens including those families living with autism.

The way people think about autism has changed, and currently the favored term is Autism Spectrum Disorder (ASD). This is used because no two people with an Autism Spectrum Disorder are exactly alike (Gill & Liamputtong 2009). Social autism spectrum disorder (ASD) symptoms broadly include disturbances that interfere

with the child's ability to interact with peers, caregivers, and family. Some of these symptoms include a lack of interest in social activities; problems in expression or engaging with others emotionally, and an inability to respond to requests or to determine socially appropriate behavior.

It is widely acknowledged that the number of children identified with Autistic Spectrum Disorders (ASD) is increasing (Dymond & Gilson 2007). This has an impact, particularly in the provision of services. For example, The Center for Disease Control in the United States estimated that one in 150 children in the US have an autism spectrum disorder (CDC 2007 cited in Bryson et al. 2008). The estimated prevalence of ASD ranges from two to six per 1,000 children in western societies; in Turkey, the prevalence of children with autistic disorder is approximately 12:1,000 (Bilgin & Kucuk 2010). The issue of the increasing number of children with autism is gaining the public's attention and autism has made it onto the public agenda in some countries. Although ASD is commonly recognized in Europe and America, it is a relatively new concept in Asia. As a result of this, the prevalence of ASD in Asia is less known (Sun & Allison 2010) and services less well developed.

Autism has been described as a major health problem, which imposes a great cost burden on the individual, family and community (Gordon et al. 1993). Even though there is little information about the cost of health and social services for children with autism, the cost of those services tends to be quite high when compared with other children with disability (Bebbington & Beecham 2007). For instance, one study discovered that the average lifetime cost of supporting a person with autism and a learning disability in the UK was £2.94 million and the cost for a person with high

functioning autism was £875,000 (Jarbink & Knaap 2001 cited in Bebbington & Beecham 2007). This creates financial hardship for parents of a child with autism in terms of affording treatment for the affected child.

2.3.2. Service Delivery for the Children with Disabilities: Autism

The fundamental goal of public policy for human services is to connect service delivery capacity with the objective needs of citizens. Public policies act to transfer demands into programs and service delivery systems. The outcome of policy is usually focused on the ‘what’ – what is provided or delivered or funded, and the ‘who gets it’ – groups or individuals (Wanna et al. 2010). Service delivery is a system of how to provide services to citizens in accordance with their individual needs. As well, the system of services is designed to assist citizens or individuals to meet their own needs. In terms of human services, Agranoff (1991, cited in Voydanoff 1995) stated that systems of care designed to respond to the needs of individuals who are at high risk, such as people suffering Autism Spectrum Disorders (ASD), require a diverse array of services and support. Because of the continued increase in the number of children with autism diagnosed, demand on service delivery systems is intensifying. It is important to know that services delivery for children with autism are critical ingredients in promoting successful child development and life chances as they make the transition to adulthood. Various services are essential to meet the needs of children and their families, so, the needs of all families and children should be considered. Sometimes children with autism and their families present a complex array of needs that can only be met by the provision of multiple services (Daka-Mulwanda et al. 1995), and parents of children with autism report a need for more autism-specific intervention (Hare et al. 2004). The multiple services for children with

autism include health services and education facilities. Meanwhile, early intervention services are becoming more important in the lives of many individuals with special needs. Many researchers have shown that interventions are most effective when they are implemented as early as possible (Jones et al. 2005). In the case of autism, the optimal time to get treatment interventions is as soon as the child has been diagnosed with autism, with diagnosis occurring no later than three years of age.

As the service delivery system for children with autism is becoming more important, there is growing research about autism and its service delivery system (Aylott 2010, Bebbington & Beecham 2007, Dymond & Gilson 2007). There is a primary challenge for services to ensure that children with autism and their families actually receive a multiple needs assessment and appropriate interventions (McWilliam et al., cited in Kohler 1999). Feinberg and Vacca (2000) argued that services should include a range of public and private agencies with a shared obligation. However, it is difficult to identify how to determine which services should be made by public and private agencies.

Meanwhile, as the numbers of children identified with autism continue to increase, the demands on the service delivery system will intensify and it needs to expand to meet these needs. There is a literature investigating the variety of services and treatments for children with autism as well as many issues relating to services availability and costs to families and service agencies for providing services. A broad range of services for children with autism comprises early identification and diagnosis, prevalence tracking and treatment (Lord & Bishop 2010), appropriate public education (Dymond et al. 2007) and special education systems (Feinberg & Vacca

2000), and evaluation of the efficacy of treatment approaches (Dymond 2007) such as applied behaviour analysis, special diets and vitamin therapy, floor time, social stories, speech therapy and others. In terms of therapy performed with the child with autism, the approach of one-to-one activity is still the most 'accurate' means of treating autistic behaviors (Huws & Jones 2010). This approach means that one therapist performs therapy with one of the affected children at a scheduled time.

There is some literature showing the type of service delivery for autism in Asian countries. For example, in Hong Kong, the historical emergence of a model of services for children with autism arose because of increasing awareness, increasing prevalence, and pressure from parents and support groups (Wong & Hui 2007). Public awareness of autism increased in the early 1990s. Hong Kong has programs for children with autism focusing mainly on speech therapists and occupational therapists for group training or referral to preschool training programs in early education and training centers (EETC), integrated child-care centers (ICCC), and special child-care centers (SCCC). In Malaysia, the concept of integrated special education classes was developed from 1988 to accommodate the educational needs of children with learning disabilities (LD) in which Learning Disabilities terminology covered autism and the other types of children with disabilities (Saad 2006).

Children with disabilities typically need a developmentally appropriate sequence of special, interdisciplinary, or generic services, individualized supports, and/or other forms of assistance that are usually of lifelong duration (Parish & Whisnant 2006). These programs aim to help children with disabilities to develop their cognitive, emotional, academic and physical capacities. Conditions such as autism, like cerebral

palsy, result in elevated needs for primary and specialty care. Reviews of the education and treatment of children with autism make clear that, while the behavioral adjustment of children with autism can be much improved with early intervention, there is no interventions as yet where the results in an effect on long-term prognosis cure. Interventions can improve life chances and quality of life, and consist of medical and educational services (Wolff 2004).

2.3.3. Diagnosis of Autism

Research literature on experiences of parents seeking a diagnosis for their child is receiving more attention recently. This is an important point in the life of a child with autism. Diagnosis is a kind of health examination procedure for people assumed to have a particular illness. It takes a lot of time for the process of autism diagnosis to proceed, before reaching an appropriate diagnosis. In the case of autism, the parents of the autistic child are important persons who must communicate about their observation of their disabled child in the process of the examination. Autism is a diagnosis that no parents want to hear. As a family who has a child with autism can attest, receiving that diagnosis begins a journey that places profound demands on the family's human and financial resources for the remaining lifetime of the child (Schall 2000). Diagnosis is usually made in early childhood after a multi-disciplinary assessment of behavior, developmental level, and communication ability. According to Smith and Daughtrey (2000), diagnosis is a key stage in the lives of parents of children with disability, and the details and shock of a first diagnosis can remain with parents for years. Some parents can still recall word for word how the professional informed them of the diagnosis of their children.

The diagnosis of autism is described in some detail in the small book of developmental psychopathologist Simon Baron-Cohen. He states that a multidisciplinary team often carries out the diagnosis process, typically taking two or three hours based on interviews and observations (Murray 2012). Child psychiatrists, clinical or educational psychologists, pediatricians and other health professionals will conduct interviews. They will ask the parents various questions. Some questions might include: “have they found it difficult to make and keep friends?”; “do they show a lack of normal social awareness?”; “do they resist change?”; “does the person have trouble understanding non-literal language?” It should be noted that a single interview is insufficient to gather all the information needed for diagnosis. Follow-up interviews and evaluation processes are needed and also all of the professional team needs to meet before reaching a final decision on diagnosis. Baron-Cohen stressed the need for parents coming to the interview process to make an appointment in advance for this process. Lisa Sanders (cited in Murray 2012) stated that the central element necessary in the process of diagnosis is the “patient’s story”, noting that the great majority of medical diagnoses are made on the basis of the patient’s story alone. According to her, this is crucial information as the patient’s story (or in this case the parents’ story) is important in terms of making a diagnosis for a child with autism.

Diagnoses are the classification tools of medicine. A diagnosis is both the pre-existing set of categories agreed upon by the medical profession to designate a specific condition it considers pathological, and the process, or deliberate judgment, by which such a label is applied (Blaxter 1978). Diagnosis is integral to the system of medicine and the way it creates social order. It organizes illness: identifying treatment options’ predicting outcomes, and providing an explanatory framework. Diagnosis also serves

an administrative purpose as it enables access to services, from insurance reimbursement to access to restricted-access medication, sick leave and support group membership and so on (Jutel 2009). Meanwhile, in the process of a diagnosis, the diagnosis acts as a “framing event”, as it transforms a set of behaviors into symptoms and constrains the meanings around the illness (Rolland 2012). In the case of autism, the diagnosis tends to occur over an extended period of assessment and seldom occurs before three years of age (O’Reilly & Wicks 2008).

O’Reilly & Wicks (2008) explained in brief about the process of assessment and diagnosis of autism in Australia. According to them, the processes of assessment for children who suffer Autistic Spectrum Disorder are provided by a range of agencies including specialized services funded by state governments, state-based autism associations and pediatricians, and child psychiatrists and psychologists who are working in the private sector but are partly reimbursed on a pre-service basis by government. Government-funded diagnostic assessment is usually performed by a multi-disciplinary team, which may include a psychologist, a doctor (pediatrician or child psychiatrist) and a speech pathologist and, in some cases, an occupational therapist (OT) and/or social workers. These multi-disciplinary assessments may take place over several appointments on several days. In the process of diagnosis, each participating child must undergo thorough medical examinations including testing of their immune systems, brain structures and function, genetics, environmental exposures and blood subgroups.

2.3.4. Early Intervention for Children with Autism

After diagnosis, early intervention is the next step for a child with autism. Behavioral and other therapeutic interventions early in the life of a child with autism are critical for improving communication, forming relationships, decreasing maladaptive behavior and developing independence (Larsson 2005). Intervention strategies are expensive. Many strategies require long hours of one-on-one interaction with a trained therapist or use of costly foods or drug supplements. However, personal funds or health insurance schemes fall far short of covering these needs. Having a child with autism can affect family finances (Sharpe & Baker 2007). Costs associated with having a child with autism are not limited to the cost of interventions; families often face greater outlays of time in addition to money. Sharpe and Baker state that specialized childcare is costly and often such care must be purchased for a longer period of time than a neurologically typical child would need.

The goal of early intervention is to prevent or minimize the physical, cognitive, emotional and resources limitations of young children with biological and environmental risk factors. An important premise of early intervention for young children is the family's key role (Blackman 2003). Without family involvement, interventions are unlikely to succeed. The intervention must target the family, to assist in implementing therapies concerned with children's growth and development. The community also plays an important role. Children thrive only if society cares enough and has the resources to support families. Therefore, there are two elements, families and society that are the key to the success of early intervention.

2.4. Review of Empirical Studies:

Mothering of Children with Autism and Services for the Child with Autism

Research studies over many years have documented the experiences of mothers of children with autism. In terms of cultural context, You (2010) examined the meaning of mothering a child with autism in two countries: the United States and South Korea. The overarching research question focused on how socio-cultural ideas about mothering and disability, particularly autism spectrum disorders, shape women's understanding of themselves and their children with disabilities. Through in-depth interviews with twelve United States mothers and fourteen Korean mothers who have children with autism, the study found that these mothers understand themselves to be empathic supporters, mediators and advocates for their children with autism. From the findings, the study collectively demonstrates that mothering a child with autism is gendered, specific to ones' understanding of autism, and both oppressing and empowering to women. In the light of mothers' views on raising children with autism, a study in Australia has been applied to provide new knowledge on how the mothers of children with autism perceive themselves as mothers and their lived motherhood experiences (Gill & Liamputtong 2009), by using a combination of in-depth interviews and a solicited diary method. Another study has been conducted to focus on the difficulties and experiences of mothers in raising their children with autism, in which mothers expressed feelings of burden and stress due to the behavior of their children. Based on semi-structured interviews with forty-three mothers regarding their experience with their children, the study indicated that parents need support from both formal and informal support systems, and this study has been designed to enhance the public understanding of autism, particularly in Turkey (Bilgin & Kucuk 2010). Another study reveals that the mothers were challenged by the demands of their

multiple roles while dealing with their children with autism, in terms of accepting the disability of the child and managing their role, their emotions and their child's behavior (Safe et al. 2012). By using in-depth interviews with seven mothers of children with autism and then analyzing the data using interpretative phenomenological analysis, this study found that the professionals working with the mothers need to support them in managing various aspects of their lives, both the affected children and their mothers.

In terms of experience with the autism diagnosis of the child, studies have been done to emphasize the feelings and reactions to diagnosis among mothers of children with autism. When a child is diagnosed with autism, mothers experience a range of difficult feelings, and this is not addressed in child-focused interventions. Wachtel and Carter (2008) noted that there is the importance of considering a mother's resolution about her child's diagnosis and suggested that maternal emotions and cognitions associated with the diagnosis may be targets for interventions. They used a larger longitudinal study examining developmental trajectories of young children with autism and their families. Another study highlighted a high level of depressive symptoms and distress in mothers of children with autism, particularly in the week after receiving an autism diagnosis (Taylor & Warren 2012).

The purpose of the Ozden and Tosun's (2010) study was to determine the level of adaptation the mothers of children with autism experience, in which mothers used coping strategies to help them to get through with the diagnosis of the autism of their child. From the point of view of the mother's coping strategies, studies have been conducted to focus on the question of how coping strategies are used by mothers of

children with autism. Based on semi-structured interviews with thirteen Turkish mothers of children with autism, with interview questions that were designed to investigate the mothers' experiences, they found that most of the mothers lacked accurate information regarding the disability, and mothers indicated that they did not see themselves as fully informed about the situation. This study also noted that the support provided by family members was the main coping source for the mothers and the study revealed that understanding the experiences of mothers or parents of children with autism is crucial in the design and delivery of appropriate counseling services.

Marshall and Long's (2010) study of five mothers whose children with autism were between the ages of six and eleven years explored new knowledge to understand mothers' coping strategies by using the tools of narrative analysis. The primary purpose of the study was to explore the coping processes revealed in the stories told by mothers of children with autism. The study's findings reveal many of the stressors faced by mothers of children with autism, and the behavioral and cognitive strategies the mothers used to mitigate the stressors. The life stories they told also reveal the meaning-making processes as mothers came to terms with their children's autism.

All of these studies seem to show that mothers of children with autism in various countries experience a good deal of stress and that the services provided for them and their children, while often of a good professional standard, are inadequate overall. So, in a way, not only is there a gap in the literature regarding services for families with children with autism in Asian countries such as Indonesia, there is also a gap in the provision of sufficient high quality services.

2.5. Present Study

From reviewing the above literature on the experiences of mothers of children with autism, it is apparent that these studies were conducted in the context of developed countries. However, on how mothers cope in other societies, particularly in the context of Indonesia, there is still very little research documenting the experiences of mothers of children with autism (Mashabi 2009) and of parents of children with autism (Lubis 2009, Muniroh 2010). As well, there is a paucity of research focusing on autism and the delivery of services for children with autism. Taking the case of Indonesia, this study will fill the gap and explore points of view from mothers of children with autism on the phenomenon of autism and the delivery of services for children with autism. Therefore, this study addresses the question of how mothers of children with autism perceive the phenomenon of autism and the services for their children with autism in Indonesia.

Chapter Three:

Methodology

3.1. Introduction

The purpose of this chapter is to provide a detailed description of the methodology and to discuss the methods used in relation to the data collection for this study. This chapter will outline the components of the methodology and explain the justification for why these methods were used for this research. The chapter starts with a justification for using a qualitative research design to gather the experiences and information from the participants in the interviews that were conducted from November 2011 to February 2012 in Indonesia.

The qualitative research design of this study is important as this is the way to understand the complexities of the phenomenon of autism in Indonesia from the viewpoint of mothers who have children who have been diagnosed with autism and how to understand the ways that parents deal with the problems they come up against after and before diagnosis, particularly with the services and professionals who get involved with them. Therefore, the present study seeks to contribute to the knowledge emerging in this area of disability. In selecting Indonesia, the study examines the delivery of services in the area of disability in a developing country. There is silence in the Indonesian literature on this perspective, especially about the parents and/or mothers of children with autism, as the focus of the analysis. This study is thus important due to their views still being understudied. Therefore, in order to capture the points of view emerging from the mothers, a qualitative study design has been applied.

A qualitative approach is suitable for investigating complex topics and understanding diverse points of view. It is suitable for understanding the views of mothers of children with autism on autism, the delivery of services for their children, and how they interact with service providers. A qualitative, inductive approach with descriptive methods of data collection was utilized giving the exploratory nature of the research questions: “How do mothers of children with autism perceive the phenomenon of autism and how do they experience autism services in a regional Indonesian city?” In order to answer the question, it was expanded into some sub-research questions, as follows as set out in Chapter 1:

1. How do participants understand autism?
2. How do participants think about support needs for children with autism?
3. What do participants think of the existing service delivery for children with autism?
4. What are participants’ perspective on the role of government and non-government organizations in the delivery of services for children with autism?
5. What do participants think as mothers of children with autism about the impact of service delivery on them?

This chapter outlines the overall research design and rationale employed in this study. It includes a discussion of the basic research design, selection of participants, data collection and management methods, data analysis strategy, and ethical considerations. These sections will be explored in detail below.

3.2. Design of the Research

Merriam (1988) has identified some assumptions that undergird qualitative research. She described these assumptions as follows: Qualitative research assumes that there are multiple realities, that the world is not an objective thing out there but a function of personal interaction and perceptions. It is a highly subjective phenomenon in need of interpreting rather than measuring. Beliefs rather than facts form the basis of perception. Research is exploratory, inductive, and emphasizes processes rather than ends. In this research approach, there are no predetermined hypotheses, no intervention trials, and no restrictions on the end product. One does not manipulate the variables or administer a treatment.

Creswell (1998) states that in qualitative research the researcher builds a complex, holistic picture through analyzing the words and ways of talking about a phenomenon and reporting the detailed views of informants. In the field of disability research, qualitative methodologies have become known as important tools in understanding the complexity of disability in its social context (Benderix et al. 2006; Bumiller 2008). Qualitative research can help us to better understand the lives of people with disabilities. Research is currently based more on the life experience of people with disabilities at first-hand, to access their unique knowledge as disabled people. We need to know the complexity of their life experiences in their own voice. In-depth interviews with selected people with disabilities can gather data on perceptions and life experiences of these people. Essentially, qualitative research aims to capture lived experience of the social world and the meanings people give to these experiences (Corti & Thompson 2004). Based on this rationale, this study has used the qualitative methodology to capture the lived experience of mothers of children with autism, in

particular on raising their children and dealing with the service system for their children with autism. A qualitative methodology also has enabled the researcher to build relationships with the participants, who have allowed the researcher to gain detailed answers on areas often considered private.

The data in this study reflect thoughts, feelings and interpretations of the experiences of mothers who have a child with autism. Qualitative methods of data collection and analysis allowed the researcher to reach an in-depth understanding of autism and how mothers of children with autism experience the delivery of services and bring up their children with autism, as well as their points of view on this. This research design employed focus groups and individual interviews with selected mothers of children with autism. The research is descriptive in nature, as it seeks to present the mothers' perspectives on themselves and their experiences as they raise their children.

3.3. Methods

The unit of analysis for this study is mothers of children with autism and their experiences of services and the impact on their lives and the lives of their children with autism and family. This research used two focus groups and a semi-structured interview with members of parenting groups as a means to gain knowledge from mothers of children with autism about service delivery for their children. Seidman stated that interviews provide access to the context of the behavior of people and also provides a way for researchers to understand the meaning of behavior. It allows the researcher to put behavior in context and provides access to how people understand their actions (Dilley 2004). Through the process of interviewing, the researcher sought to understand how mothers constructed interrelationships with service

providers including medical persons, principals and teachers and therapists, and others in their community as well as with their extended families.

3.3.1. Selection of the Participants

This study employed purposive sampling in order to select the participants. The overall criterion for sample consideration was that participants were mothers of children with autism who indicated a willingness to participate in the semi-structured interviews as well as the group discussions. The mothers who were approached to participate in the study were parents at supporting schools for children with autism and rehabilitation centers. According to Creswell (2007), a purposive sampling strategy means that the researcher selects individuals and sites for study because the participants can inform the researcher and contribute to understanding of the research problems in the study. In this process, the researcher needs to decide who or what should be sampled and how many people or sites need to be sampled. In this research, the participants are the mothers of children with autism who had joined in parenting groups at supporting schools for children with autism and rehabilitation centers.

Recruiting mothers of children with autism in Indonesia as participants is difficult due to the sensitivities and feelings of shame about having a child with a disability. In the context of Indonesia, parents tend to hide their children from public sight if they have a child with a disability, either physical or mental. However, they will speak up about their children with disability and their experiences of raising their children with a person whom the mothers have faith in and where the husband has given permission to the mother to discuss their experiences with people who are not part of their family.

In the early stage of the process of recruiting participants, the researcher contacted a mother of a child with autism that the researcher had known as she lived in the same neighborhood. She has a child who had been diagnosed with autism. She was contacted first to discuss the study. She agreed to participate in this study and later introduced the researcher to another mother who agreed also to be a participant. The snowballing process began with this as the second mother introduced the researcher to her friend. At this stage of recruiting, there were three mothers who agreed to be participants. From a friend of the second mother, the researcher came to know of a non-profit organization providing services for children with disabilities that she used for her child. Actually, the researcher already knew about this institution as this institution is well known nationally as a non-profit organization providing services for children with disabilities. However, the information about treatment for children with autism being provided was new. Following on from hearing this information from the participant, the director of the centre was contacted. The purpose of this communication was to get access for recruiting participants, who, in this research, are mothers who have used some of the services on autism from this institution.

After an introduction to the principal and discussion of the study, the principal agreed and opened her arms to the researcher. The discussion shared information including a brief of the study, the school, the parenting group, and information about another school targeting pupils with autism. On another day and after she signed the consent form, she explained her own experiences as a mother of a son who has been diagnosed with autism. The principal was then asked to send the invitation letter that had been prepared to all the mothers who were members of the parenting group, to invite them to participate in the interviewing process for this study. The second

school mentioned by the principal was also approached and the same procedure was followed. Finally the director of a rehabilitation centre was approached, as a mother who agreed to participate in the study informed the researcher about the centre, which she visited to receive treatment for her child.

All participants who had joined in the focus group discussions had been recruited from two different institutions, the first autistic school mentioned above and the rehabilitation centre. The participants in this component of this study were eighteen mothers, whose children were autistic and were attending classes in one or both institutions. The school particularly has provided educational services for children with autism. All mothers were recruited on a volunteer basis through letters that the researcher sent. Prior to conducting the fieldwork, the researcher proposed to invite almost forty mothers to participate in this study from two institutions, to get involved in the semi-structured interviews and focus group discussion sessions. A letter was sent to mothers who were members of parent groups from these institutions. The principals and the director of the centre helped the researcher to handle the letter to mothers. The letter consisted of information detailing the study briefly and the invitation to get involved in this study. There was no bias in this selection, as the principal was informed about the study and the letters were sent to all potential participants. The information sheet was also given out through the monthly meeting as well as handing the letter to mothers directly when the mothers picked up their children at school. Later they gave their response by informing the principal that either they agreed to join in this study or did not. When they agreed, they notified the principal of their approval, and the researcher then dealt directly with them. Once contact was made with the mothers, it was discussed with them that their participation

in this study was voluntary and they were reassured that if they decided not to proceed with an interview, it was acceptable and would not be a problem either for them, their children or the research.

As a result of the invitations, there were fifteen mothers who agreed to be participants in the individual interview component of this study, adding to the three already recruited. These fifteen mothers also participated in focus group. The response to the letter varied, ranging from refusal, no reply to the letter, reluctance due to the absence of permission from their husbands, and they themselves not being willing to speak with a stranger who is not part of their family. The background of the participants of this study is presented in the table below, including those who were recruited from the initial snowballing, not from the invitation and who joined in the semi-structured interviews only.

Table 3.1.

Backgrounds of Mothers

Participant	Child's Gender	Education	Occupation	Child Diagnosed by	Position⁵
M1	Male	Master of Education	Principal	GP	2/2 ⁶
M2	Male	High School ⁷	Self-employed	Therapy Centre	2/2
M3	Female	Bachelor of Science	Book-writer	Public Hospital	1/1
M4	Male	Diploma	Housewife	Public Hospital	1/1
M5	Male	Bachelor of Arts	Early-retired	Public Hospital	Both of them/2
M6	Female	Bachelor of Arts	Housewife	GP	2/2
M7	Male	High School	Housewife	Therapy Centre	2/3
M8	Female	Bachelor of Education	Housewife	Therapy Centre	2/2
M9	Female	Bachelor of Economics	Assistant Teacher	Public Hospital	3/3
M10	Male	Master of Education	Lecturer	GP	1/3
M11	Male	Master of Education	Lecturer	Psychiatrist	1/3
M12	Female	Bachelor of Arts	Housewife	Therapy centre	1/3
M13	Male	High School	Housewife	GP	1/2
M14	Female	High School	Housewife	Therapy Centre	1/1
M15	Male	High School	Housewife	Therapy Centre	2/3
M16	Male	High School	Housewife	Therapy Centre	Not Stated
M17	Male	High School	Housewife	Therapy Centre	Not Stated
M18	Male	High School	Housewife	Therapy Centre	Not Stated

The table above shows the various kinds of occupations that the mothers worked in, including principal, book-writer, owner of small business and academic staff member. However, they mostly are housewives. The principal who agreed to participate is a mother of two children and it is her second child who had been diagnosed with severe and complex autism. She told the researcher that she built a small private special school targeting children with autism at young ages, and she dedicated it to children with autism, as her son was affected. She also built the special school, as there are still

⁵ This means the position of the affected child in the family.

⁶ This code means the second child is affected in a family of two children.

⁷ High school in Indonesia is equivalent to Year 10 to Year 12 in Australia.

not enough facilities in the area of education services intended for young children with autism. By establishing the school she can help other children as well as her own son. Another case demonstrated how the permission from the husband is important for the mother when she decided to speak with researcher. One of the mothers (M2) discussed how she was willing to speak with researcher after getting permission from her husband. The husband asked the mother about the information that the researcher wanted to ask and the husband agreed with two conditions, (1) the material of interview should be about their son, instead of family problems; and (2) he asked for the process of the interviews to take place at their home. In this situation, those requirements were agreed upon, and the material was focused on her experiences as a mother of a son who has been diagnosed with autism and how she dealt with the problem in terms of raising her son, before and after the child obtained the diagnosis of autism. During the interviewing process, the husband did not accompany the mother, and he left to work outside. It is likely that often other participants sought the approval of their husbands before volunteering for the study.

Table 3.1 shows that nearly half of the participants involved in this study have completed high school⁸ and the rest hold Master's and Bachelor's degrees. In an Indonesian context, this is a well-educated group. Being an atypical group, this must be taken into account in interpreting the interviews with the mothers. However, there are some advantages to having participants who are articulate and able to reflect on and pass on information giving the mothers' perspectives to the researcher. The mothers were well educated, their thinking horizons are broad and they were continuously weighing up and deciding what was in the best interests of their

⁸ Completing high school in Indonesia means that a person has completed 12 years of the compulsory school attendance, starting from primary school grade 1 to grade 12.

children. The effect of the education that the mothers have can influence the way of thinking and handling the problems related to bringing up their children who have been diagnosed with autism. A different group from a rural area or with only primary school education may yield different perspectives. This study shows that mothers are trying to find information relating to the condition of their children and where they should bring their children to get treatment. Education can help orient mothers to seek understanding and information on autism. A group lacking high school and post school education may have different needs. Education gives mothers more confidence in making choices and greater power to decide over the health condition of their children. The above table shows also that mothers mostly went to the rehabilitation centre rather than the public hospital in terms of the place they brought their child to get a diagnosis. This is partly a reflection of how they were recruited but also reflects their above average family incomes.

3.3.2. Data Collection

The data was collected through an interviewing process with mothers of children with autism and included the focus group or group interview method and semi-structured individual interviews. In addition, document analysis was used to provide insights into policies in the area of disability in Indonesia and to gain an understanding of information sources on autism in Indonesia. The detailed explanations of the methods used follows.

3.3.2.1. Document Analysis

Document analysis is a systematic procedure for reviewing or evaluating documents, both printed and electronic (computer-based and Internet-transmitted) material.

Document analysis requires that data be examined and interpreted in order to elicit meaning, gain understanding and develop empirical knowledge (Corbin & Strauss 2008, cited in Bowen 2009). Documents contain text (words) and images that can be used as sources of information and can be recorded without a researcher's intervention. The documents include background papers, books and brochures, diaries and journals as well as annual reports of government or NGO programs. These types of documents are found in libraries, newspaper archives and organizational files.

This research used document analysis as a method for understanding the government policies and programs regarding the service delivery system for persons with disability and children with autism (where it exists) in Indonesia. In this research, the researcher used government reports, legislation and NGO annual reports to identify policies on disabled persons and children with disabilities in Indonesia. Those papers helped the researcher to understand the implementation of written policy, particularly disability policies in Indonesia.

In addition, this study also used computer-based documents such as website materials. This source can help participants to understand autism and provides information on services for children with disabilities and autism. Many of the participants found it is easy to get information via computer-based documents and as most of them were lay people they turned to on-line sources to understand autism terms. The language of website materials they accessed was mostly in *Bahasa Indonesia*, allowing participants to fully understand it. The materials contain information about the meaning of autism and types of treatments and were analyzed by the researcher as part of this study.

Websites mentioned by the mothers interviewed included those of the *Yayasan Autisma Indonesia* and other websites. This website reported on its organization and the community awareness programs it is running online. Parents can order print materials such as a video or booklets on early autism treatment and other services, a question and answer to and from the provider about autism and any information about the therapy practices across this country. The websites also provide contact details for health and education services able to diagnose and respond to children with autism; parents and carers of children with autism can access the website deliberately.

3.3.2.2. Focus Group Discussions

A focus group is a kind of group discussion. Any group discussion may be called a focus group as long as the researcher is actively encouraging of, and attentive to, the group interaction (Kitzinger & Barbour 1999, cited in Barbour 2007). Being actively encouraging of group interaction relates to running the focus group discussion and ensuring that all participants talk amongst themselves. According to Khan and Manderson (1992, cited in Liamputtong 2009), a focus group interview is a qualitative method with the aim of describing and understanding interpretations and beliefs of the selected participants to obtain understanding of the particular issue from the perspectives of all the participants. The participants discuss the particular issue with the help of a moderator, who, in this research study was the researcher. This method was useful in exploring and explaining what the participants think, how the participants think and why the participants think the way they do about the particular issue.

The focus group discussion also is useful to encourage the participants, to speak up and express their ideas and experiences as mothers who are raising a child with autism. In the focus group session, all participants were questioned about their hopes, expectations, barriers and needs, and asked to provide recommendations regarding services for their children with autism. In this study, the researcher used a face-to-face focus group interview as one source of data collection. The focus group method was chosen because it facilitates all participants identifying and describing particular issues, which are important for them.

In terms of the diversity of the educational background of participants, there was an impact on how the mothers expressed their thoughts on the particular issues of this study. This affected the extent to which the mothers contributed to and were involved in the discussion by speaking up on the various issues. This study showed that those who have a higher education seemed to always dominate the conversation in the discussion session. With hindsight it may have been better to have two focus groups with women grouped according to similarities in their educational backgrounds.

The advantage of focus group discussion is that one comment from a participant can generate information from other participants. Thus opinions and ideas can be developed from the conversations among individuals. On this point, the mothers are persons who have knowledge and are able to share with others including the researcher on particular issues relating to this topic. Mostly the background of the mothers in the discussion group is the Javanese culture, thus they sometimes still found it was hard to express their views, even though they had full knowledge of the topic as they were experienced as mothers of children with autism. Javanese mothers

are not accustomed to speaking frankly, particularly in front of many other people. So the researcher realized that one or two mothers could dominate the focus group communication. However, the moderator always encouraged mothers to express their knowledge and to speak out in front of the other mothers. Under these conditions, it turns out that mothers gave encouragement to other mothers to speak up during discussion session. So it happened that they all shared their experiences and knowledge and a good mix of experiences and perspectives were explored.

Mothers who agreed to participate in focus group discussions were contacted in advance one week before the session, and again they were reminded about the session one day before the scheduled time through short message service (SMS) and phone calls. Focus discussions were conducted in a place where 6 – 8 mothers could be seated and assured of some privacy. To minimize boredom, the discussions are not stretched beyond two hours. In addition, the timing of the discussions needed to be convenient to all mothers. While waiting for other mothers to arrive in the place, the time was used to get information about the mothers' backgrounds. The first group was conducted in the one of the classrooms at the autistic school and the later group was done in the backyard of the rehabilitation centre. These appropriate venues were a neutral place that was free from distractions and where all mothers could talk openly. However, there were still many interruptions to the discussions in the second group. Interference came from their children, who wandered in and out of the centre. As a result, some of the mothers declined to continue discussion in the middle of the process, as they had to attend to their children. As a researcher, it was experiences such as this that provided insights into the everyday lives of mothers raising children with autism. Screaming and crying due to the children feeling restless and tired after

class hours interrupted the discussion of one group. Fortunately, the mothers agreed to continue communication with the researcher through the semi-structured interviews.

3.3.2.3. Semi-Structured Interviews

Semi-structured interviews were used for exploring the understanding of autism and experiences of the delivery of services for children with autism. In addition, the semi-structured interview is suitable for this research because it ensures consistency across participant interviews. In this type of interviewing, the researcher has an interview protocol, but the interviewee has free expression in response during the interviewing process. Sometimes the questions may not follow in order, based on the interview protocol. The primary forms of data collection came from the interviewing processes, which Fontana and Frey (2000) have described as one of the most powerful ways to understand another's perspective.

Eighteen mothers of children with autism participated in this study. However, just fifteen mothers agreed to be involved in the semi-structured interviews. This process was chosen in order to capture an understanding of the lived experience of the mothers of children with autism regarding services for their children. All mothers who agreed to participate were interviewed, either in their homes, or the backyard of the school, or the centre, at a time of their convenience between November 2011 and February 2012. The main criterion for participation was to be a mother of a child with autism, and they participated on a voluntary basis and no compensation was provided. Each of the participants was interviewed once, lasting from one to two hours. All the interviews were open ended and guided by an interview protocol. It sometimes happened that the researcher probed with specific questions, following up what the

participant had provided. The aim of this interview was to explore how the participants understand autism, and how they personally experience autism services when their child has been recognized with the symptoms of autism, and how they deal with mobilizing the support they need in raising their children.

The time and place of the semi-structured interviews were decided entirely by the mothers. Mostly they asked the researcher to meet them in the place where the child attended class or treatment. Only the mother was present for the interview; even in the interviews done at home, the husband or other family members were not present at the time of the interview. Before conducting the interview, they were provided with a consent form to sign. It was assumed they had already known the consent form as it was sent to them in advance, together with the information sheet. In terms of signing the consent form, some mothers were reluctant to sign a consent form and questioned its usefulness. This initially sparked discomfort among them because it was something unusual for them. They said that they would still be willing to be participants in this study even without signing the consent form. However, most of them agreed to sign it, and another decided to continue through without signing the form and gave permission to the researcher orally.

Choosing the times of the interviews was not easy, due to the pre-arranged times of interviews with the mothers sometimes having to be cancelled, due to various reasons. One of the reasons was that they were still busy with their children with autism. In this case, a new scheduled arrangement with the mother was made, for a later meeting to interview her. All the interviews were tape-recorded and transcribed in *Bahasa*

Indonesia as mothers were interviewed in *Bahasa Indonesia*, and then their words were analyzed verbatim as stated in the next section.

3.4. The Process of Data Analysis

Creswell (2007) and Merriam (2002) stated that researchers using qualitative research view the process of analysis and interpretation of data as an interactive and rigorous process. Therefore, as a qualitative researcher, the researcher first transcribed the data that was collected from the semi-structured interviews and focus group discussions. During the conduct of the data collections, audiotape was used for recording the interviews. The process of data analysis started from listening to the data recordings and then typing the text into word processing documents using Word:Mac 2008. In the semi-structured interviews, the data was not transcribed verbatim but detailed summaries of the participants' interviews were produced. However, full transcripts and notes came from focus discussions. The transcriptions were analyzed manually by creating codes and category names. Creswell (2007) said that there are several steps in this process, including creating the themes through a process of coding, condensing the codes and representing the data in figures and tables.

In terms of the coding process, the transcribed data was first read carefully by reading data line-by-line, which in this study was in *Bahasa Indonesia*. The data came from the participants in this study who are mothers of children with autism. The text was numbered, based on the questions the participants were asked, and notes or comments were also written on the text as memos. This memo process helped the researcher to understand the situation surrounding the interviews. Then the data was divided, based on meaningful analytical units and created into text or narratives on each of the

themes, which included seeking information, understanding of autism, reaction to diagnosis, interacting with medical professionals, perspectives on services among mothers, and so on.

3.5. Ethical Considerations

All researchers should act ethically. The rule of ethical conduct for a researcher is that subjects should not be harmed in any way, mentally or physically. Therefore, strict rules need to be applied in any research involving humans who agree to be participants. Participants should be completely informed about the research. According to Bogdan and Biklen (1999), there are two important issues in research involving human subjects, including informed consent and the protection of subjects from harm. They argue that one who agrees to be involved in any research should do so on a voluntary basis and must not be exposed to unnecessary risks and that risks should be minimal and considered against benefits.

Prior to conducting the data collection, the researcher had already gained an approval letter from the University of Canberra Ethics Committee. Recruitment letters were sent explaining the research and making it clear that interviews would be conducted using a semi-structured interview process and that these would be recorded. The questions included the history of treatments, the mother's knowledge of autism, the mother's interactions with professionals such as medical and education personnel, the mother's efforts to cope with the autism of her child, as well as her experience as a mother of a child with autism. Mothers were also encouraged to speak freely about their experiences of bringing up their children with autism.

3.6. Limitations of the Study

There are some limitations emerging from the methodology employed in this study. First of all, the locus of the study, where recruitment was concentrated in a supporting school for children with autism and the rehabilitation centre in Barang providing services for children with autism aged between 7 – 12 years old. Recruiting through organizations with which the mothers already had connections and had built up trust made it possible for the study to locate and receive support from mothers of children with autism, who are a difficult group to reach, given the misunderstanding and shame attached to autism in Indonesia. This meant, however, that the groups participating were limited to mothers of children who were born between 1999 and 2005, with the focus on primary school children. Mothers of very young children with autism and of adults with autism were excluded from this research. Based on this, it cannot be claimed that this research will represent the experiences of all mothers of children with autism.

Additionally, the education background of mothers impacted on how they performed in their ability to speak in the group. The higher education levels of some of the mothers could influence them to speak more bravely in a group. The opposite group could be more reluctant to speak due to culture constraints. Javanese women, as a majority of the mothers, are reluctant to speak up if their counterparts have a higher level of education than they do. As a result, this situation also contributed to the decreased richness of information coming from all mothers in the focus group sessions.

The mothers who are participants in this study reside in one of the regional cities that are far from the capital city of Indonesia. This town has several private autistic schools, which were built by parents (particularly mothers) of a child with autism. However, the number of services available for children with autism has limitations in regional cities, compared to Jakarta as a capital city, for instance. As a result, the complexity of services and provisions are different in the different geographical areas.

This study also has some limitations in terms of location, race and class. The study was conducted in a single regional city in East Java. Indonesia is a very diverse country both culturally and geographically. Thus the findings of this study cannot be assumed to apply to other groups of mothers in other locations. Hopefully this study will spur other researchers to investigate other contexts. In particular, the range of services available in the capital, Jakarta, may well be more developed than in Indonesia's regional provinces. The situation of rural mothers and families living with autism is also likely to raise different perspectives and issues of concern. And the situation for residents in more remote provinces, even in cities of similar size may be different.

The exact location of the city where the study was conducted has not been revealed in order to provide some protection for the participants' confidentiality and was a requirement of the Ethics Committee at the University of Canberra. Gaining the consent of the organizations that participated in the study raised sensitivities due to the scarcity of services for children living with autism. Revealing the name of the city where the study was conducted would risk identification of these organizations and the trust and the facilitating role they played in enabling the research.

All studies are conducted with time and resource constraints. This study faced the added difficulty of recruiting participants and asking them to discuss matters considered private and highly sensitive. Families living with children with disabilities, and particularly with behavioral and developmental disabilities, still face social stigma in Indonesia and so to speak openly about their experience with autism is challenging. Given these constraints it was decided to locate the study in one city and the choice of city was made to make use of the researchers' connexions and existing support networks. All study designs have trade-offs and this single city design enabled the collection of in-depth information from the group of mothers who participated. While this limits how broadly the views can be generalized, it has enabled an important voice to a group rarely heard from in policy and service design in Indonesia, the users of services, here particularly the mothers of children with autism.

3.7. Strengths of the Study

As stated in the previous section, this study addressed a limited number of participants. However, the mothers' experiences of services for their children with autism can be used as a vast contribution to understand the role of the government and non-profit organizations in providing services for people with disabilities in Indonesia. This study has also captured the experiences of mothers firsthand and their perspectives on services in a regional city that has complexities at the different levels of government.

Nevertheless now that this study has identified the kinds of experiences of mothers with children with autism and their experiences of services, it would be valuable to undertake

a quantitative study to explore the distributions and frequencies of such experiences more broadly in the Indonesian population.

Chapter Four:

Contextualizing Disability in Indonesia

4.1. Introduction

This chapter aims to examine disability in Indonesia specifically autism. In order to do so, there are some points I discuss in this chapter relating to the contextualization of disability in Indonesia including the complexity of service provision for people with disability, the number of people with disability, government policies on disability, and service provision and support for person with disability. The information analyzed in this chapter was obtained from the document analysis process using multiple sources including non-government organizations annual reports, government regulations on disability as well as articles from journals.

4.2. The Complexity of Services Provision

Every country in the world, both in developed and developing countries, has populations who have limitations, such as people with disability either physical or mental disabilities. WHO estimated that over 650 millions people live with disabilities worldwide, or 1 in 10 of the world population. Of those, 80% live in low-income countries with inadequate access to health and rehabilitation services (Pechak & Thompson 2007). In a developing country such as Indonesia, a child with disability may not have any access to education, for instance. By adult age partly as a result, he or she will have few opportunities for employment.

The existences of persons with any disability are a challenge for all governments in the world, particularly in ensuring their human rights and treating them well and

providing services for them as citizens. In Indonesia, the challenges faced can create a complexity in the delivery of services as service availability is influenced by factors including the geography and the demography of the region, and the state of development. It is not easy to service the Indonesian population to meet their basic needs, as many obstacles will challenge the government in many ways. It is widely known that Indonesia consists of approximately 17,000 islands and is the largest island nation in the world, about 6,000 of which are populated. Its islands form an archipelago that bridges the continents of Australia and Asia. The total landmass, which includes five major islands, is 2 million square kilometers. By looking at the picture of the overall situation of the Indonesian territory will bring up a range of complexities in the administration of the delivery of service to the people with disabilities in particular. Geographically, Indonesia's population lives scattered unevenly. People who inhabit in some islands such as Java, Sulawesi, Sumatra, Kalimantan and Bali are more concentrated in urban areas as a result of the high rate of urbanization on those islands. On the contrary, people living in Maluku, Nusa Tenggara Islands and other small islands are largely residing in rural areas or villages. As a result of these isolated conditions can create difficulties in terms of the delivery of services to the people with disability in particular those who reside in the remote areas. According to SUSENAS⁹ in 2000, the percentage of persons with disabilities in rural areas is 0.8% higher than those who live in urban areas with a total amount of 0.63% of the Indonesian population (Wirawan 2005). The government operates its services in the main town of a region (Kabupaten/Kota). Poor transportation networks within many regions are a prominent reason why the service of delivery outside the main administrative town of a region is not available. There is even difficulty in some

⁹ Indonesia's national census on social and economic issues.

regional centers located far from Jakarta of maintaining regularly the procurement of goods and services.

Moreover, the demography of Indonesia also adds to the complexity of delivery of services as Indonesian population has variations of language and ethnicity backgrounds. There are over 700 languages, and perhaps 1,000 ethnic or sub-ethnic groups. Approximately 42 percent of population is Javanese, the largest ethnic group who mostly speak a Javanese language or *Boso Jowo* (Burnell and Randall 2008). However, there is still large population, who cannot speak and understand *Bahasa Indonesia* as they speak in local languages, this is particularly the case for people who reside in the regional areas. It actually is really hard to disseminate information to affected people who are from different local languages. Across the country a handful of aides to assist the process are needed for instance. However, there are lots of limitations on staffing making performing of such tasks difficult if not impossible. These are many obstacles that still continue to operate in terms of communicating information about the availability of services to the broader community.

Indonesia administratively (Figure 4.1.) contains 33 provinces (30 provinces, 2 special regions including Aceh and Yogyakarta, and Jakarta as capital city region) that are headed by Governors. Each province is subdivided into district – the decentralized units (*Kabupaten*) and municipalities (*Kota*); as well there are additional administrative units the sub-districts (*Kecamatan*) and villages (*Desa* or *Kelurahan*). Since 2001, Indonesia called for decentralization across the country. Decentralization involves the transfer of management responsibilities and powers from national governments to local institution as a way to increase popular participation in

governance; promote more equitable, responsive and efficient management of resources; and reduce the responsibilities of the centre (Agrawal & Ribot 1999). Decentralization is seen as a way of increasing the accountability of governments to their citizens and of improving transparency of government decisions. For the social services such as education and health, decentralization is often considered particularly important; therefore, the quality of service becomes a key aspect of any process of decentralization. However, it has been found in Indonesia that local governments lack the basic skills for managing the programs to ensure the quality of services and efficiency of public spending (Commins 2009). Unfortunately, mostly the allocation of public spending has been focused on public facilities in cities instead of reaching all regional areas. This problem is exacerbated by the lack of preparedness and capacity of many of the newly empowered local governments to carry out their new responsibilities efficiently as well as the concentration of personnel in an already overstaffed civil service being located in certain legacy areas rather than where they are needed. These problems add an additional level of complexity in terms of delivery of services under the implementation of decentralization in Indonesia. As a result of the situation, the affected people such as persons with disability have to rely on their own capabilities in meeting their basic needs.

Figure 4.1.

The Administrative Map of Indonesia (2011)¹⁰



The map above shows a picture informing Indonesia as the largest archipelago in the world and inhabited by the population of 238 millions in year 2010¹¹ with the population growth rate at approximately 1.50%. The average annual rate of population growth was 2.1 percent during the 1980s, but it declined to 1.5 percent by 1999. Meanwhile in terms of child population, as the table below shows those children between the ages of 0 to 17 years old are approximately about 83 millions in

¹⁰ Source of the map is come from www.nationsonline.org. In addition, there is a new province that has been added in the administrative maps of Indonesia in 2013. It was named Province of Kalimantan Utara (North Kalimantan). Based on this information, Indonesia administratively contains 34 provinces including 403 *Kabupaten* and 98 *kota*. The province has been drafted as a new region administratively since October 2012.

¹¹ Based on the results of Population Census in 2010 (SP2010), the population of Indonesia is numbered 237.6 millions comprising 119.6 million males and 118.0 million women.

year 2011 (SP2010). The large size, diversity and geographical spread of the Indonesian population including its children create a vast task for governments to ensure service provision. In the areas of health and education accessibility needs to be ensured by the Indonesian government. It is widely known that those areas of human services have a primary impact on the welfare of every citizen of Indonesia as part of human basic rights, and these rights had been stated clearly in Indonesian Constitution of 1945. In terms of education services for example, Indonesia is a nation whose constitution obliges the government to run one national educational system; the state is obliged to assign at least 20 per cent of the national budget to education, but also local government budgets are required to support the needs of education system in their areas (Soedijarto 2009). The budget system in education is aimed at providing services universal education from ages 7 to 14 years old (Year 1 to Year 9) for the massive Indonesian population requires pupils to attend classrooms regularly.

Table 4.2.
The Indonesian Population Based on Age and Sex 2011
(In millions)

AGE	MALE	FEMALE	TOTAL
0 - 17	42, 332	40, 206	82, 572
18 +	80, 146	81, 056	161, 260

Source: The Prediction of Indonesian Population year 2010 – 2035 (SP2010¹²)

In terms of the Gross Domestic Product and Human Development Index, Indonesia in 2011 hit a milestone as it chalked 6.5 percent GDP growth, the highest since 1996. Indonesia is also ranked as one of the top 10 upward movers in human development

¹² Sensus Penduduk Tahun 2010 (translating into English is population census in year 2010).

over the past 40 years, as measured by the Human Development Index (HDI¹³). The HDI of Indonesia continued to improve the ranking in 2011 and is in the Medium Human Development group (UNDP 2012). However reducing the poverty situation remains a challenge as 29.2 million people in Indonesia still live below the national poverty line in September 2011. Actually, the proportion of population living in poverty dropped dramatically from 60% in 1970 to an estimated 17% in 2004. However, the achievement received a setback in mid-1997 with the economic crisis (WHO 2008). The World Bank estimated that in 2010, 13.3%¹⁴ of Indonesian population was poor. People with disability are part of the Indonesia population who frequently suffering poverty caused by discrimination in education and employment; as well they very often have a poor quality of life. The rising level of HDI has not seen an even spread of the rise in quality of life of the Indonesian population. Those with disabilities especially are yet to see this rise in the HDI translated into better life quality.

4.3. Definition of Disability and Number of People with Disabilities

From the total Indonesian population, there are about 1.49 million people who are categorized as person with disability. Nevertheless, it is hard to describe the exact population with disability due to poor data and census recorded (Irwanto 2010). The cause of impediment or the definition of disability itself has varied. Especially when the making of the definition has been associated with groups such as NGOs or other countries who have conducted surveys on the disability population. The result thus

¹³ The Human Development Index measures development by combining indicators of life expectancy, educational attainment and income. The index can take a value between 0 and 1. Countries with an index over 0.800 are part of the High Human Development group. Between 0.500 and 0.800, countries are part of the Medium Human Development group and below 0.500 they are part of the Low Human Development group (UNDP 2012).

¹⁴ The rate is the percentage of the population living below the national poverty line.

will yield some differences in terms of counting population with disability. Nevertheless, whilst it appears to be difficult to determine the exact number of disability population in Indonesia, various authorities estimates have been made.

The government conducted its first national survey on People With Disabilities in 1980 as part of the 1980 population census. The survey took place is approximately 5% of household throughout country. In 1995, 1998 and 2000 additional information on People With Disabilities was collected as a supplement of SUSENAS (Irwanto 2010). The initially there was a random survey conducted at some provinces between years 1976-1978. The National Institute of Health Research and Development in the Indonesian Ministry of Health carried out a random survey in 14 provinces. The survey revealed that prevalence of functional impairment was 15.5% and of disability was 14.1% from the total population of 114.8 million at that time. The survey conducted by The Ministry of Social Affairs in 1995 revealed the total population of people with disability was approximately 6.1 millions or 3.2% of the total population of 194.8 millions.

Disability was defined on the basis of functional limitations in mobility, self-care, communication, or learning; therefore, children with disability represent approximately 0.55 % of the population of children aged 0 to 17 in Indonesia. Based on the prediction of National Census 2008, the number of school-age-children with special needs (5-18 years old) were 330,764 children; however, the numbers of children with special needs that have attended educational services in special schools from kindergarten to secondary school level are 85,645 children. As a result, there are 245,119 children who do not attend school (74.1%). Meanwhile, the quantity of

children with autism who studied in formal special education in Indonesia is 638 students (2007/2008). From this it can be concluded that there are still small numbers of pupils with autism attending formal education in Indonesia.

In terms of prevalence of autism in Indonesia, it is still hard to ascertain the exact prevalence and the numbers of the affected children due to the absence of recent data about numbers of children with autism. There is a single estimate regarding the prevalence¹⁵ of autism in Indonesia based on a research conducted by Wignyosumarto et al. (1992). The study found that the prevalence rate of children with autism within the birth cohort who was born between June 1984 and May 1991 was 12 per 10,000. Giving an example of Australia as compares, there was a study conducted by Williams et al. (2008) reported rates of autism from 2003 to 2004 for 6 – 12 year olds to be 9.9 – 40.8 per 10,000. It is important to know the prevalence of autism in a country (Matson & Kozlowski 2011) as recognizing autism prevalence enable the planning of services in order to help the children with autism. The same can be said for other categories of children. It seems that the Indonesian government is still not aware of the importance of producing information about prevalence of autism.

According to Act of the Republic of Indonesia No. 4 of 1997, the definition of persons with disabilities is:

Person with disability is someone who has physical and/or mental abnormality, which could disturb or be seen as obstacle and constraint in performing normal activities, and consisted of i) physical disabled, ii) mentally disabled and iii) physical and mentally disabled.

¹⁵ Prevalence of autism means how frequently autism occurs in the general population (Matson & Kozlowski 2011).

A common sense definition of disability might be that it is a lack or limitation of capacity. Disability is more known by its contrast to an ideal of normal capacity to perform particular activities and plays one role in social life. As the result of this, disabled people cannot be cured but function can be improved through rehabilitation. Disability is used to refer to limitations resulting from dysfunction in individual bodies and minds. The core of understanding disability for most is blindness, lameness, mental deficiency and chronic incapacitating illness (Whyte and Ingstad 1995). According to Nicolaisen (cited in Whyte and Ingstad 1995), disability has been defined as a biological or physical impairment that limits major life activities like walking, hearing, seeing, speaking, breathing, learning and performing manual tasks. World Health Organization (2011) admitted that disability is part of the human condition. Almost everyone will be temporarily or permanently impaired at some point in life, and those who survive to old age will experience increasing difficulties in functioning.

Meanwhile, the Indonesian Bureau Statistic (2012) defines people with disability as person who is no longer able to do the job that provides a decent income earned in accordance with their education, expertise, skills, and experience. Based on this definition as well as according to Indonesian Law number 4 year 1997, the categorization of people with disability includes people who have speech disorders, hearing impairment, behavior disorders, vision impairment, physical impairment, and learning impairment/disability. Disability classification and definitions are according to national standards that were developed by the Ministry of Social Affairs¹⁶. People with disability in Indonesia are addressed in day-to-day conversation as *penyandang*

¹⁶ *Kementerian Departemen Sosial.*

difabel or penyandang disabilitas; meanwhile, *anak difabel or anak disabilitas* means any child with any disability. The term disability in Indonesia covers a range of physical, intellectual and psychiatric conditions that may range from severe to mild. In addition, Indonesia has been aware of the International disability rights movement for some time and has been influenced by the International context and multilateral organizations such as the World Health Organization (WHO). It has in recent decades been endeavoring to build various policies relating to civil rights of people with disability.

Kartari's (1991, cited in Irwanto 2010) definition of disability as being functional limitation and/or impairment leading to existing difficulty in performing one or more daily activities is widely accepted in Indonesia. This definition means that people who are identified as having disabilities will be affected by their inability to perform daily activities. Based on the definition, she divides disabilities into inability to perform social activities, to perform household chores, to perform employment activities and to carry out daily activities. Many Indonesian rehabilitation programs have adopted this understanding of disability. Such as programs are promoted by the Indonesia Government and aim to enable people with disabilities to be independent. The programs have been focused on restoring function and independence for people with disabilities.

4.4. Community Attitudes to Disability

There are difficulties of daily living experienced by persons with disability in many countries including Indonesia. From social-historical perspective, people with disabilities have faced many restrictions due to societal concepts of disabilities, as

well as community and families attitudes to their members with disability. As a result of this, restrictions can affect people with disability regarding how they play a role in society. Social norms can create discrimination towards the disabled in many places, not only in the workplace but also in the community. Although disability is an integral part of Indonesian society and important aspect of human condition, Indonesians have yet to fully understand the situation of the lives of people with disability.

There is a negative concept among society member in terms of interactions with persons with disability. Thus people with disabilities have lived through situations where they have been rejected, hidden and discriminated against in family life and society. In the context of family life, shame is often borne by families who have a disabled family member and the disabled person is often hidden because it is a disgrace to the family. Sometimes the parents and/or family decided to let their children with disabilities live in outside of their home or away from the family home such as in the dormitory of a rehabilitation centre under the residential school program (Steff, Mudzakir & Andayani 2010). This action maybe taken by the parents because they feel embarrassed to have children with disabilities in their home. Moving them to a residential school located far from their home can contribute to creating social exclusion from the neighborhood for their disabled child. It can also reduce some of the burden on the parents' shoulders in terms of looking after them on daily basis. However, this is not surprising, as historically and in many countries, people with disabilities have largely been provided for through solutions that segregate them, such as residential schools. These circumstances usually happen for the affluent family. Meanwhile, poor families who have children with disability decide to keep them from public sight and lock them inside the home. Extended

families from poor households such as grandparents or aunts and uncles share responsibility for supporting and caring for their relatives with disabilities.

The behavior of people with disability can create a sense of shame and pity, even among the family members and community. Lack of understanding is a major factor leading to discrimination and exclusion of people with disability (Jones & Webster 2006). Parents or other caregivers such as extended family members are often feeling fear and shame for their children with disabilities. The result of parental fear can contribute to creating the exclusion and segregation of children with disabilities from the community, particularly for persons or children with intellectual disability such as autism and Down syndrome. The most reasonable parents are concerned to protect the child from accident or from abusive actions from community or other family members. As a result of concern for the protection for their child, many children with disabilities are kept inside the home. It often gets worse as the children grow older and parents cannot manage them; parents sometimes decide to tie up their children in order to prevent them from wandering off or hurting themselves. As stated at Chapter 1, the action parents decided is called as *pemasungan*¹⁷. Many families from rural areas or families who living in poor households routinely applies it if they have a family member who has intellectual disability or mental illness. This is happening due to their inability to control the children who behave abnormally.

¹⁷ In year 2012, Ministry of Health noted about 20 thousands people with psychiatric problems shackled by their families and communities due to tantrum and family feel ashamed of them who suffer from mental illness. According to the definition of the Ministry of Health, the *pemasungan* means that a person is deprived of their liberty taken away, not only chained or shackled with wood, but can be as locked down so that the rights are neglected. The action was taken to prevent they hurt themselves or others, and this action for most people regarded as inhuman, but this is the action that had to be done by the family (Muridan, 2012).

On another case of discriminated from society, people with disability are excluded from employment and education (Wilkinson & Marmot 2003). The result of this situation, they tend to have lower than average levels of income. Therefore, they might not be able to contribute financially to the household as well as community. They will be labeled by the term of unproductive person and worthless. In term of quality of life, they still underwent with a poor of quality. It is not uncommon in Indonesia to come a cross people with disabilities begging at street corners, inside of markets, and public transportation mode such as buses and trains. In some cases, they had been organized to be a beggar for collecting money in order to support the family or organization where they lived in. In general, the attitudes are often reinforced in societies where they are relatively large numbers of people with disability making a living by begging (Jones & Webster 2006).

In terms of intellectual and mental health disability, throughout history people have been treated in degrading, paternalistic, hostile, disrespectful and sometimes cruel ways. They have been institutionalized, marginalized and systematically avoided. People with intellectual disability are often excluded from the types of counseling and personal supports available to other members of the community, and professionals working in these roles are subject to the same misunderstandings and inexperience with this group as the wider population (Goggin & Newell 2005). While there have been significant shifts towards a higher level of acceptance and understanding of people who experience intellectual or mental health disability, in reality community and individuals still view differently people with intellectual and mental health disabilities. For example, people who do not experience intellectual disability are sometimes afraid of interacting with people with an intellectual disability, due to their

own inexperience, lack of understanding and pervading negative social views about intellectual disability. Some people still think that persons with intellectual disability are similar to persons with mental health problems. In Indonesia, people with intellectual and/or mental disability are still considered like an insane man (*orang gila*). The community members often seek to avoid the insane man. This condition causes the person and the family to become isolated from interaction with the wider community due to reluctance of people to accept them as a part of the community (Spicker 2011).

4.5. Government Policies on Disability

In Indonesia, the government sees people with disabilities as an integral part of society and they enjoy the same rights and obligations as other Indonesians. Programs to promote the welfare and total integration of people with disabilities are implemented both by government and non-governmental organization (NGOs). The welfare development program covers areas such as prevention, rehabilitation, social assistance and care.

Currently, there are 12 separate statutes that can be used as the basis to advance the welfare of people With Disabilities in Indonesia. Every governmental agency and institution is required to formulate their own policies, strategies and programs to improve and promote the welfare of disabled persons. Some of the key legislative acts are as follows:

1. Presidential Decree Number 39 of 1983 focused on coordination of social welfare for People With Disabilities. Coordination of social welfare for people with disabilities is carried out through a consultative and coordinative team. All financing related to the duties of the team budget directorate of general of rehabilitation and social services.

2. Government Regulation number 43 of 1998 focused on generating social welfare for disabled person. The term of social welfare according to this regulation includes the equality of job opportunities for people with disabilities. This regulation is structured to provide clarity and outlines the Law No. 4 of 1997 with respect to improving the social welfare of people with disabilities by covering the equalization of opportunities, rehabilitation, social assistant and maintenance of social welfare. This regulation sees these as being implemented by shared responsibility between local governments, communities, families and people with disabilities themselves. Article 11 (2) of this regulation states that government information services should be provided through channels of voice, sound and text catering for people with visual and hearing disabilities. Provision of accessibility is to be achieved by considering the ability of government and society, and based on the needs of and priorities of persons with disabilities (article 20, paragraph 1). Article 25 of this regulation also states that the need for special education for persons with physical or mental disabilities should be met.

3. Presidential Decree number 83 of 1999 focused on agency for coordination and control in generating social welfare for People With Disabilities.

4. Government Regulation number 2 of 1988 on Child Welfare. This regulation is intended to improve the welfare of children in Indonesia. The focus is on the welfare of children who are categorized as abandoned, orphans, disabled, poor children and children who delinquent.
5. Government Regulation number 20 of 2003 focused on the education system in Indonesia. This regulation recognizes early childhood education (the Early Childhood Care and Education in Indonesia), which is not part of the formal education system. According to this regulation, this program is a step towards basic education and stipulates children to attend classroom after completing the ECCE. The Early Childhood Care and Education system can be organized into a formal, non-formal and informal format. There is cross-sectoral departmental responsibility and accountability its implementation.
6. Government Regulation Number 72 of 1991 focused on special education for People With Disabilities. This regulation stipulates equal rights and access for children and persons with disabilities to education and defines guidelines on the establishment and arrangement of special education at primary and secondary education levels.

There are various policies for person with disability including children with disability as target population of the policies focusing on the different areas namely education, health and social services. The existence of various laws such as Law no 23 year 2002 on Child Protection, Law no 20 year 2003 on National Education systems, Law no 36 year 2009 on Health and Law No. 11 year 2010 on Social Welfare. These policies

demonstrate the extent to which the Indonesian government has been concerned and built some foundations to improve the welfare of children in general and children with disability in particular.

According to law number 23 of 2002 on Children Protection, the definition of children with disability is a child who has a physical and/or mental impairment that can limit their development as a child. This law stated that it is compulsory for the government to facilitate some services to all children with disabilities in Indonesia, and these children must have their needs for special treatments and protection met not only coming from family and community but also specifically from governments – either National or Local. Under the implementation of this law on Child Protection, the Indonesian government has targeted early detection, early intervention and education programs for children and youth with disabilities. This law set a target that by 2015 all boys and girls will complete a full course of primary schooling. By 2010, at least 75% of children and youth with disabilities were able to complete a full course of primary schooling.

The right to education for all children with disability has been enshrined in this Indonesian Law number 23 of 2002. In the field of education, all children must attend and complete courses at least for 9 years starting from Primary school to junior school (year 9) including children with disability. This compulsory provision of schooling attaches to all children with disability in special school as well as normal children at mainstream schools. The Indonesian government has prioritized integrated education. Integrated education is a model of education for children with disability, which sees them being educated jointly with normal children in a general education institution.

In terms of special education in Indonesia, historically the first special school for children with disability was established in Bandung, West Java in 1901. Later, the Indonesian government has opened some schools for children with developmental disabilities. In 2000, the Indonesian government developed special education by expanding the Education to include the Directorate of Special Education. This Directorate decided to start the process towards inclusive education to increase the process of enrolment for children with disabilities and other special needs children in regular schools. The mission of the Directorate is to enlarge the educational services for all children with special needs. An inclusive school is a school for children with disabilities who attend class joining with normal children in one place. The basic law of inclusion education in Indonesia is the Indonesian Constitution article 31 that any citizen shall have the right for education and learning. Meanwhile, the law 20 of 2003 on national education system article 2 stated that citizens with physical, emotional, mental, intellectual, and/or social disability should have the right to special education. The constitution established the legal framework for the rights of person with disability and/or children with disability to be included in the education system, as well as the obligations of the state and society in general toward disabled populations.

Meanwhile, there are some laws and regulation underpinning the implementation of Inclusive Education in Indonesia as follows:

1. The 1945 Constitution of the Republic of Indonesia; article 31 (1) “Every citizen has the right to receive education”, (2) “Every citizen has the obligation to undertake Basic education and the government has the obligation to fund this”.

2. Act No.4 year 1997 on people with disabilities; article 6 “Every person with disabilities has the right to get education at all education units, programs, type, and level of education.
3. Act No. 23 Year 2002 on Child Protection, article 48 – 53.
4. Act of the Republic of Indonesia No. 20 Year 2003 on National Education System, article 5, 12 and 32.
5. Act of the Republic of Indonesia no. 28 Year 2002 on Construction Building, article 27, 142, 146.
6. Draft of regulation of Minister of National Education on Inclusive Education article 4 and article 5 include children with special needs. In article of 5, it is stated that pupils of the inclusive education include pupils with special needs and pupils in general.

The Ministry of National Education has some policies focusing on the implementation of Inclusive Education in Indonesia, as follows:

1. Circular Letter of Directorate General of Primary and secondary Education No. 380/C.C6/MN/2003.
2. Indonesia Towards to Inclusive Education, known as Bandung Declaration 2004 (UNESCO 2009). This policy aims to:
 - Ensure that every child with disabilities and other children with special needs receive equal access in all aspects of life (education, health, social, well being and security).
 - Ensure that every child with disabilities and other children with special needs grow as dignified individuals to receive good humane treatment, and quality education which develop their potentials and meet demands of the society.

- Implement and develop inclusive education supported by good synergy and productive cooperation among stakeholders in particular government, educational institutions, related institution, and parents as well as society.
 - Continuously promote and socialize inclusive education through mass media, scientific forum, and education.
 - Design plan of action and allocate the needed funds to promote physical as well as non-physical accessibility, quality education service, health and well being of all children with disabilities and other children with special needs.
3. Guideline of inclusive education implementation.

The Indonesian government also has programs aimed to train teachers through pre-service and in-service training in order to train teachers so they can teach children with disabilities and special needs. The institution that's responsible to implement the programs is called the Centre for Empowerment and Training for Teacher and Education Personal in Kindergarten and Special Needs Education. This institution provided a specific program relating to specific special services such as services for children with autism, therapeutic play, etc.

The Indonesian government provides education for children with disabilities in special schools. Administratively, special education is under the management of the *Direktorat Sekolah Luar Biasa*¹⁸, a directorate in the MONE that takes responsibility on the implementation of Inclusive Education in Indonesia. Special education is

¹⁸ The directorate of Special Education, and under the 2003 Education bill the task of this directorate has been divided into two – special education (*Pendidikan Khusus*) that taking responsible for organizing education for children with disabilities, and special educational services (*Pendidikan Layanan Khusus*) is responsible to manage education for other marginal groups such as elderly persons, abandoned children or people reside in the remote area.

provided at the primary and secondary education level and is part of the national education system in Indonesia. Students with disabilities can enroll at:

1. SDLB / Sekolah Dasar Luar Biasa (Special Primary School)
2. SLB / Sekolah Luar Biasa (Special school consisting of kindergarten, primary school, junior secondary school and senior secondary school)
3. An integrated school
4. Inclusive school.

There are many categories of special schools (SLB) that each of which is intended for a specific type of disability as follows:

- SLB – A Special schools for visual impairment (*Tuna Netra*)
- SLB – B Special schools for hearing impairment (*Tuna Rungu*)
- SLB – C Special schools for mild intellectual disability (*Tuna Grahita Ringan*)
- SLB – C1 Special schools for moderate intellectual disability (*Tuna Grahita Sedang*)
- SLB – D Special schools for mild physical impairment (*Tuna Daksa Ringan*)
- SLB – E Special schools for emotional and social behavior difficulties (*Tuna Laras*)
- SLB – G Special schools for multiple disabilities (*Tuna Ganda*)
- SLB – M Special schools for children with autism (*Autis*)

Inclusive education¹⁹ in Indonesia is a priority from the Ministry of Education in order to spread educational services for all children with special needs (CSN). Under

¹⁹ *Pendidikan Inklusif in Bahasa Indonesia*

the inclusive program, children with disabilities such as autism and Down's syndrome are enrolled in regular schools, in which teachers have received training on how to deal with the children with special needs. The policy direction and focus of national education development priorities is based on three pillars; they are: (1) expansion of access and equality of education; (2) improved equality, relevance and competitiveness; and (3) strengthening of management, accountability, and public communication. In the term of inclusive education, the first pillar gets a vast attention, which is completing the compulsory nine years primary education with quality and equality through the application of special education, special services education and inclusive education (UNESCO 2009).

An integrated school or inclusive school is a regular school in which students with special needs are learning together with children without special needs. The Indonesian government is piloting an inclusive education program in several schools in several provinces. There are approximately 240 special schools run by the government and 760 by NGOs (International Bureau of Education 2009). In these school, students with disabilities study together with normal student within a regular classrooms. In order to succeed the pilot programs, school managers and teachers of the pilot school are offered training in the area of inclusive education.

Inclusive education has become the main program of the Indonesia government since 2003 for providing education for children with special needs in mainstream schools. However, many schools are not aware how to conduct the inclusive education. Despite government policy intent children with disabilities who live in rural and

remote areas still have little access to educational facilities, and most regular schools do not have accessible facilities for children with special needs.

Therefore, there are many problem and issue relating to the implementing of special education. Those problem included (1) the numbers of special school are not enough to supply the needs of children with special needs, (2) the special schools are located in major cities rather than rural areas, and (3) the lack of adequate facilities to promote special education. According to the SUSENAS survey in 2000, 43% of school-aged children with disabilities did not attend school.

It should be noted, the collection and analysis for this thesis of Government policies relevant to autism in Indonesia was primarily conducted in 2010. Since then there have been some important developments on how the Government of Indonesia reacted to new developments in the disability area. In 2011 the Indonesian Government signed the UNCRPD. The UNCRPD is the United Nations Convention on the Rights of Persons with Disabilities (UN 2006). This organization has as its main task to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. The task it also has is to promote respect for the inherent dignity of people with disabilities. By signing this, Indonesia committed to follow and adopt some UNCRPD principles, and to ensure an Inclusive Education System at all levels and for life-long learning. Indonesia has developed policies and/or programs to serve people with disability and to empower them to live with their dignity. Therefore, following the signing of the UNCRPD by the Indonesian government, the government issued Government Regulation number 19 of 2011. The regulation ensures all Indonesians with

disabilities obtain the same human rights to dignity as other people in the Indonesian population.

One of the principles of UNCRPD is respect for the evolving capacity of children. Indonesia as a country ratifying the UNCRPD principles has some obligations to do so through delivering education services for children with disability. The Indonesian government has committed to taking appropriate steps to accommodate the affected children by ensuring children with disability obtain access to attend classrooms on a daily basis, and the government is seeking to ensure all affected children the enjoyment of educational services on an equal basis. Since this effort, there is evidence that the government is adopting UNCRPD principles to influence new policy in the disability area in Indonesia. In terms of funding for education services, the Indonesian Government, along with the BOS (*Bantuan Operasional Sekolah*, the general per capita funding for either public or private schools) issued additional funding for pupils with disability who attended in special schools (SLBs or *Sekolah Luar Biasa*) in 2012. The funding is called the BOI (*Bantuan Operasional Institusi* or in English the Institution Operational Supports).

4.6. Service Provision and Support of Person with Disabilities

The World Health Organization (2011) states that rehabilitation is important for people with any disability. Rehabilitation is essential to being able to participate in education, the labor market and civic life. In all cases, rehabilitation programs should help to empower a person with disability and his or her family. Article 26, Habilitation and Rehabilitation, of the United Nations Convention on the Rights of Person with Disability calls for:

... appropriate measures including through peer support to enable person with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

Additionally, the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities states that rehabilitation and medical care should be requirements that are met for persons with disabilities in order for them to obtain and to enjoy equal participation in their family and communities. Meeting these requirements is important for any persons with disabilities to empower themselves to be active in the community. However, in the field of global public health, rehabilitation services is still under review by governments in developing countries as they are still more focused on combating other diseases. For example, Indonesia still faces some infectious disease public health problems including Tuberculosis, Malaria, Pneumonia among vulnerable persons such as children and elders, and many more. Therefore, the availability of rehabilitation and medical rehabilitation in Indonesia has been overshadowed by efforts to combat these problems.

Government priorities in the area of disability have focused on supporting the person with disability so they are able to adapt or be adapted to the environment and get a job. From this perspective, the primary goal of most rehabilitation programs is to prepare the person with a disability for work (Bryan 2010). Thus most legislation supports this effort and the emphasis is on self-reliance of people with disability through involving them in the rehabilitation process. In Indonesia, rehabilitation programs are essentially aimed at making people with disability more independent. The rehabilitation programs are run by some government agencies that have been taken by two different ministries. In the field of education, the agencies are involved directly with disabilities is Special Education Directorate under the Ministry of

National Education of Republic Indonesia. This directorate has a program that is divided into several types of school based on disability students carried. It is known that most schools in Indonesia are still under government funding through the *Bantuan Operasional Sekolah* (BOS) scheme and this occurs since decentralization in Indonesia. This scheme also has been applied for school performing the special education or Inclusive Education.

Meanwhile, the Directorate of Social Rehabilitation Services and Disability under the Ministry of Social Affairs of Republic Indonesia has responsibility to provide rehabilitation for disabled people. The programs aim to help people with disabilities through efforts to increase community participation in organizing social services and rehabilitation of persons with disabilities, expand the range of services and social rehabilitation for people with disabilities, improve the quality and professionalism of social and rehabilitation services, both those organized by the government and civil society, and strengthen social services and rehabilitation management with disabilities. Service efforts for people with disabilities include social rehabilitation, social assistance, maintenance of living standards and accessibility programs.

In terms of accessibility for people with disability, the Indonesian government has programs concerned with giving easy accessibility. This program called the National Public Accessibility Movement (GAUN²⁰) 2000. This program aims to focus on people with disabilities in order to obtain the services that any other normal person would have. The aim is that persons with disabilities will have equal opportunities (Rusdiansyah 2005). This program appears to be more geared towards an

²⁰ *Gerakan Aksesibilitas Umum Nasional.*

infrastructure development for facilitating mobility of people with disabilities, and this policy also emphasizes local government's role to monitor public buildings and ensure they provide some facilities accessible to persons with disabilities such as toilets, parking lots, lifts and safety roads for persons with any disability who use the facility and reside in the buildings. However, this program has only been implemented in urban areas; its outcomes are hard to find in rural or remote areas. Accessible buildings providing are not available in the rest of the country as this kind of buildings is only in some big cities such as Jakarta, Bandung, Yogyakarta, Surabaya, Medan and Makassar.

According to Government Regulation number 43 of 1998, the development of services to people with disability includes their access to information. The information can help the affected people to understand situation. This type of service is called as special services. Special services are intended to provide information for people with disability relating to the transportation mode that can accommodate them, designated road with ramps, the buildings and public facilities providing access for disabled persons. However, for example, there is not yet a widespread system of transportation services for people with disabilities. In these circumstances, persons with disability must rely on their own ability to transport themselves to a desired place. For example, parents of a disabled child must manage by themselves when they decide to bring the child treatments. The inaccessibility of transportation systems to accommodate persons with disability can become barriers to acquire an appropriate health services as a results.

In the terms of provision of education service for children with special needs, the implementing of special education and inclusive education are divided into two institutions, namely government schools and private schools. In the fact, the higher percentage of the implementation of education for children with special needs is held by private institutions (76%) in which the implementing of special education includes funding support, special planning of school programs and building of accessible schools. Some of these private schools providing special education are provided by national or local organizations based on religious values, others are secular, non-profit organizations (*Yayasan*). There are approximately 630 special schools run by the government and 1,112 by private organizations. For example, the *Muhammadiyah* as a charity based-religion organization runs 71 special schools (*Sekolah Luar Biasa*) throughout Indonesia (*Muhammadiyah Network 2010*). Another example, the *Yayasan Pendidikan Anak Cacat* (YPAC) provides education services for children with disabilities through the implementation of the inclusive education. Meanwhile, the quantity of children with autism who studied in formal special education in Indonesia is 638 students in 2007/2008 (UNESCO 2009). Children with autism can enroll in special schools (SLB²¹) – M, a type of special schools for children with autism. According to Department of Education 2008, there are 20 M-typed special schools in Indonesia. Most of these schools were run by private organizations such as foundations, charity organizations and religious organizations (mostly by Islamic and Catholic schools).

There is an interesting phenomenon in Indonesia related to the existence of special schools for children who are diagnosed with autism, where the establishment of the

²¹ *Sekolah Luar Biasa*.

institution was based on the awareness of parents of children diagnosed with autism to establish special schools. This was the case for the school in which this study is based; the reason for the establishment is the lack of the availability of education services for children with autism, and the Indonesian government having not yet paid attention to the needs of the affected children. It triggers some parents of children with autism to initiate the building of private institutions for providing education services for their own child as well as for others children with autism. On this point, the government is still struggling to implement article 31 of the 1945 national constitution of Indonesia that states that education is a right for every citizen without exception. This and subsequent policy legislation as discussed above provides a clear mandate for the government to shoulder the responsibility for providing the services for children with autism and with disability in general.

However, most people with disabilities in Indonesia go without government welfare, specialized medical treatment and assistive technology (Byrne 2013). Indonesia is still struggling to provide funds to maintain the social welfare of people with disability. Therefore, it is hard for any person with any disability to get funding to meet their needs in particularly in the area of health and education. If they intend to obtain funding for their care, actually there are several programs devoted to the interests of all Indonesian citizens in general but there are very few programs specifically designed for people with disability. There are two funding schemes that Indonesian populations would recognize as schemes that should support people with disabilities. The first scheme is BOS that is intended especially for all school pupils who enroll in any school. The scheme aims to help many pupils – either with special needs or not – ensuring they are able to attend classroom regularly. Another scheme is

JAMKESMAS. The Jamkesmas is intended to support the poor and the nearest to poor to gain free health services in Community Health Centers (PUSKESMAS²²).

These schemes I review in brief as follows:

4.6.1. BOS²³

In terms of education funding, the Indonesian government had decided to increase its education budget by 20% from the overall of the National budget or APBN (UNESCO 2009, p.35). Funding for special education and inclusive education are separately allocated from general education with 0.74% of the National Education Budget, for instance, the funding of those programs was Rp. 328,000,000,000 in 2009 from the total of Education budget (Rp. 44,058,393,000,000), which is managed by the Directorate of the Special Education. The responsibilities of this directorate included (1) developing policy for special education, (2) planning and programming the development of special education, (3) developing and standardizing curriculum and evaluation system for special education, and (4) monitoring and evaluating development programs for special education. In addition, the government provides subsidy for inclusive education to make accessibility, equipment and supporting infrastructure for inclusive school providers. This subsidy may compensate the children, particularly for the children whose parents have relatively low income. Although the subsidy is given to the school, the amount each school receives depends on the number of students enrolled in the school.

The prominent method of funding education services is the School Operational Assistance (BOS). There are some law bases for this scheme including the 1945

²² *Pusat Kesehatan Masyarakat.*

²³ *Bantuan Operasional Sekolah (School Operational Assistance).*

Constitution Article 31 of paragraph 2, which states, "Every citizen is obliged to follow the compulsory basic education under the government funding". Another regulation is the Law number 20/2003 on the Indonesian Education System that states that every citizen aged 7 to 15 years must obtain a compulsory basic education. The article 34 of this regulation states that the national and local governments must ensure the implementation of the policy by providing school education without charge. Based on these policies, the Indonesian government issued the policy called with the *Bantuan Operasional Sekolah* (BOS) since July 2005. The BOS is a government program providing funding for non-personnel expenses for schools. This scheme aims to ease the burden for financing public education in the context of the 9 years of compulsory education in Indonesia. Funds are provided to all students who are attending school by the implementation of this scheme. The targeted pupil of this scheme is person who is currently attending school, either at the primary or secondary level (BPS 2012).

This scheme also targets all pupils with disabilities who are attending at special schools. The entire amount of the BOS funds received by the school must be used towards the expenses of the operation of the school itself. Thus, schools should not charge such for operations to the students concerned. As a result, students attend class free of any charge. Meanwhile, it is widely known that the needs of the pupils who are attending at special school are different comparing with pupils at regular school. In fact, the assisting money received by disabled pupils is equal with pupils with non-disability who are attending the regular classroom; meantime, their needs are totally different. As a result, the scheme does not meet the needs of pupils with disability for helping them obtain an appropriate education services. Thus the Indonesian

government through the Directorate of Special Education and Special Services under the Ministry of Education issues additional funds for pupils with disability through a program called the *Bantuan Operasional Institusi*²⁴ (BOI).

In general, the accessibility of education services for children with disability is still relatively far behind comparing with the normal pupils in regular school in Indonesia. Educational services for children with special needs require adjustment in teaching and learning. Therefore, the adjustment needs to be aided by the provision of facilities and infrastructures to suit with the circumstances of educating the children such as autistic pupils. In terms of the activity inside the classroom, due to the very special needs of an autistic pupil, more attention from the teacher and teacher assistant to handle the process of learning is needed. It is widely known that the teacher or teacher assistant must assist every pupil with autism during the class activity. This one-on-one requirement is rarely used and there are major limitations of education staff to manage class activities on a daily basis that cater to the needs of children with autism.

4.6.2. JAMKESMAS²⁵

Health is the most valuable asset for a person. The founders of Indonesia were fully aware of the importance of health; therefore, health has become a key point mentioned in The Indonesian Constitution 1945. Health law 23 of 1992 formulated health as the state of welfare both mentally and physical that allows every citizen to flourish. This law states that the government is responsible for providing health services to every citizen. According to the World Health Organization (WHO), it is

²⁴ The Institution Operational Supports is an additional funding under the BOS that is given to special schools. The mechanism is similar with the BOS. It means that every special school receives funding assistance from BOS dan BOI.

²⁵ Jaminan Kesehatan Masyarakat (Public Health Insurance).

estimated that there are 16 physicians for every 100,000 people in Indonesia. There are 34,600 physicians and 108,000 nurses conducting health services out of 680 public hospitals, 7,237 public health centers, and 21,267 sub-centers. Total expenditures on health were Rp. 18,475,260,479,000 in 2008 (WHO 2008).

There are health institutions associated with government health services in Indonesia operating at different government levels: national, provincial, and district or municipality. At the level of the district or city there is the District Health Office which has the main task of addressing and handling Hospital care - any type, and public and/or private, and Community Health Centers (Puskesmas²⁶) - each district or city has an average of 1-3 community health centers depending on population (Ito 2001).

The government of Indonesia and non-governmental organization (NGOs) provide health, education and other social services for persons with disabilities. Health services, preventive, curative and rehabilitation services are promoted and provided in Indonesia. The provision of rehabilitation services within Indonesia began in 1950s and is part of the National Development Plan. Health services in Indonesia have developed since 1969 through the implementation of the national Development Plan. As a result, many hospitals have added rehabilitation units to their existing facilities in order to prevent and address disabilities caused by illness or accidents.

An integrated health service system for villages has been effective for the early detection and identification of infants with disabilities. The community health centers

²⁶ Pusat Kesehatan Masyarakat.

that are located in every sub-district have become important links between the community and main branch hospital. Meanwhile, the government provides the medical rehabilitation through its specialized hospitals, the orthopedic hospitals and general hospitals. Pechack & Thompson (2008) stated that medical rehabilitation ideally includes medical care, rehabilitation nursing, physical therapy, occupational therapy, speech therapy, psychosocial therapy, prosthetic and orthotic services, and vocational therapy. In Indonesia, there are medical rehabilitation centers in the major cities of Jakarta, Medan, Surakarta, Yogyakarta and Makassar. Yet it is hard to find the centre outside of those cities. In fact, rehabilitation facilities for the other type of disabilities such as visual and hearing impairment, and intellectual disability are still limited.

In term of funding health services, Indonesia has some programs focusing on health insurance targeting the population particularly those who live in poverty or just above that. The prominent scheme was the JAMKESMAS/JAMKESDA targeting to the poor and the nearest poor aiming to increase access to health care services and financial protection for the poor (Dwicaksono et al. 2012). This scheme was previously called the ASKESKIN (*Asuransi Kesehatan bagi masyarakat miskin* - public health insurance for the poor), and in 2008, the scheme evolved into *Jaminan Kesehatan Masyarakat*. The goal of this scheme is intended to achieve universal health coverage for poor population in Indonesia, and had been expanded in enrollment to cover over 70 millions people. Meanwhile, the *Jaminan Kesehatan Daerah* or JAMKESDA (translation: public health insurance on district) established district-based insurance scheme that cover the poor or those not covered under the JAMKESMAS and is designed as extension of the Jamkesmas. District can add

specific services to the scheme that the Jamkesmas does not. The target population of this scheme is persons not covered by ASKES²⁷ (*Asuransi Kesehatan*) or any private health insurance.

The users of health services can use this scheme to get health care at Community Health Center or public hospitals. But in reality, many users who reside in rural or remote area prefer to visit the Community Health Centre rather than public hospitals due to barriers of transportation. They will go to public hospital if there is not availability of particular services they need in the centre (Dwicaksono et al. 2012). The scheme is allowing all Indonesian to use health care services without charge. The free of charge services include medicines, surgeons, inpatient and outpatient care, and blood transfusion. This scheme excludes the ambulance services, and this can make it hard for poor patients to get transport into local health centre or public hospitals.

The targeted population of this scheme is Indonesians regardless they are persons with disability or not, Indonesians who are poor and nearest poor. It means that any person with any disability can also use the scheme for getting health care services with no fee charge. The scheme nevertheless is not providing some services to meet disability needs such as therapies and rehabilitation care. It is widely known that the cost of therapies and rehabilitation services for people with disability are expensive and particularly since they must often extend throughout their life. They as person with disability need these crucial treatments in their life. As a result, they still rely on an out-of-pocket funding to pay some of those treatments. For poor disabled persons, a

²⁷ *Asuransi Kesehatan* (translation: health insurance) is intending to person who are working as Public Servants in across of the country, and this scheme also cover their family on health expenses including in and outpatient care. They can use the scheme in the private clinic for limited services.

good and regular health care services will be more difficult to obtain as they are not able to afford the services.

In conclusion, Indonesian government has many policies and programs intending to accommodate the needs of people with disability. Some of the general provisions for the Indonesian population of education and health services provide some support for disabled people. The policy intention of the Indonesian government is clearly aimed at meeting the needs of the disabled and legislative provision of policies has been strengthened in recent decades. Nevertheless, there are many gaps between legislated policies and their implementation. The following chapters describing how the mothers interact and experience firsthand the reality of implemented policy in action through services for the children with autism.

Chapter Five:

The Life Journey of Mothers of Children with Autism

5.1. Introduction

This chapter explores the life journey of mothers raising and caring for children with autism. The journey starts from the early life of their child and extends to their recent situation. This is a journey that includes mothers' struggles with caring for their child; it's also a journey that brings them into a network of health and educational specialists that can provide support but also presents challenges. The views and experiences of mothers presented in this chapter are mostly based on the individual interviews with them as a mother of a child who has been diagnosed with autism. The interviews were conducted in November 2011 to February 2012.

5.2. A Promised Future or a Nightmare

In this section, I describe the experiences of mothers from their hopes upon the birth of this child, to their first understanding of the child's condition, to how they developed an understanding of the reality of their child's health condition. Every mother dreams that her baby will be healthy. When a woman has a baby, she acquires with it the role of mother. In some families or cultures, babies or children may be regarded as necessary to a marriage or a family; they are often wanted for companionship, and to create a full family life. For some mothers, the arrival of a baby brings to life their joyful hopes. In the context of Indonesia - and particularly in the Javanese community - the birth of a baby is celebrated by praying and hoping that the child will bring happiness and a hope that the child will have a better future than the parents experiences. Sometimes it has been a dream since before they were

married. One mother (M5) mentioned: “ I have always dreamed of having a healthy child since I was single”. Every baby born, every child will take a place in a family and a community that has anticipated their arrival with joy and hopes. In some places and cultures, the baby is seen as providing future security for the family. Babies or toddlers who grow into adulthood are expected to be able to help their parents. For example, one mother (M9) mentioned that she had vast hopes that, someday in the future, her expected baby would help her and her husband to cultivate the farm; she expected a healthy baby who could fulfill this future role.

When that child, who they had dreamed would grow and develop into a healthy young adult, did not experience smooth progress and development, they started to realize something was different about their child. Then they questioned the cause of their children growing up “improperly”. At this point, mothers in this study diverged in the way they understood and accepted the situation; this study revealed a range of coping strategies.

5.3. Blaming Herself

One strategy some mothers used was to look for causes of their child’s disability; in doing this they often blamed themselves. They sensed that there must be an explanation of their child’s disability, and they searched for such an explanation. One mother (M9) said that what happened to her daughter was the result of a mistake against her mother that she (the mother in this study) had committed when she was single. According to M9, her daughter’s autism was a kind of punishment from God. She explained:

I sometimes wondered to myself, my born daughter might be a kind of punishment on me as I have dared to oppose and fight against my mother who ... gave birth to me. God has punished me for it. I never thought that my daughter would be born this way. What I expected is my daughter would look like her eldest sister, a healthy child.

Another mother indicated that the reason her child was not healthy was because of mistakes during her pregnancy. She mentioned that it was difficult for her body to take in enough nutritious food; she believed that this impacted on her daughter. She thought that what happened to her child was the result of her inability, during her pregnancy, to eat well because of nausea; therefore, she blamed herself for the abnormality of her daughter. She said:

At the time of my second daughter's pregnancy, I had a pregnancy problem. It was hard for me taking any food, even just a couple of fruits. When I ate, I always vomited and threw the food back on the floor. Until the seventh month of pregnancy, my body was vulnerable, as I could not consume enough food. I was thinking all the time, it might have an effect on my pregnancy. The result of this, I gave birth to an unhealthy baby, I guess. (M9)

5.4. A Polluted Environment

Another belief developed by some mothers as they looked for explanations of what was happening to their child was that the bad environment had affected them – that the place where she lived during her pregnancy was the cause of her child's disability. One mother (M8) said that the location of her home was bad and had unhealthy sanitation, including polluted water. She added: "We consumed water from the wells near our home and I thought perhaps it was contaminated"; she thought that this contamination was a possible cause for her daughter being born disabled. One other mother (M3) believed similarly: that an unhealthy environment had contributed to her daughter being born with autism. She explained:

When I was an undergraduate in university, I lived in the boarding house near a smelly murky river. I always bought some foods and groceries at the shop near it. Sometimes I thought maybe lots of bad bacteria on my body affected fetal development when I was pregnant with her because I regularly bought contaminated foods since I was student.

These two mothers (M3 and M8) had similar but separate views about how environmental factors in the place where they lived during the pregnancy caused the autism of their child. However, scholars still debate whether the environment is a cause of autism. The mothers in this study had no information about the cause of their child's autism, so they thought that the cause of autism in their children was either malnutrition during pregnancy, or a mistake they committed towards their parents, or spiritual challenges, or a polluted environment. While there is no evidence to support these views on possible causes of autism in their child, doctors and researchers still have no clear understanding of the causes of autism in children. However, these mothers' lack of information on the causes of autism led them to consider possible reasons why this has happened to their child; they looked at all sorts of factors to fill the 'information gap'. Their explanations align with broader Asian views identified by other researchers: that disability is viewed as a consequence of inappropriate past deeds (Berger 2013).

5.5. A Shocked Moment

The second stage in the mothers' journey started immediately after their child was born. Mothers often noticed something was different about their children when they compared them with siblings or with another child. Some mothers noticed, in the first two years of their child's life, what they later come to recognize as signs of autism. When they found no unexpected conditions on the body of their child, they looked for

comparisons with other children. They began talking first with family members including mothers, mothers-in-law, sisters and sisters-in-law. After conversations with family members, some mothers felt unsatisfied, and then sought discussions with a neighbor or a close friend who had a child with autism. Sometimes someone they knew told them about other friends or family members who have experience bringing up a child with autism.

One mother (M9) mentioned that first she talked to her mother-in-law, as her own mother lived in another town. She and her husband shared a house with her husband's parent. She said: "I asked my mother-in-law why my second daughter did not walk and did not say any words at age of almost two years old. This daughter was totally different from her eldest sister who was a normal child. And my mother-in-law just comforted me with saying: 'You do not need to worry too much about your daughter as every child will grow up differently'. Her answer did not make me happy as I knew that my daughter suffered something and I still did not know what it was". This mother later turned to her eldest sister for a deep discussion about her second daughter's health.

To take the discussion outside the family was viewed as a big step, and was not taken lightly. But some mothers did decide to discuss their child with people outside the family in their effort to obtain information about this child. Having discussions with other people who have a child with autism made those mothers feel less isolated. According to those mothers, these conversations were important; they learned from each other. Sometimes they also gained knowledge from conversation with the neighbors, family members and close friends on particular aspects of autism. One

mother (M4) mentioned this: “I also asked ... some mothers who have children like my son about anything on autism matters, particularly on ... his [slow] development. He was not a normal child. I as parent had a huge worry at that time”.

Some of the questions troubling them related to what they saw as the health of their child. They were particularly concerned about their child’s early growth and development, which looked different when compared with other children. According to some mothers, one characteristic of their child included being hard to cuddle or be hugged or be handled by their mothers. This was very challenging for most mothers, as most mothers want to be physically close with their baby; mothers believed the babies or toddlers were hard to cuddle because they had something wrong with their bodies. One mother (M3), when saying that her daughter was hard to cuddle or to handle, conveyed her distress that her daughter cried when she tried to hold her. She added:

My daughter seemed to have her own world; I could not enter her world. I did not know what she wanted there. She was always walking around home every single minute. Sometimes what she was doing is running in all directions. Every night was a nightmare for my husband and me, as she could not sleep. When the night came, I lay her down in her bed, but she tried to get out from her bedroom by banging the door and trying to pull the door lock...she seemed to give a sign she wanted to get out. How sad for all mothers in the situations like this.

One mother (M7) said that her second son used to sit by himself in the corner of their house and make a bizarre tone or a weird vocalization. However, she added that her son loved to do coloring in a book of animal images. She said: “My son would not make a bizarre tone if he was doing his coloring the book”. Some other mothers mentioned the difficulties their child had with communicating, walking, or holding

something in their hands. One mother (M17) mentioned how hard her son found it to hold something in his hand, even just a spoon or fork. As a result of the characteristics of their child, it was difficult for some mothers to understand what their child really wanted. Another mother (M16) explained the difficulties her third child had when communicating verbally with other people:

My third son is suffering autism. I remembered when I first ... knew the symptoms of autism on him. He suddenly stopped talking and communicating with us, he then could sing a lullaby song and make sounds, and later he stopped singing it. At age of 2.5 years old, my son was not able to point at what he wanted. If he wanted something, he would walk to a person near him, and grab his or her hand and take the person over to what he wanted.

Another mother (M9) mentioned how difficult her daughter found it to talk with other people; as she explained: “My daughter screamed when other people, who are not her father or sister, tried to talk or communicate to her”. Some mothers recognized their child had difficulties making eye contact with other people. One mother (M2) said: “He (her son) did not care about other people, even me. He did not look at me and he was not aware of my presence. He refused to [make] eye contact with me. It made me upset”. For many children with autism it is very difficult to make eye contact or communicate with people, even with those closest to them, including their parents or siblings. And it is a common pattern for them to demonstrate their refusal by screaming when someone else is trying to communicate with them. This affects even breastfeeding; one mother (M9) mentioned how difficult it was to feed her child when the time came for her baby to drink, either breast-feeding or bottle-feeding. She said: “Every time I gave a feeding to my daughter, she never responded. I needed to get her

attention by opening her mouth, and her eyes looked at the ceiling, instead of my eyes”.

These statements by mothers show clearly that their children had some unusual behaviors, which they realized after seeing and comparing them with other children, whether siblings or unrelated children. Those behaviors led the mothers to feel scared. As a result, the mothers were alarmed as they continued searching for information about the behavior of their child. Mother M9 mentioned that she continued to seek any information related to her daughter’s health. At this point, these mothers needed help from other people.

5.6. The Conflicts

This section is about the conflict mothers faced after their child’s disability had been diagnosed. The conflicts could be within the mother herself or could involve other family members. The mother faced inner conflict (internal conflict) when she felt that, while her child looked physically normal, the reality of the child’s behavior did not seem to be normal. A different kind of conflict was that between the mother and other people, including her husband or other family members.

Internal conflict develops within the mother if she cannot accept the condition of her child. Some mothers, as a result of this inner conflict, began to treat their child like “normal” children. One mother (M4) said: “Sometimes I asked my son to play football. I just wanted him to play football like any other normal child”. It is a form of inner conflict that mothers wrestled with when trying to accept the reality of a child

with autism, given that their child *looks* physically normal and healthy, but does not act normally.

This situation made them confused, as they understood that the term ‘disability’ refers only to a visible physical disability, and there was no visible difference in the body of the child. As one mother (M4) said:

I did not understand what people thought about my son. They said my son is disabled due to him not being aware about anything, he could not talk and he played with toys by himself. I said to myself that he was not impaired on anything as he could walk and he has strong legs. My son is so healthy.

Her confusion resulted in her pushing her son to play football like a normal child. This statement by M4 clearly shows that some mothers looked only at the body of their child. When her son did not do what a child of his age would normally do, the mother began to suspect that something was wrong with the body of her child. Hence, the body of the child has always been the center of attention for these mothers. They understood that their child's behavior seemed “abnormal” and believed that this must be the result of something wrong with the body of their child. Their observations showed something unusual but it was behavioral rather than physical. Based on this confusion, some mothers searched for information to help their child get treatments.

External conflict differs from internal conflict, as it involves another person - usually family members, particularly the husband. Mothers said that they first discussed their child with their husband; to get solutions for their child’s problem, mothers needed to involve fathers. Discussion between the two parents usually resulted in one of two

responses: one response was acceptance by the father about the child's condition, and the other response was rejection by the father of the child's condition. If the father accepts, sometimes he helps his wife gain information about experts or places that they could go to get help for their child. One mother (M8) said: "We discussed about our second daughter over [a] couple of nights after we recognized possibly that she suffered from something different ". Another mother (M7) said that her husband comforted her after the GP examination showed that her second son had autism; she said:

I informed the result to my husband. When I heard the diagnosis of autism on my son, I did not have any excessive fear at that time. He also did not seem too surprised. He just told me, 'we need to have patience with our child'.

This statement by M7 shows that both parents were ready to accept their child unconditionally; it is likely that both mother and father were already aware of the different symptoms their daughter displayed when they compared her to their first child, or to other children.

Sometime, acceptance by fathers of their children's condition enabled them to support their wife as she sought treatments for their child; lightening the burden of his wife was a way he could help her. When children underwent therapy during the day, one husband drove his wife and his daughter to therapy and then picked them up again, after he finished working. As the mother (M3) said: "He really understood about how hard it is to raise a child with autism, and I do understand he was so busy at his workplace so sometimes (he) was feeling guilty. Thus he maintained his daily routine by doing this". This statement indicates that the driving of his child and his wife to

therapy is a way that this father showed his sense of responsibility, and his care for his wife and his autistic child; this daily act of care was done in conjunction with his role as the earner who paid all the expenses of the therapy.

There is another way that a husband shows that he accepts and takes responsibility for their children: it involves negotiating the division of labour in the household. The husband shows his acceptance of their child's condition by asking his wife to focus on the care of their child. One mother (M5) who has two autistic boys said: "He asked me to drop [my] job ... in order to focus [on] the caring of my boys".

The role of husband as sole breadwinner to support the family's expenses, including the cost of their child's treatments, has been a finding of this study. With the family income coming only from the husband, they were able to or compelled to adjust their expenses to meet the needs of their child for their special care and child's therapy costs. As one mother (M8) told me:

Once we knew our daughter has autism which appeared from the results of a medical examination at the Cipto Mangunkusumo Hospital, Jakarta, at that time I was still working at the public school, I was asked to give my job up by my husband and I also agreed because it was tough for us as we both worked and meanwhile my daughter had been [taken care of] by a part time-babysitter. And since then, my husband's income had to meet the needs of a family with an autistic child financially. And I am more focused on my child's care at home.

One mother (M8) explained that the money generated by her husband was partly spent on the care of their disabled child. Sometimes the mother felt sorry about this situation because her husband wanted to buy something, but could not because all the money he earned had been used to pay for their child's treatments.

Those statements indicate that there were negotiations between the mother and her husband about taking care of their child during daily activities. The negotiations happened after they received their child's diagnosis of autism. At this point, the husband played a role as the head of the family, whose duty was to earn money to meet the needs of family life. On the other side, the wife has a role to take daily care of the family, and to give maximum care to the child. This is very normal in marriage relationships between husband and wife in the context of Indonesia, where the husband still plays an important role as the main earner, and the wife as housewife. In addition, in households where a child may have a disability, either physical or non-physical, mothers have a primary nurturing role.

Another, quite different response from husbands is to reject the reality of their child. The form of this rejection is by refusing to hug or touch their child. Such a situation makes the mother feel very sad and upset about her husband's actions to their child.

One mother (M17) said about this:

My husband did not want to hold or hug his son. He just looked at him without wanting to hug him, or addressing compassion [to] his son. And he even let his son [go] when my mother took my son to foster care because my mother felt so sad [for] me as I took care [of] him alone without my husband's help. I am sure now that my husband actually was sad seeing his son [go] with my mother.

One reason for rejection by a husband who suspects their child has autism is because of feelings of shame about their child's condition. It is based on the husband's understanding that he comes from families who had no children with disabilities; all members of his extended family have children who were born "normal", instead of "abnormal". As a result, it was difficult for such a husband to understand this situation. Thus, one mother (M9) mentioned how difficult it was for her husband to

show his doting to her daughter in her early years. Her husband even pushed her (the mother) to not communicate with outsiders (friends or distant family) about her daughter's syndrome. She said to me: "My husband asked me forcefully to hide our daughter from other's eyes. He did not like people to see over our daughter and stare. He felt shame [at] this situation". This situation made the mother upset about his rejection of their own child. She added:

My husband did not [even] give me permission when I wanted to bring my daughter [for] treatments in her early ages. The reason was my husband felt shame [at my] daughter's condition and was feeling sad [about] her also. That condition caused my daughter to be late for getting treatments. If my husband at that moment was willing to accept her, she would recover faster, I think.

From this statement of M9, it is clear that the delay in getting treatment for this autistic child could be a result of the conflict between the parents. Treatment for children diagnosed with autism should be commenced as soon as possible after the diagnosis. Failure to do this will have a negative impact on the child.

In the context of the Javanese community, discussing something that brings shame on the family is taboo and inappropriate. Talking about their child with autism in front of strangers or neighbors should not be done. However, some mothers in this study rejected this statement, and felt that discussing their own child's diagnosis of autism was reasonable. They hoped that such discussions might bring useful information about how to heal and deal with their child. As one mother (M3) said:

I realized the situation was different (from the past, when), if we had a child who was "sick" they should be hidden from outsiders. I think now we were not doing so in this time. We have to accept anything as we have a child with a

certain condition. Maybe from that, we can even get help for healing our children - who knows?

One other mother (M5) had similar views about how she has to open her mind to obtain knowledge or information by communicating with other people. She said:

At first there was a feeling of awkward[ness] to talk with others about our child, but I think it will not help to solve the problems. [Now] it is comfortable for us when we talk [with] each other ... [as] parents of children with autism. Sometimes I admit I got information including knowledge of diet for children with autism this way.

This shows that communication and discussion is important for mothers, even if they received a different reaction from another person, including their own husband. Some reason for the rejection by husband of their child with autism includes cultural belief about disability in the wider community that they live, and also their sense of shame. In this situation, some mothers experienced conflicts in the process of searching for information about their child's condition.

Another scene of conflict is the relationship between some mothers and their husband's family members, especially the mother-in-law. This conflict can be particularly evident when the husband and wife decide to live, temporarily or permanently, under the same roof as the parents of the husband; this is a common form of households in Indonesia, especially for couples who are married but do not yet own their own home. Generally, this situation can create conflict between the couple and their parents; however, the situation becomes particularly difficult for the young couple when their child has been diagnosed with autism. However, the problem

of funding childcare in the city (which is very expensive) means they may need to stay with her husband's parents for some time. One mother (M8) reported:

When we knew that our daughter has autism, we decided to move out of Jakarta and decided to move back to Barang and we lived in the home of my husband's parents. The main reason we moved was ... [that] the cost of care for our daughter was very expensive (in Jakarta) and we could not afford it. But since then, it started ... creating ... ongoing conflicts between my mother-in-law and me. She blamed me [for] my child's disability. And she hated me and she did not care anything to my second child who suffered autism. She just cared [for] my husband and my first child only. At that time we had no other choice, instead of living with them. I am just lucky my husband always supports me.

For this family, their inability to afford treatment for their child with autism encouraged them to decide to move from one city to another in the hope of reducing this burden. However, these conditions created new burdens amid new conflicts with their own parents. Others, even family members, were not always willing or able to understand the situation of children with autism. Sometimes the conflicts emerge from misunderstandings on a particular aspect of how to deal with autism, or more generally with an autistic child. This mother (M8) explained:

My mother-in-law did not know what exactly happened to my second daughter. She [found it] difficult to understand the behavior of my daughter. She did not [have] a room to herself since we lived together. She accused me I could not discipline my daughter and educate her. How could I set up an autistic child to be a good girl; I wish I could. As a result of that, she blamed me because I have borne a child who was not normal.

Conflict between family members often occurs when they do not understand the actual conditions of children with autism. As a result, a misunderstanding creates the conflict between them. The autism is a symptom that occurs because of damage to their brain, and that damage causes "disordered behavior". This damage does not appear physically, but it can be observed from the child's behavior. People who do

not understand autism may have unrealistically high expectations of children with autism, and expect them to behave like other ordinary children; such people can include other family members, such as grandparents. The statement by M8 shows that the mother-in-law still believed that her granddaughter was not sick, so she asked M8 - as her granddaughter's mother - to discipline her child like any other normal child.

The statements above indicate that conflict happens due to ignorance about autism, and also about how to treat children with autism; such conflicts can involve family members such as husbands and grandparents. However, such conflicts can actually be a catalyst for some mothers to find better information about the child's condition, and about how to help their child; this search for useful information is a positive side of the conflict experienced by some mothers. Helping a family member to accept and understand the reality of their child can be a challenging task, and a struggle for some mothers.

5.7. Seeking Information on Their Child's Condition

This stage is about how mothers started finding a way to help their child who they think may have autism. This journey involves the struggle of mothers to understand the condition of their child, and to get appropriate treatments for them. They begin to search for information on "what really happened to my child". In the early stages, they also experience confusion. After they understand their child is suffering "something", they start to think about how to deal with their child's conditions.

The child's characteristics cause mothers to question what is happening to the body of their child, so they look for information about what is actually happening to their

child. One way they do this is to find information by comparing their child with other children, either in the family, or in the neighborhood. At first, they discussed the problem with family members (mothers, mother-in-laws, sisters, aunties), and later with people from outside the family (friends, neighbors, friend of friends) who might have had a similar experience, or who have a child with autism. From these conversations with other people, some mothers learned what to do next about their child's condition. One mother (M2) talked about this pathway:

When I realized that my second son did not look like any “normal” child, I was confused and did not know what I should do. One of my husband’s friends told us to take our son to the rehabilitation centre.

M2’s statement shows that the information about where to take her son for treatment came from a friend of her husband. She had no earlier information about where she could take her son. The lack of information created confusion for mothers, and caused them to turn to other people in their search for information.

One mother (M9) explained her confusion over what happened to her daughter. She said:

I did not know where to go to find a cure for my daughter. I even visited the medicine man in order to know what was wrong with her; I was thinking at that moment probably my child had been affected by a demon as my neighbors told me. When she was ... two years old, she could not say any words, ... [only] tones. There were a couple of times I brought her to the medicine man and he gave her traditional herbs, but it did not work. I was so desperate at that time. I knew there was something wrong with her.

This statement by M9 indicates that she did not know where to go to heal her daughter. The first thing she did was to visit the “*wong pinter*” (the medicine man) as suggested by a neighbor; she thought that only this kind of person could cure her daughter. But this treatment did not make her daughter better, according to her observations of the body and behavior of the child. She said: “...but it did not work”. In this context, the mother accepted that her child’s medication could be either herbs or medicine. She believed that autism, like many other diseases, could be cured with medication. It is a life mission for a mother trying to find a cure for her child when there is inadequate information about autism and treatment services for it. This inadequacy of information is more likely if the mother lives in a rural area, where it is particularly difficult to get information about autism and how to deal with it. So the mother chose to consult a person who probably had no knowledge about autism - the ‘*wong pinter*’.

Such an event, however, can be the beginning of the mother’s encounter with people beyond her inner circle; she may visit a pediatrician, a child psychiatrist, or go to a hospital, to learn in detail about her child's condition. The mothers ‘became eager to find’ any clues or any information from experts that would help them understand what exactly has happened to their child, and the next chapter addresses it.

Chapter Six:
The Experiences of Mothers on Services

6.1. Introduction

This chapter portrays the experiences of mothers of a child with autism as they interacted with service providers (and similar people) as they sought help for their children. This portrait starts with how they looked for information on the Internet and from other sources to gain a better understanding of the meaning of autism, and follows the mothers as they interacted and communicated with General Practitioners, Paediatricians, Therapists, school principals and teachers. This chapter will be grouped into a number of sections: understanding of autism, interacting with medical professionals, and delivering of services for children with autism including affordability of services, type of services, partnering with services, education services and funding of services. The views of mothers presented in this chapter are mostly based on the discussions with them as a member of parenting groups in institutions where I conducted the focus group process that was conducted in November 2011 to February 2012.

6.2. Understanding Autism

The experiences of the mothers who were interviewed for the study discussed in this chapter starts the mothers' struggle to build their knowledge about autism following their child's diagnosis. This is followed by discussing their experiences after diagnosis as they expand on their experiences as they seek help aimed at assisting their children to grow up. For the mothers, two questions were on their minds. The first was to understand the medical diagnosis. The second was how to live as a family

with children with autism. What should they, as mothers, do to best help their children grow up as well as possible. The mothers tackled this question by seeking information about the biomedical meaning of autism; they wanted to know what had actually happened to their child's body. This study shows that some mothers initially had difficulty recognizing and understanding the meaning of autism. Some of them had never previously heard or known the term (see Chapter 5). One focus for the mothers was to identify a 'trigger' event or cause for their child's autism. For most mothers, the fact that their child did not have visible physical bodily impairment created an additional challenge to understanding the meaning of autism. They wanted to physically locate the cause of autism on or in their child's body; however, this was hard to find. So they searched for information to help them understand autism. One mother watched a television program about the life story of a family who had an autistic child, and after watching the program she (M6) compared her son's behaviour with what she had seen in the program. She felt that her son had an obvious similarity with the child on the program.

Once their child's autism was diagnosed, mothers sought information from the Internet. M4 explained to me that, from the Internet, she learned more about autism, and about its symptoms, and how to deal with it. As she said, she was consulting the Internet even before the diagnosis:

This is the modern era; the easiest way to find it [information] is to use the Internet. I read some articles on the Internet about autism. And then I compared it to my child's condition. I noticed there seems to be similarity between the symptoms of what I read compared to him (her son). However I was still not a hundred percent sure whether he suffered autism, before I consulted with a paediatrician.

Another mother describes a similar experience. One mother, M3, found all the information about autism and how to care for children with autism from the Internet. This study shows that the Internet was an important source of information about autism for these mothers. Many other studies have also indicated that parents of children with autism consider using the Internet to gain knowledge about autism (Blume 2007, Kenway 2009). Searching the Internet for information appears to be a convenient way for parents to learn about possible diagnoses for their child's condition. However, the Internet was not the only information source these mothers turned to. For instance, M5 said she turned to books to gain a deeper understanding of autism.

Despite the use of digital and print resources, the most important source of information for these mothers was conversations or consultations with medical personnel and teachers. A medical examination was often the first opportunity for these mothers to find out about autism. A frank conversation with a doctor can sometimes help mothers of children with autism to begin the journey of developing their understanding of their child's conditions. Open communication with a doctor will encourage parents to find further information about autism.

Following the suggestion from the doctor, several mothers said that one thing they sought information about was on suitable diet for a child with autism; on web sites for instance, they found some information written by dieticians about particular foods for a child with autism, and they applied it to their child. Sometimes, this situation had a positive effect as a coping strategy for parents, because they had a strong desire to help their child. Motivation may be for the sake of their children in order to make

them independent in future, or it may be for the sake of the parents themselves so their child for the rest of their life will not impose them on.

As stated in the previous chapter, some mothers had not identified a problem with their child before they visited health services for a normal childhood illness, such as a high fever. Mother 4 stated: “Initially I did not know that my son is autistic. Once I took him to the general practitioner because his ears [were bleeding], and at that time the general practitioner asked me whether my son is autistic as he observed my son’s behaviour.” One mother mentioned that when her son had a high fever, she brought him to hospital and the paediatrician who checked her son informed her that her son might have autism. Some mothers initially contacted and liaised with health services pursuing their curiosity about what exactly happened to their children, even if the encounter with a health service related to ordinary childhood illness, this contact provided an opportunity for health personnel to begin the process of autism diagnosis. Most mothers, once they decided there was something abnormal about their child, consulted health practitioners such as a general practitioner or a paediatrician for a medical examination; for one mother (M4), it was such a visit to a general practitioner that alerted her. However, another mother (M12) refused to visit a general practitioner as she thought they would just give a drug treatment for her son. She said:

I actually did not like to visit a General Practitioner to consult [about] my son’s health as they always gave a prescription for him, and I did not have any reason to bring my son to visit the General Practitioner.

Consultation with a child psychiatrist is another way that mothers learned what was abnormal about the development of their child. Mother 8 explained: “Initially I felt that something was not normal in my daughter. I suspected that she had autism, [but] I

was not sure. I was recommended by a child psychiatrist to have her checked at the public hospital, in the section of child development.” However, for M2 it was a friend who suggested she take her child to get a medical diagnosis, as the friend saw her confusion about her child’s condition. She explained:

When I realized that my second son did not look like any normal child, I was confused and did not know what I should do. One of my husband’s friends suggested we take our son to the rehabilitation centre.

Finding information about services for their child was crucially important. Through the process of searching, some mothers initially struggled to get the information they needed. Some of them did not know where to look for information on services for their child. Sometimes they used networking with friends to get this information. One mother (M2) said:

One of my husband’s friends informed me about a rehabilitation centre that was close to my home. I actually did not know where I should look for a place to take my son to get therapy. But he [my husband’s friend] helped us [by finding] where the place was.

One mother (M5) said that she obtained information about a therapy centre from a friend who also has a child with autism. She said:

A friend of me informed me about a centre providing therapy for child with autism, ... I was really happy with the location of the centre, it was just a couple of blocks from my place. I had not noticed; even though sometimes I had passed the building.

This study indicates that a network of friends proved to be positive for mothers in their search for information about available services for their child. A friendship

network can be an important way to expand their knowledge about information and services; particularly about what next steps the mother could take. Before friends shared this kind of information, many of these mothers had no idea about how or where to get services.

Most mothers indicated that information about services for their child with autism was extremely important for them. The information helped them understand not only that a therapy centre could provide treatment for their child, but also about types of treatment available, and the kind of care that is appropriate for their child. They needed to know which therapy centre their child should visit to get treatments. To choose a suitable therapy centre, the parents needed information on the location of centres, the treatment programs that are available, and the costs of all available services.

After the diagnosis [discussed in the next section], the first information they were looking for was the location of the therapy centre. This is crucially important for some mothers because of difficulties in getting their child to and from the hospital or rehabilitation centre; in particular, some mothers have difficulty in controlling their child's behaviour during travel to the place of therapy. One mother (M4) said: "I catch public transportation to the centre; sometimes it is hard to ask my son to sit properly in the vehicle as he always wants to get out of it. My house is about 13km from the centre. I could not rely on my husband because he had to work to meet the needs of all of us". This mother's statement shows how the location of a services can determine which service they will choose for their child's therapy, which is such an important step on the pathway of developing a system of service and support for their

child. One mother (M2) explained the difficulties in bringing her autistic child to the public hospital. Treatment at the hospital involves waiting in line for a ticket while her child screams, struggles to run away, and becomes increasingly distressed in the strange environment. As a result, she decided to change the routine during the next visit to hospital. After obtaining the ticket, she returned home to summon enough energy to then take her child to the hospital for the therapy session at the time shown on the ticket. The reason for this complicated routine is to reduce the difficulties associated with the uncontrollable behaviour of her autistic child while waiting for treatment.

6.3. Interacting with Medical Professionals

This section is about mothers' perceptions of their interactions with medical professionals. Most mothers eventually consulted at least one medical professional about their child. As already discussed medical practitioners sometimes initially saw the child for another illness, but also diagnosed autism.

The views and information received from medical practitioners were highly valued by all the mothers interviewed for this study. However, getting the right information and the diagnosis of autism from a medical professional was not always easy for these mothers.

Impediments to diagnosis included the mothers' lack of access to medical professionals, their perceptions of doctors, the lack of general practitioners' knowledge about autism, lack of trust, poor communication, as well as inadequate knowledge of the relationships between various health services, and of where to go

for further treatment, assessment, or information. This section explains in detail how the mothers interacted with medical professionals in the process of obtaining a diagnosis for their child.

After finding some information that indicated the possibility of autism in their child, some mothers made contact with professionals, in the hope of learning for certain whether this was in fact the diagnosis for their child; and this was needed before they could have formal access to service providers.

After the initial confusion about their child, the act of seeking a formal diagnosis actually reassured most mothers. Getting a diagnosis gave them some certainty. One mother (M6) stated: “It was just making me sure whether my daughter had autism or not.” This statement shows that getting the actual diagnosis for their child with suspected autism gave important reassurance about their child. For this reason, gaining a diagnosis as early as possible is strongly recommended. Another reason for this strong recommendation is that early intervention is crucial for children with autism, because delayed diagnosis results in delayed therapeutic interventions. Children whose mothers participated in this study were diagnosed between the ages of 3 and 7. One mother (M7) said “The diagnosis of autism [for] our son [was] when he then was 3 years old. Now he is almost 7 years old”. Meanwhile, one mother (M2) said that her son has been diagnosed when he was 6 years old.

Some mothers knew that a public hospital or a rehabilitation centre was the place to bring their child for a diagnosis. A few mothers first brought their child to a private rehabilitation centre from where they obtained an appropriate diagnosis of autism for

their child. For example, M10's son was diagnosed with autism by a private rehabilitation centre. However, the children of two other mothers (M2 and M3) were referred by a private rehabilitation centre to a public hospital for diagnosis.

The main reason for getting an appropriate diagnosis from a public hospital is that this is the way to gain a 'referral letter' to therapy services. The referral letter is a statement of diagnosis that is issued by a public hospital after an in-depth medical examination has been done. However, in some cases, a referral letter can be issued by a private hospital or a private rehabilitation centre. M10 mentioned that she got a letter about her daughter's diagnosis from a private independent rehabilitation centre in Barang. The referral letter is important as it entitles the autistic child to gain treatment in a rehabilitation centre, either public or private. One mother (M8) mentioned that her daughter obtained a referral letter from the child development section of a public hospital; she added: "After a detailed medical examination by Paediatrician, my daughter was diagnosed with autism, mild autism." All parents need to know how the system of diagnosis and treatment is organised, so that they know where to bring their child.

The detailed medical examinations itself may not be simple. One mother (M2) remembered that it was a difficult part of obtaining the diagnosis for her child. The paediatrician in the Child Development section of a public hospital asked her some detailed questions about the symptoms of autism might be suspected to her child. The expert discussed the symptoms with her in couple times of meeting, and she said: "He (the paediatrician) has a long list of questions, If I said 'yes' to any such question and I answered correctly, he put mark on the question lists". And after long examinations,

she knew that her child is autistic child, and she got the official statement from the paediatrician about the condition of her child.

After giving the diagnosis, the general practitioner or the paediatrician would advise the parents (or the mother) to immediately access treatment for their children. One mother (M7) said: “After the examination, the general practitioner said to me that my son has been diagnosed with autism, and also he asked me to get some therapies for him as soon as possible.” Another mother (M2) said that the paediatrician suggested enrolling her son in any rehabilitation centre as she already had the diagnosis letter from hospital; she chose a private centre rather than a public hospital.

One mother (M10), when informed of the diagnosis, realized that it had helped her to understand how she should deal with the health of their child, as the medical person had given her some information about raising children with autism. She said: “They told me what I should do to help my son. They provided me (with) some information on how to deal with my autistic son”.

Most mothers indicated that they found it hard to accept their child’s diagnosis of autism – and that they were still struggling to accept it. There is almost no empirical research on how parents, whether fathers or mothers, come to cope successfully with their child’s diagnosis of autism. My study shows that the reaction to the diagnosis can range from outright rejection to relief and ready acceptance. Sending a child to a regular class or public school, instead of to a special school, can be a form of rejection of the diagnosis of autism. One mother (M4) explained:

I wanted my son to be like any normal child, to play football or such things. Logically, it would not happen as my son has been diagnosed with autism. Because of that thought, initially I enrolled my son in Public Kindergarten.

Another indicator of non-acceptance of the diagnosis is forcing their child to get along with other children. One mother (M12) mentioned that she sometimes pushed her son to play football with children from the neighbourhood so that he would get used to getting along with other people. In other cases, some mothers even refused to tell the principal or teachers of their child's diagnosis. One mother (M5) described this situation: "When my son attended class in primary school, I never told his teacher that he had been diagnosed [with] autism." One mother (M4) later realized that it was not appropriate for her child to attend an ordinary school rather than a special school: "Later I realized that the decision was not appropriate for him, and then I put him [in a] therapy centre". Most mothers decided either to send their child to an ordinary (public) school, or hid the child's diagnosis from the teacher; this is a form of rejecting the reality of their child's condition. Sometimes they realized if they forced their children to be a normal child, it would have an effect that would be even more distressing to the child or the parents themselves. One mother (M4) said:

I really wanted to treat my son like a normal child, but I suddenly realized that it was not going to happen because he was different compared with other normal boy. On the other side, we should have thought of it as he would have to be independent for his future, because we are going to die someday; so who will help him afterwards.

On the other hand, some mothers indicated willingness to accept the diagnosis of autism for their child. They reasoned that as the child is theirs, they must take care of them; that is their responsibility as mothers, and if they didn't, who would take care of them. One mother (M7) explained: "...we as parents have to accept this condition,

that's all. My husband and I need to find the way to make a healing process for my son.”

For some mothers, the diagnosis brought relief. While they had previously struggled to understand their child's behaviour, now their goal was clear: to find appropriate treatment for the child. This was the case for M8: “The diagnosis of her autism made me relieved on the one hand”, but she added: “it has scared me about her future on other hand.” There are contradictory feelings of relief and fear in the reactions mothers experienced after the diagnosis of autism. They were no longer blamed for poor mothering to account for their child's behaviour, but at the same time they needed to come to terms with their child having a serious disability.

Most mothers indicated that their feelings of fear about their child's future were hard to handle by themselves. Even now, the feelings still emerge when they think about their child. “I was scared at the moment I got his diagnosis”, one mother (M9) said. Another mother (M8) told the researcher: “I am still scared about the (future) life of my autistic daughter and am so scared and always cry every time I think of her”. One mother (M16) added: “It just came up in my mind whether my son can get married one day and work like everyone else. It was hard for me thinking of this.” Another mother indicated that the feeling of fear was not essential as long as they as parents focused on the need to take action for their child as soon as possible. One mother (M7) explained:

When I heard the diagnosis of autism with my son, I did not have any excessive fear at that time. I just was thinking of the situation, we as parents have to accept this condition, that's all. My husband and I need to find the way to make a healing process for my son.

Yet another mother (M8) said that she was scared at the moment she learned her daughter's diagnosis, but she could not continue feeling sad or mad, because her husband asked her to handle the situation after her daughter's diagnosis. She said: "My husband handed over [to] me how and where I [would] seek professional help and information about my daughter's situation. He totally relies on me, but he ... helped me to find information [about] therapy centres." This shows that the mother's fear for the child's future is sometimes reduced when mothers act to find solutions for their child's health problems. As a result of these actions, they found information about appropriate treatment or therapy, and about education institutions for their child. This is a kind of journey among mothers of children with autism as they deal with the process of finding help for their child.

As shown in the previous chapter, the main initial concern of mothers was to get a diagnosis of their child; this is a crucial first step. Encounters with medical practitioners at this stage had long lasting impacts. Mothers are motivated to seek out medical practitioners. As one mother said: "I was always trying to get the appropriate diagnosis for my daughter, because I wanted to be sure of what really happened to her" (M3). This statement shows how important it is for parents to know exactly what happened to their child. Many mothers brought their child to doctors or paediatricians for a diagnosis. However, this was sometimes an unpleasant experience, particularly if these experts used inappropriate language, or if they delivered information in an inappropriate way. Negative experiences like these resulted in some mothers refusing, later, to consult certain general practitioners or paediatricians. One such mother (M10) said:

I saw something not normal in my little son when his age was 7 months. He did not grow up like other normal children. [At some time], I realized that a brain bleeding caused it. And that time the GP had informed me that he might have abnormal growth. He had not yet done a detailed examination of my son, but he had had a final result. Since that happened I stopped consulting with any doctors in seeking a cure for my son.

Some mothers thought that neither general practitioners nor any medical professional would understand autism and how to address it; one mother said (M10):

Although I feel connected with the services for special kids in the city of Barang, I have not yet found medical people who will be concerned about any child with special needs, particularly a child with autism. There were many services for children with physical disability, but few for children whose disability is not physical. I just was thinking it might be this thing is quite new; some people think this [autism] not new though. I admitted that many people did not know what exactly autism is. After I visited many doctors, I realized that they actually did not really understand what autism is and how to address it.

Just providing a diagnosis of autism did not enable mothers to fully understand their child's condition. For one mother, this process was harmful as the doctor said that her child would not be able to grow normally, and the condition was difficult to cure; this doctor did not provide the best solution for the child and family. One mother (M10) said: "I knew there was something wrong with my son; ...a doctor, as an experienced person, should be encouraging me as parent or giving me information about my son (by using polite language)". This statement shows that communication style is particularly important in complicated and difficult situations such as these mothers faced. A doctor can help to bridge a knowledge gap, and may give new insights for patients and their families. However, the mother's statement above shows that the opposite can also happen; the outcome was that this mother refused any further contact with this doctor.

Communication between the health expert and mothers of children with autism should aim to build a harmonious relationship, as well as skilfully sharing knowledge. The need for shared knowledge is based on the understanding a mother has about symptoms that their child displays. Initially they do not know that these are symptoms of autism. Thus information from paediatricians (as a health expert) is essential for any parents, including mothers in Indonesia. Such information should include an explanation, in ways that parents can understand, of characteristics of autism in children, as well as information to guide them about how to bring up their autistic child.

How information is delivered is very important, according to some mothers in this study. Explanations should use simple language, should bring hope if not for a cure for the best possible life for the child, and the communication style should be one of building an equal partnership between parent and expert. One mother stated (M10):

He said to me 'It is correct that his bleeding would affect your child's development, and you did nothing on this case to help your child. You just need to make him independent in future'. I would be always remembering [his] words as they struck me and made me upset. He was so rude I think; he was a well-known general practitioner in this city though.

The transcript shows that the mother found it hard to accept what the doctor said, and as a result they [the mother as well as her child] suffered emotionally. It also shows that the process of communication between mothers (as the user of health services) and health experts in Indonesia are not always as successful as mothers want them to be. The users need information about their health problem, and will take their questions to health experts for answers. One mother (M11) stated: "Honestly, we hope the doctor can deliver a detailed description about the condition of our son".

In other circumstances, mothers who visited health experts perceived their experiences as positive; this research also indicates that getting advice from experts was generally a good experience for mothers. Generally, health experts gave them advice and guidance about what to do with their children. A detailed description of the condition of their children was an important part of communication. One mother (M9) said that there was a good doctor who discussed her second son, and explained why this child's behaviour was different from that of his older brother; he also explained what to do with this younger child, and how to raise him. The mother (M7) was given a choice about where to take her son for therapy. The doctor recommended where her son should be rehabilitated, although none of these options suggested by the doctor were realistic for her family. As she said: "I could not afford to help my son through getting his treatments at private rehabilitation centre as the doctor mentioned". Basically, all of the decision to do something for the good of their children will be back to the family's decision and their resources. This is something doctors need to consider when making recommendations.

One mother mentioned that the gender of a health expert could affect how they communicate with mothers, and how information is delivered during the consultation. The research reported in this thesis shows that mothers felt more comfortable discussing their child with female experts than with male experts. These mothers said that female experts showed a more sensitive understanding of their situation in the challenges of raising a child with special needs.

I was feeling more comfortable consulting with a female doctor; she also explained in detail about my son. And I also felt free to ask as much as I could about my child. I guessed she was a woman as I am, so she would understand ... my feelings as a mother of an autistic child. (M8)

I had met several doctors for consulting [about] my daughter's condition; at last I found one female paediatrician who ... was a polite person, she had a willingness to explain all the details about my daughter with simple language I understood. Since then I always [consult] with her. (M6)

According to the mothers in this research, communication with female experts was easy, as they could clearly explain information about the child to the mothers. In the context of Indonesian society, a woman may feel reluctant to speak with men who are not members of the family, particular on some specific issues. Thus when mothers needed to understand their child's situation, they preferred to choose a female doctor.

The desire of mothers to get the best possible knowledge about their child with autism, including an understanding of what should be done after the diagnosis, encouraged them to visit doctors, especially paediatricians. As expressed by one mother: "Visiting the paediatricians came to my mind when I realized there was something wrong with my son, who [did] not grow like any other child of his age" (M11). This statement indicates that the mother believed that the doctor could help them gain the information and understanding that they were seeking about their child. But parents who live in rural areas, due to lack of health facilities and medical personnel, may instead visit a local figure (*the dukun*) who is believed to have spiritual powers to dismiss local problems or diseases, as mentioned in the previous chapter.

From meeting with the doctor, the parents usually get advice or guidance including procedures for what to do next for their child. One essential recommendation is to get a diagnosis, as discussed in the previous section; the diagnosis is essential as it is a

form of label that is needed to get treatment and therapy for their child. Usually, the diagnosis process would include a full medical examination, and so it could take some days before the mother obtains the appropriate label.

Doctors played an important role in guiding mothers on what to do once the diagnosis of autism was obtained. They suggested that, the mother should regularly take their child to a rehabilitation centre. Some also informed the mother about rehabilitation centres or public hospitals that provided services for people with disabilities. In one case, a mother mentioned that the doctor had a private clinic providing rehabilitation for their child. One mother (M14) said: “I brought my daughter to consult about her situation with a paediatrician who had a private rehabilitation facility; after check[ing] her condition she asked me to take my daughter [to] her clinic regularly. I agreed at that moment, as I did not know what I should do with her”. However, in some cases, one mother (M7) refused to follow a doctor’s suggestion to take her second son to a private rehabilitation centre that was owned by the doctor. The mother (M7) said: “It [would] put me in financial hardship if I agreed to his suggestion”. She did not follow the doctor’s suggestion because she could not afford to pay the cost of treatments. Eventually, she went to a local non-profit organization that provided services for disabled people, including children with disability. These statements show that, while doctors advised mothers to immediately to get treatments for their child, and suggested where to get such rehabilitation, the mothers themselves decided whether or not to follow these suggestions. Mothers recognised their freedom to choose how they would improve their child’s well being. Necessarily, the decision has to be made based on the family’s financial capabilities.

6.4. Delivery of Services for Children with Autism

This section expands on the experience of mothers once their child has been diagnosed, and has received some services. After gaining their child's diagnosis of autism, the mothers started another stage of their journey: to help their child obtain appropriate health treatment and education services. This stage of the journey includes decisions they had to make, and issues that they needed to attend to, in order to get regular treatment for their child. This section of the research identifies some common issues experienced by most mothers: the affordability of services, type of services available, accessibility of services, funding of services, and the outcomes of services. This research indicates, and elaborates on, a link that exists between these themes.

6.4.1. Affordability of Services

In assessing which services she will choose, the first thing that these mothers looked at was their affordability. Affordability was a high priority for parents as they also needed to take into account the needs of the family as a whole; they needed to look after their other children as well as their child with autism. One mother (M8) explained:

I was really looking for a therapy centre in accordance with our financial capabilities. I would not deny that the cost of caring for children with autism is very high and meanwhile I still have another daughter who needed attention and funds for her school. So it was hard to ...[balance] attention between her and her eldest sister.

While mothers were concerned about spending for their special-needs child, they also had concerns for other children in the family. Choosing a rehabilitation institution for their child occurred in the context of the whole family. Registering a child to get therapy in the rehabilitation centre is less expensive when compared with a privately

owned treatment by a doctor or other professional. The mother needs to balance the needs of all members of her family. One mother (M7) mentioned that she struggled hard to meet the needs of their children: "I was so afraid, I could be accused of neglect by my other child as I tended to focus [more] on my autistic son rather than his siblings". Another mother (M2) explains:

I ended up choosing an institution that does not burden our family. I was able to give treatment to my son but also I cannot ignore the needs of our family. I chose this treatment for him by attending twice a week.

Sometimes affordability can be achieved by adjusting the length of the treatments their children will attend. In one case, a mother (M10) who works as lecturer at the state university said that it was hard for her to maintain her time working outside the home while also caring for her son with autism. So she decided to enrol him at an institution that provided her son with treatments and therapy throughout the day. She said:

It was hard to get balance between working and looking after my autistic son. And it was hard to leave my son at home without supervision. Then I chose the therapy centre providing a longer case for the children on weekdays, so I can work and my son gets appropriate treatment. I would pick him up in the afternoon after I finished teaching.

6.4.2. Type of Services

This section explains the type of services mothers used to help their children. Mothers thought that some treatments and therapies could help their child to be independent in the future; this is why the mothers see attending treatment sessions as vitally important for their child. There are various types of services mothers chose for their

child with autism. How do mothers choose one particular service, and what influences their choice? Some kinds of services are well recognized by the mothers, including health treatments or therapies (at a rehabilitation centre), and education services such as classes or schools for children with autism.

To get treatments, mothers must enrol their child to attend treatment sessions at either private or public institutions. As earlier mentioned, this decision is often based on the family income. Some mothers prefer to bring their child to services at a private rehabilitation centre, but a consequence of such a choice is high out-of-pocket expenses. One mother (M5) said:

I want him to get care, so I decided to enrol him in this centre. Indeed, the consequence is the cost I spend - it is quite expensive. But I am satisfied. I'm trying to do what is best for my child. I want him to be independent someday.

It appears that this mother is looking for treatment for her son that will lead him eventually to be independent. She then adds that he attends several therapy programs, including occupational therapy, behavioural therapy, and speech therapy. She sees behavioural therapy as the most important for him. She said that:

My son seems to need behavioural therapy more than other therapies. I felt he would need it because I saw him able to communicate, but he found it difficult to manage his behaviour. For example, he suddenly opened the front door and got out onto the roads [near] our home without supervision (M5).

However, she follows the programs recommended by the institution as it provides treatments for young children with autism among other disorders. Another mother (M2) mentioned that she chose a particular service for her child because the coordinator of the rehabilitation centre (who was also a child psychiatrist) had

determined the therapy her son must follow. She added: “I agreed with the decision as long as the procedure of treatment for him is based on the main standard of treatments”.

Sometimes, the mother’s desire guides the form of therapy. An example of this is when the mother wants her child to be able to speak and communicate, so she enrolls them in a speech therapy session. One mother (M18) said: “I want my son to be able to call my name, ‘mommy, mommy, so I enrolled him [in] speech therapy”. Another mother (M2) had a similar situation: because she wanted her son to say her name, she enrolled him in a speech therapy session at the local rehabilitation centre, but later she changed her decision because of a suggestion made by the child psychiatrist.

This study also indicated that toilet training is one of the valuable services that children with autism can receive in a rehabilitation centre. One mother (M3) said: “My daughter has been taught how to go to the toilet and how to use it. Her teacher shows it to her patiently. Toilet training is hard for her - she always cried as she did the training”.

This mother (M3) mentioned that the rehabilitation centre in which she enrolled her daughter was a non-profit, which means that it was more affordable.

My daughter got some therapies from the centre, including behaviour therapy, occupational therapy, toilet training and speech therapy(and), she has been taught how to wear her coat on rain days.

At the same institution, another mother (M4) said about the treatments her son attended:

Currently my son [has] physiotherapy, speech therapy ... [and] occupational therapy. I also ... learn how to do [diet for] him and need to be careful with food choices, as I know ... particular food is important for him. I also see a good result of these therapies on him.

All parents of children with disability have high hopes that their child will be able to be independent one day. They hope that therapy now will mean that their children will not rely totally on their parents for the rest of their lives. Inspired by this hope the parents seek treatment and education services that can be applied to their children. They hope that all services will have a positive influence on their child's behaviour. This study found that most mothers think that therapy will affect their child through building good communication and behaviour. One mother (M8) said that the outcome of attending regular treatment was a positive change in her daughter's communication and behaviour:

I feel relief now as my daughter has a regular therapy at YPAC. I admit that her progress [toward independence] has not been significant yet. I cannot imagine what (would) happen to her if she did not get regular treatment. And now, she can talk with me, she tries to understand what we are talking about. It really makes me happy when she calls me, 'mommy...mommy'. She can also point to food when she wants to eat it. At age 3, she could do nothing, she could not walk, and she could not talk. I needed to wait for almost 4 years to (see) her progress.

This mother (M8) also stated that it would take a long time to get best result for her daughter. However she sees that the processes are enabling good progress.

Another mother (M7) revealed her joy in seeing the progress of her son who now recognizes his own name when she calls him. She said: "After the therapy, there were many changes that happened to my son. He ... immediately could turn his face to me

when I called him, for instance”. This example shows how much mothers value the progress of a child after gaining successful treatment.

But sometimes parents believe that, because they have a better understanding of the needs of their child than the experts do (because the child spends so much time with them – particularly with the mothers), that as parents they can better identify what will have a positive effect on their child. This research shows that mothers do understand some of the needs of their child, and they seek freedom to choose the services that they think will most benefit their child. The mothers who contributed to this research and who had no input to the choice of therapies (or to what happens in a therapy session) said that there is such a choice needs to be a priority.

6.4.3. Partnering with Services

Some services have been chosen by mothers not just for their child’s direct benefit but also for their contribution to their own role as the main carer for their autistic child. One such service provides information about diet for the child with autism. One mother (M7) explained how important dietary information is for a child with autism. She said:

His therapist informed me about the dietary food. They gave me some information regarding the advantages and disadvantages of some food for children with autism. And I need to follow the instruction in order to get healthy and appropriate food for him. But sometimes it was hard due to the high price of particular food. However, this information will be good for my autistic son.

Some mothers realised the duration of treatments their child needed could not be met by therapist alone. Some of them asked the therapist or child psychiatrist, while others

obtained the information from social media or the Internet. As one mother (M5) explained: “I was doing research on Internet about what autism is. I found some information that children with autism need to be treated by some therapies for eight hours in a day ...”.

However, in reality there was a discrepancy between the actual treatments their child received and what some mothers expected from the information they had found. While the information they found said that every child has to go through with the treatment process for 8 hours a day, there were several reasons why this could be difficult to implement using outside experts. One reason was the financial ability of parents to pay for treatments. Here is how several mothers saw this problem:

The cost of one therapy for one hour was Rp 55,000. It means that I need to spend lots money for all treatments. It was hard for us, particular in my case. I have two sons - both of them have been diagnosed with autism. (M5)

I think it is all about the cost of caring [for] our children. I know the cost of therapy for our children is very high and costly. It must be a lot of money to spend. (M8)

One response to this problem is that mothers want to be involved in the treatments or education their child received. Their involvement could be to go along and learn from the therapist in treatments session, for instance. However, this desire was not always put into practice, as it was hard to get along to the treatments of their children. Providers were often unwilling to give a chance for mothers to come in to the room where their children were being treated by the therapist. One mother described this situation as follows:

I really want to know the process of therapy for my son directly. However, it seems it is hard to make this happen, for me to come and join them in the room. Basically, I wanted to know how they did therapy for my son. I had a reason [for] this. My child spends lots of time with me at home. So I want to do therapy with my son by myself, when he was at home (M13).

She also added that she was concerned about the lack of use of closed circuit TV (CCTV) in the room where her son was being treated, so that, from the waiting room she could monitor the activity inside the room. She explained this after she saw the therapy process at a private rehabilitation centre in Jakarta that her friend's child attended. This screen helped her friend imitate and implement the process of therapy with her child. She said: "I could not totally rely on another person to help my son be independent. He spends lots of time with me in daily life". Her statement shows that some mothers want to understand how they can treat their child themselves. Knowing how to provide therapy for their child can be an important way for a mother to help the child improve by getting sufficient therapy intensity. However, it still is hard to implement, as the therapy providers seem to have some objections about transferring knowledge about the therapy to mothers. They may object to the presence of parents in the therapy room because they consider that would interfere with the process.

Accessibility of services includes the mother being able to talk about the one-to-one-activity between therapist and their child during the therapy process. Some mothers wanted to be involved in their child's therapy and wanted to learn about appropriate activities for them to do with their child from the providers.

They mothers fully understand that one-to-one activity is most effective if there is only one therapist and one child in the session. This means that no other child can share the same activity with the treated child in the same room.

6.4.4. Education Services

The accessibility of services for their children is a matter not only of providing services in the area of health but also in the area of education; this includes services in a class, or in a school for children with autism. One mother (M8) mentioned that she enrolled her daughter at a class for pupils with disability. According to her, it took lots of processing time before her daughter was able to attend the class. She explained that the policy of the organization her daughter attended stated that every child with disability who finished a course of basic therapy could attend the class. She added that the basic course of therapies - including speech therapy, occupational therapy and behavioural therapy - were compulsory and must be attended. She said: “My daughter needed to spend more than three years before she was accepted to enter school”. Attending school classes did not mean that her therapy process [and expense] had ended. After being enrolled in the class, her daughter still needed to participate in therapy sessions after school hours.

One mother (M5) explained that she had enrolled their sons in a private Islamic school in order for her children to get an education that was appropriate for them. When he reached school age for primary school, the mother enrolled her son in a mainstream school without telling the principal that her son had been diagnosed with autism. She followed the standard enrolment procedure for a new pupil who will attend the school. She said:

I tried to hide from him (her son) that they (principal and teachers) might not know [he] had autism. Fortunately during the interview process, my son did not show the strange things [that] showed that he is autistic. My son is smart. And he finally passed ... the interview process.

Another mother (M4) also did not disclose that her child had autism. She said that she enrolled her son in a public pre-school that was funded by a local community, and did not inform the principal of her son's diagnosis. However, the principal finally recognized autism in her son, and later asked her to withdraw him from the pre-school, and take him instead to a rehabilitation centre.

However, sometimes mothers are very aware of the many problems that can be experienced when educating a pupil with special needs in a mainstream school. One mother (M5) said:

From age 4 to 7, my son took a class in Kindergarten in conjunction with some treatments at a private rehabilitation centre. He had shown good improvement in his behaviour and communication skills. As a result, I decided to enrol him in a private mainstream school, and I never told the principal or teachers that my son suffered autism. My aim was he could socialise with normal pupils. However, his friends often bullied him. This happened in his early years [of] school. Currently he can defend himself from the situation.

Some mothers chose a mainstream school rather than a special school for their autistic child. One mother (M5) explained: "I want my two children with autism [to] interact with other normal pupils, although I realize it will be a burden for my two boys". This mother wants her children to be involved with other normal children, even though this decision might create some challenges for her children.

Mothers who are aware of funding for education of school-age children also feel this problem: *Bantuan Operasional Sekolah* – BOS - is the name of the scheme under which children receive assistance. This scheme applies to every pupil who attends the class, no matter whether or not they have a disability. However, it is not easy for children with special needs to enter the classroom, either in a regular class or in a special class. One mother (M8) explained:

My son will get assistance through the mechanism of BOS when he could otherwise follow specific class. It means he can go to class when he has ... passed the process [of] at least 3 years of ... therapies in the rehabilitation centre. And now he attends school and still has to follow some treatments in the next building. He got funds from government.

6.4.5. Funding of Services

A crucial element of this study is the funding of services for children with autism. This study indicates that parents face barriers in funding services for their child. The costs of treatments for children with autism can be very high, and can have a continuing effect for the rest of their lives. One mother (M8) said: "I think it is all about the cost of caring [for] our child, and I am really aware that the cost of therapy for our autistic child is very high". A similar view comes from M5:

The cost of therapy for a child with autism is very high and expensive. Our child still needs different types of treatment in conjunction with a regular process. So I cannot imagine how many rupiahs that we as parents have had to spend. In my case, most funding relied on our family funds. The cost for a month is almost a million rupiah.

This study indicated that paying for a service received by a child with autism is sourced from personal funds, and from funds such as insurance schemes (public or

private). Funding services for a child with autism is a priority for parents, and sometimes also an obstacle; family problems can emerge as a result. Parents often found it hard to afford appropriate services, and this study revealed that some mothers similar problems as found other studies.

This study shows that some mothers used personal funds to pay for their child's treatments. Some did not have financial problems. However, most of these mothers faced financial hardship in providing good services for their child. As a result, they rely on their out-of-pocket money in order to pay for their child's treatments. Mothers said that out-of-pocket expenses are incurred when they use treatments at private institutions or when they visit medical professionals such as psychiatrists or GPs. Sometimes financial hardship leads to a family decision to withdraw the enrolment of their child; M14 described this:

Once I knew that my first daughter suffered autism, I enrolled her into a private rehabilitation centre. However, it was [for a] couple months only as the fee for treatments was so high, and hard for us to continue her treatment regularly

A similar story emerges from M7, who said that she could not afford to send her second son regularly to a therapy centre, as the fee for his therapy was so high that she decided to withdraw his enrolment. Such cases will happen if the family is facing financial hardship particularly if they are also raising other children.

This study indicates that access to services for children with autism can be limited by the capacity of parents to pay for them. The extent to which parents allocate funds for treatments depends on their financial situation. Here is how some mothers described this issue:

[There are] many things to be considered for selecting what kind of particular services to provide for my kid. For me, it is about how much ... cost would be incurred when we decided to enrol our son in a particular centre (M7).

As my daughter got services from a private institution, they asked me to choose how many ... treatments in a week based on ... our financial [ability]. So my husband and I decided to bring her [for] all weekdays treatments (M8).

These statements indicate that the decisions parents made were based on their ability to spend personal funds on getting care for their child. However, they also used public insurance when they were not able to provide for their children's needs by personal funds alone. This study shows that one mother used a public insurance scheme to help her son get treatment. This scheme is the *Jaminan Kesehatan Masyarakat* (JAMKESMAS) for people who have been identified as having particular circumstances (e.g. poor people). But this fund seems only intended to pay particular services, for example, when one mother (M7) bought a certain medicine and doctor's fees:

I decided to apply the JAMKESMAS for medicine purchases so our family fund could be more focused on the payment of therapies for him (her son).

Another mother (M2) explained how she refused to use the JAMKESMAS scheme for therapy services as it meant attending at a public hospital. She also used it only for buying particular medicines. Consider this transcript:

If I brought my son to the Public Hospital in order to get therapy services, I then could use facilities that are funded by JAMKESMAS. It means that I did not pay anything for service expenses. But I did not use that due to the long process to get services, it was a long queue. There were many steps to get free-of-charge therapy in the Public Hospital. So I had to pay any expense of my son's therapies so I decided to bring him [to] YPAC.

Another mother (M9) questioned the adequacy of this scheme in terms of helping them to fund treatments for their child with autism. It did not cover all treatment expenses for their child, as one mother explained.

At the other end of the spectrum this study shows that when they can afford it parents are willing to pay for service. These parents believe that if they spend a lot of money, this will ensure good quality services for their children. One mother (M14) said:

Once I enrolled my daughter at a private rehabilitation centre ... I fully understood as I decided to enrol her in private one, the fee of enrolment must be expensive. It was okay as long as she got good quality treatments. As I experienced, there were many problems in how to manage the treatments to all children, I guessed. For example, sometimes the therapist came late to treat our children, and that was happening [several] times in week. So, poor services we received. I was angry with the situation due to the high price of treatments ... and we did not receive ... good service.

This statement by M14 reveals that good quality services for their children, that meet the child's needs, is crucial what parents expect when they pay high fees. Failure to meet the needs of the child, including the way that treatments are delivered, will be seen and named as poor services. Parents feel that money paid for the care of their child has been wasted if delivery is inconsistent with what was expected.

In conclusion, the mothers of children with autism are still experiencing difficulties and obstacles in using the services for their child, even though such services and funding of services exist. These difficulties include accessing the services and communicating with the professionals. The experiences of mothers interviewed will be discussed and analysed in detail in the next Chapter.

Chapter Seven:

Policy Implications

7.1. Introduction

This chapter presents an analysis and discussion of the key findings of this study. These key findings highlight some areas of possible policy action including asking parents about the information they need, designing an official website to help parents, changing cultural understandings of disability, and improving access to the education services and therapeutic treatments needed by children with a disability. This chapter takes the insights presented in Chapter 5 and Chapter 6 to show how to improve the implementation of Indonesia's policy for children with disability, and particularly for children with autism. This chapter continues to draw on analysis of the empirical data collected from interviews with participants between November 2011 and February 2012, and combines this analysis with that of the policy documents. Each section begins by considering the implementation of specific policies relevant to disability, especially in the areas of health, education, and social services in Indonesia.

7.2. The Need for Information

Families and parents of children with disabilities need access to information and advice; this need is identified throughout this study. Information is a pivotal resource for parents of children with disability as they bring up their special-needs children. The need for information for people with disabilities and their families has been acknowledged in many ways. For example, The United Nations Standard Rules on the Equalization of Opportunities for Disabled Persons declares (1994):

States should ensure that responsible authorities distribute up-to-date information on available programmes and services to people with disabilities, their families, professionals in the field and the general public.

This statement shows that disabled persons and their carers (including family members) need more and better information, which needs to be provided in ways that they can easily access.

Information about autism and other developmental disorders emerges from this research as perhaps the most important unmet need among parents of children with autism. The need for information experienced by mothers is intense, and this encourages many mothers to create themselves as information seekers. Parents want to understand what is happening with their child, and they see information as a key resource to help them raise their children in the best possible way. Once their child has been diagnosed as autistic, parents want information that thoroughly covers the needs of children with autism, and also the needs of their parents. Parents particularly want information about services for children with autism. This is particularly important because knowledge about early intervention can make a big difference to the child's future outcomes.

The improved understanding of autism in recent years has indicated that access to appropriate treatment and education services can help many children with autism to grow to be independent. The mothers interviewed expressed concern about the lack of information they received when they first approached health and education professionals. They hoped that future parents would receive better information about how and where to get involved in the early diagnosis process, as that will help parents obtain appropriate treatment and education at an early age.

Governments need to guarantee the dissemination of information to the target population. This is crucial, as The United Nations Standards rules on the Equalization of Opportunities for Disabled People state that all governments should ensure that responsible authorities distribute up-to-dated information on available programmes and services for people with disabilities. This regulation shows how centrally important is information about existing programs and services for people with disability, and how that information is disseminated. The information must be accurate, and targeted to the people who need it. This regulation also places responsibility for providing information on statutory services. It means that all agencies or department that have been tasked to perform services to people with disability have obligations to spread information to the affected person.

As shown in Chapter 4, Indonesia has legislation stating in general that ‘people with disabilities have the same rights as other members of society to services’ (UNESCO 2009). The main goal of this legislation is to improve the quality of life of people with disabilities by providing for their welfare and rehabilitation. In the field of education, some institutions have been built to pursue these goals through, for instance, special education classes. However, many people with disabilities and their family do not recognize or understand the legislation because they have insufficient appropriate information about it. As a result, many parents fail to get appropriate services for their child. At the most fundamental level for example, the mothers interviewed did not know where to go when they became worried about the abnormality of their child. If parents have information about early intervention services for their child, this will positively affect how they react to their child’s condition; such information needs to be provided as early as possible. The lack of information is affecting parents of children

with disability who, as a consequence, tend to have late contact with experts in early intervention.

In Indonesia, Government Regulation Number 43 of 1998, on the welfare of people with a disability, states that providing information is part of government obligations to deliver services to the people. Article 11, paragraph 2 (a) ²⁸ of this Regulation says that information could be provided in the form of voice, sound or poster reserved for disabled people. More broadly, this regulation spells out the tasks of government and its agencies to disseminate specific information relevant to the welfare of Indonesian people with a disability. Government's role is to build easily accessible information for disabled persons who seek information about their condition, and about services for them. Such information is highly useful for citizens who have been diagnosed with any disability, either physical or mental, as well as for their family and carers.

This study shows that more information is needed - particularly knowledge for mothers of a child who has been diagnosed with autism. Information from publicly available sources needs to become much more easily accessible if mothers are to gain knowledge on autism issues that concern them. Information can be used as a tool for coping and helping them understand what has happened to their child. However, information currently provided is mainly focused on the term 'autism', rather than explaining what parents should do to help or to support the child who has autism. What is needed is more relevant information that can help parents of children with autism gain basic knowledge about autism and how to minimise its impact.

²⁸ Pasal 11 ayat 2 (a) menyebutkan bahwa: 'Pelayanan informasi dapat diberikan melalui antara lain suara, bunyi, atau tulisan yang diperuntukkan bagi para penyandang cacat'.

What is striking in this study is how, initially, mothers did not know anything about autism – most had never heard the term autism before. This gave the mothers a major challenge, as they had to figure out its meaning. Accessing appropriate information was not easy for these Indonesian mothers of children with autism. It was particularly hard for them to obtain full information on this disability, including types of services and the places to go to get various kinds of help. As a result, mothers had to empower themselves through information seeking. This process became a ‘pivot point’ for mothers, allowing them to then seek appropriate services for their children. Self-searching for information and services for children with disability (including autism) prompted mothers to be an agent for themselves and their children with autism. This study shows that there is a category of mothers who actively seek information, searching through many different sources, including general practitioners (more than one), medical specialists, and teachers. Their experience of insufficient information being available in Indonesia led to some mothers visiting other professional and community leaders including traditional healers. Searching for information about autism became very important for mothers. In the disability literature, information is acknowledged as a vital component in understanding the practical implication of the disability and in facilitating adjustment to it (Pain 1999). Looking for information about autism is part of a strategy for coping with the child’s diagnosis. From the results of their information seeking, mothers learn what they should do in this unexpected situation of having a child with a disability - and in particular a behavioural and communication disability without any sign of impairment marking the child’s body. As other studies have shown, this study also found that some mothers could be termed ‘information seekers’; they react by gathering more and more information, sometimes ‘becoming more expert than the professionals’ (Beresford 1994).

As shown in Chapter 5, mothers began to find a way to understand the developmental abnormality of their children. According to the some mothers, the behaviour of their children with autism was totally different from that of other children, including their own other children. As a result, they started to question the causes of their children's difference. Due to the lack of information the mothers had received, they built coping strategies for themselves, but these often delayed their child's diagnosis. So if a government or a community agency were to be designated to provide supportive information for parents or carers of persons with disability, parents would know where to get this information. Availability of information is particularly important because children with autism need to receive treatment as early as possible; early treatment requires an early diagnosis. Therefore, information about the diagnosis and treatment of children with disabilities should be displayed in all places relating to public health to maximise the likelihood that all parents will understand their child such as the community health centre (the *Puskesmas*) or public hospitals. It is known that parents visit health facilities when their children are sick, as well as for vaccinations; these health facilities are also close to where parents live in suburbs. The forms of displayed information could be pamphlets or posters. Dissemination of this information has the purpose of educating parents, carers and lay people to understand what autism is, and the early signs of its emergence. The information should also include where they should take their child if they recognize any of these signs in their child. This is important as this study shows that, at first, not only did mothers not understand what autism was, but they also had no information about how to handle the problem. The information provided should help them know what they may be dealing with and where they should take their child.

Another way that mothers cope with lack of information about autism is to blame themselves or the environment where they lived during their pregnancy as the cause of their children's autism; this provides a way for them to accept their child's condition. Those explanations emerged as they struggled to understand their child with autism, and this became a strategy to cope with their child's health problem. Blaming themselves for past actions is a way to make sense of their situation. Giving an example, one participant stated that she opposed and fought against her own parents in the past and saw this mistake during pregnancy as a cause of her child's condition. Shapiro (2002) studied, in Vietnam, the influence of local culture on disability, and suggests that one way of seeing disability is as a punishment for sins committed by an ancestor. In this view, disability suffered by a child is a punishment from God for the actions of their parents in the past. This notion has evolved in the communities and cultures of Asia, including Indonesia. In line with the opinion of Shapiro, this study found that some mothers feel that a disability of their child is a punishment from God, retribution for a mistake they made in the past. As a result, these conditions, whether acquired or congenital, are associated with pity and shame. According to Shapiro, some family members (including parents) will 'take extraordinary measures' to keep the person with disabilities out of the public eye. Contrary to Shapiro's opinion, mothers in this study felt an obligation and awareness to accept their children unconditionally, and they had no intention to cover up their child. Even mothers who experienced a rejection from their husband of their child's autism diagnosis accepted their child's health problem unconditionally (see Chapter 5). On this point, mothers felt they must accept the children unconditionally instead of rejecting them.

The child with autism appears to have good health physically and grows like any normal child. However, the behaviour of children with autism differs from that of normal children (and children who have other disabilities). As seen in Chapter 5, most of the mothers admitted that they were not aware of any signs of autism in their children. They noticed something different when they compared their child with other children (including their own other children). This brought them to question what happened to the child. This is in line with Turkington and Anan's (2007) study that found parents were usually the first to notice unusual behaviour in their child. Their study showed that mothers recognized signs of behaviour difference that could be recognized as signs of autism in their child; this mother's knowledge could be better used in early detection of autism in children.

One early symptom of autism in a child is the lack of expression by the toddler to his or her own parents; a 12 months old toddler may have difficulty pointing to what they desired; gradually, they lost the ability to say words. Other signs of autism are repetitiveness and sensitivities as well as regression that can happen in children up to two years old. As shown in Chapter 2, some infants and toddlers develop normally until the second year of life, when they start to lose skills and develop symptoms of autism; this pattern is called 'regression'. The main characteristic of typical autism is severe deficits in reciprocal social interactions, communication and imagination (Bilgin & Kucuk 2010). According to some mothers studied, their children had some signs of "regression": initially their child could make some words and rhythms, but then they suddenly stopped doing either of these. Their child also suffered a setback in communicating, both verbally and non-verbally. At this point, the mothers did not know their child had an undiagnosed condition. Their knowledge was very limited, and

they started trying to find how to solve this problem. Having information about the early signs of autism in young children would have helped these mothers to get an earlier diagnosis. Because it is undeniable that early intervention is crucial for children with autism, information about early diagnosis and also early intervention are essential.

The information provided should also be easily understood by parents and carers; that mean that it should use simple language. The information must also be presented in a way that can be easily found and easily understood. As well, using informal networks to disseminate the information would be useful. The findings of this study show that mothers often have close communication with some groups of people, including family members, and parents of other children with autism. Therefore, dissemination of information needs to be carried out in cooperation between the government/agency designated to provide services and local communities. A key feature of the display of information is to inform parents and carers according to needs, in terms of the particular needs of the child with disability and the stage the parents and children are at in the development of the condition and their psychosocial needs.

Confusion can be increased if the mother does not understand why her child has been classified as disabled, as her child has no visible physical impairment. The term 'disability', according to some mothers, refers only to physical impairments. For example, a blind person has impaired vision due to a defect in their eyes. Most of the mothers in this study did not see any physical/bodily impairment of their child, who had grown normally and appeared to be like other normal children.

As seen in Chapter 2, suspected causes of autism include genetic or environmental factors, or a combination of both. Some people have recently claimed that giving vaccine to infants can cause a child to become autistic; this still needs to be examined further because there are controversies about vaccination as a risk factor in causing autism among children and medical professionals generally reject this claim. At the time of this study this debate had not yet reached Indonesia, but the problem of an information vacuum could be seen as mothers searched amongst all kinds of folk beliefs to explain their child's difference. In this study, no mothers had any information about the cause of autism in their child. This study shows that mothers had a poor understanding of autism, especially about its early signs in a child. Thus, mothers started to blame themselves and bad environment as the cause of their child's disability. This brought issues of self-blame for these mothers; Kingston (2007) also found this in parents. Parents may build a concept of autism based on what they had done in the past as the cause of autism in their child. However, as their understanding of these concepts increased, information seeking became part of their coping strategies to deal with their child's condition; this is presented in Chapter 5.

7.3. Designing an Official Website to Help Parents

Popular media and digital social networks are important ways to form knowledgeable parents of children with autism. Popular media includes the Internet, magazines, television, radio, and books. Some research looks at how parents of children with autism - or parents of children with other disabilities - turn to popular media seeking knowledge or information about their particular issue. Many parents of children with autism search the Internet to learn more (Sabo & Lorenzen 2008). Currently, some web sites provide information about autism and other syndromes among children, and

those web sites provide important information for parents. However, there are not enough websites like that in Indonesia, particularly official websites from government departments or other trustworthy sources concerning information and services for people with disability.

There is still a lack of websites that can help parents or carers of children with autism in Indonesia by informing them of services for their affected children. However, there are some websites that can contribute to help parents or carers of children with autism in Indonesia to obtain a variety of information on some services for their child. The websites contain information that parents or carers of a child with autism can read easily. Some of the websites can be read in both languages, Bahasa and English. Along with website of *Yayasan Autisma Indonesia* which parents of children with autism who live in Jakarta and surrounding areas have recognized, there are some websites including the CAE-Indonesia (2015) that is more focused on education services for children with autism. This website also contains information about parent's support groups that Indonesian parents or carers can access the information, and the group have a regularly meeting discussion based on monthly basis. This website gives information for general audiences who have or look after a child has been diagnosed with autism. Unfortunately, it is only parents and/or carers of children with autism who reside in big cities (Jakarta, Medan and Surabaya) who can get access to the services and it is still hard for parents of children with autism who do not reside in those cities. Another similar website is the *Amal Khair Yasmin* website (2015). The website gives information for parents or carers of children with autism who reside in Tangerang, Jakarta. This website did not explain information about parent support groups, instead it focused on therapy services for affected children.

Based on these websites, it can be concluded that parents or carers who can attend sessions or therapies in Jakarta and perhaps other very large cities are gradually being provided with valuable information using the internet but it is still particularly hard for parents who live in outside of those cities.

Because of this lack of information, sometimes parents (including mothers) had insufficient information about the nature and scope of resources available for their child, as well as resources for themselves. As lay parents with no knowledge or experience of autism, they started to understand some of the issues through popular media. They used information technology as a tool to search for information on the Internet. They also looked at books, magazines, and television programs as other sources of information.

Using the Internet has become routine part of life, especially for people living in urban areas. In Indonesia, using the Internet to search for information has become normal, and people who live in urban areas do not find this difficult. Families who do not have Internet connection at home can access it for an hourly rate at a rental store. Some mothers in this study said they became aware of information about autism through Internet searching, and it was not difficult for them to find information that way because they found it easy to obtain. However, there is still insufficient information about autism on some government websites. Personal blogs, personal opinions, and websites of small non-profit organizations concerned with autism were places where mothers searched for information using the Internet.

Parents and/or carers of child with autism manage personal blogs and opinion into online communications by attracting other parents or carers to get involved in online-chatting on autism issues. However, the quality of information on some websites is debatable, particularly when the authors were not medical or educational professionals with expertise on these issues. Their knowledge about how to deal with autism, medically, is insufficient. What they wrote on the website is the result of reading articles based on the opinion of autism experts; whilst sometimes this is valuable, sometimes errors occur. Information on another website included opinions based on personal experience as parents or carers of children with autism. This does help mothers to understand the practical knowledge about living with autism. In this situation, these sites did help them amid lack of information about what they should do when they find out the child's condition.

Below are two examples of information found by Internet searching by some mothers who were looking for something unforeseen that leads to autism.

Figure 7.2.

The Example of Google Search on the terms of '*Anak Autis*'²⁹,

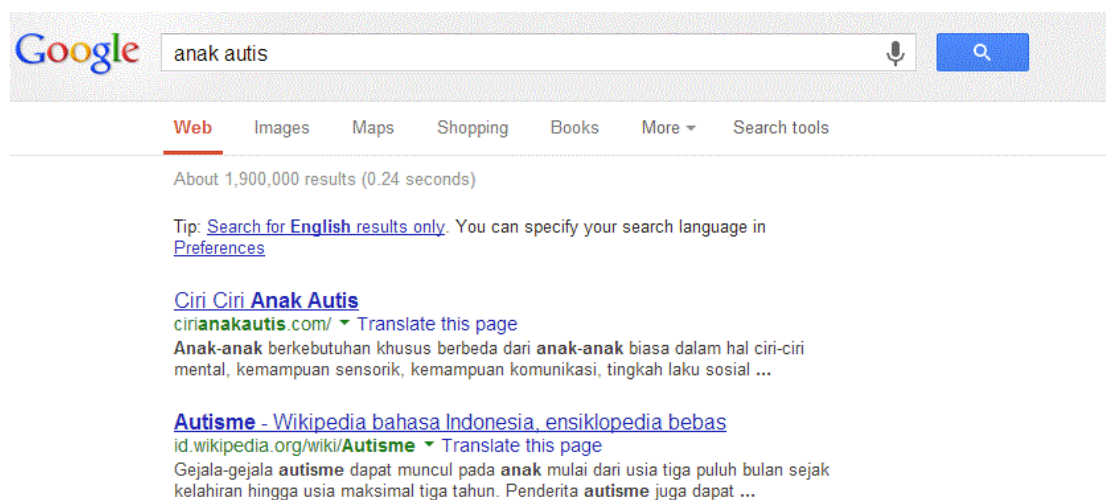


Figure 7.3.

The Example of Google Search on the terms of '*Autisme di Indonesia*'³⁰,



The images above show that no information about autism was available from any government or official websites instead of non-government organization The *Yayasan*

²⁹ Children with autism.

³⁰ Autism in Indonesia

*Autisma Indonesia*³¹ is on the top of lists (figure 3). The government is still not using Internet facilities to disseminate information about autism and relevant services; on the other hand, parents use the Internet as an essential tool in their search for information. It is recommended that government should provide a quality website about autism itself, and about relevant services for children with autism. In developing such a website, the government is in a good position to do the job of building a website or portal with cooperation with non-government organizations involved and concerned with autism - and in disability services generally. Such a site should invite people who already have knowledge and experience with this disability to communicate through the site encouraging open conversation between parents/carers and the information agency. This mechanism will bring knowledge sharing amongst parents/carers of children with autism and a respected agency responsible for moderating the site and the reliability of the information. Therefore, the government needs to design an informative website that can provide valuable and trusted information for parents and carers of children with a disability.

However, most government websites - including those of health, education, and social affairs departments – focus on information about the functions and duties of those departments, rather than on the availability of services. That kind of website is of little use for desperate parents or family members who are seeking information about services for people with disability. A more useful website of such departments would provide listings or links to relevant websites. This could be done in cooperation with non-government organizations, including non-profit organizations providing delivery of services to disabled people. On the other hand, most families of children with

³¹ This organization aims to provide services to people who are diagnosed with autism and to disseminate information to the general population as well as the professionals (in the education and health areas) about autism. This organization is located in Jakarta.

disability in Indonesia do not have access to the Internet. On this point, at least such a government website would provide suitable information about the service system and the type of services that families and carers of people with a disability can access via people they may be in contact with such as local teachers, health workers and community organization representatives.

Basic information about services for families living with autism and other disabilities should be provided on government websites, but from there information seekers could be directed to reliable NGO websites and to existing parent and autism associations and support groups in Indonesia. Community Sector Organizations are often better placed than government bureaucracies to provide and maintain websites with the kind of life information wanted by people living with disabilities. Recognizing this, governments sometimes commission NGOs to provide and maintain such websites, through contracting with relevant organizations set up by parents and others with a community focus, rather than a focus on information designed for experts. This model recognizes the significant role already being played by existing support groups and associations and frees the government to assure the reliability of the information and to consolidate navigation tools that make use of such sites to support information seekers and ensure they access comprehensive and trustworthy resources.

According to WHO (2011), most assistance and support for people with disability comes from family members or social networks. Governments do supply of formal services is generally underdeveloped and also non-for-profit organizations have limited coverage on the services, particularly in developing countries. Therefore it is rarely enough affordable support to meet the needs of the people with disability. In

terms of information services the people can access it, websites informing some services for affected persons have pivotal influences and on this point, the non-for-profit organizations have prominent role to deliver information. However, they are still hard to perform the task as many of websites have problem to deliver suitable information for affected people due to lacks of supporting assistances including person who operates and maintains the website as well as experts who shared a valuable information of autism to parents and carers of children with autism and the availability of funds. Indonesia is a good example to examine this situation. Some websites rarely are able to meet the whole package of information that parents or carers need to know.

Therefore it is recommended the governments need to help aiming to organize the websites belong to those organizations (in the area of disability) to share information. The assistance of governments can create setting standards to display information, regulating and providing funds in order to build potential and valuable organization websites focusing on services for children with disability. It is also recommended that either national government or local governments can join cooperation with the organization concerning to provide some services to person with disability including build online information, for example.

When designing a good government website it is also important to provide simple information for parents and/or carers of children with disability. Such a website would include information such as early intervention as well as the diagnosis process; it would also give information about recommended rehabilitation or treatment centres for

children with autism (and other disabilities). This would enable parents of a child with disability to know where to go.

Meanwhile, books about autism are still useful as a valued source of information for mothers of children with autism. However, buying books can be a hardship for some parents, because in Indonesia they are very expensive; as well, the availability of books on autism in local libraries is very limited. From the observations of the local library, the researcher found only three books discussed autism or children with autism. So it is difficult for mothers to use books as a source of information. Browsing the Internet is usually an easier way to obtain information. This is not in line with Mulligan et al. (2010) who found in some western countries that books were described as a 'highly accessible' resource for parents of diagnosed children with autism.

Chapter 2 showed that many parents of children with autism searched the Internet to learn more about this condition (Sabo & Lorenzen 2008). Currently, some web sites do provide information about autism and other syndromes among children, and those web sites have an important role to provide information for parents. Mothers in this Indonesian research stated that they became involved in online communication by subscribing to somebody's personal blog. The conversations there provided them with additional knowledge. So, sharing knowledge occurs in this process, according to mothers. As seen in Chapter 6, dietary information for children with autism was shared through online communication between mothers and the moderator of a personal blog, for instance. This information prompted those mothers to act as agents for themselves and their children. In doing this, they acted as information seekers for themselves as well as for their children. Another aspect of this situation is how mothers acted in

doing self-diagnosis: some mothers have diagnosed their child's condition based on information they read on the Internet or from some other source. This then led them to seek official diagnosis of their child's condition from medical experts.

7.4. Changing Cultural Understanding of Disability

According to Matsumoto (2001), culture is a dynamic yet stable set of goals, beliefs and attitudes shared by groups of people. Culture shapes how people view and think about themselves and their community. In some places, a community may largely depend on their culture. It is understood that cultural beliefs and attitudes determine behaviours, and guide decisions and interactions with broader society (Groce & Zola 1993). Children and adults with disability are also shaped by the culture within which they live. Culture can shape people in many different ways – some positive and some negative. Culture influences the family and carers of a person with disability as they seek help, as well as influencing the relationships between families and professionals, and the views they will have about what treatments will be used. As shown in Chapter 6, a mother may prefer to visit a traditional healer to seek help for her child, instead of a medical professional. Her reason for this choice may be the cultural belief that the traditional healer is able to remove evil from the body of a person with disability. However, such a cultural view - that disability is the result of evil in a particular person - is a negative view. This view can force a person with a disability to live separately from their family and their community in an isolated place.

Groce and Zola (1993) state that the family and the community may be less willing to expend scarce resources on a child with a disability; this may be the case particularly if a child's disability is believed to be caused by negative forces. Where disability is seen

either as an inherited evil or as a punishment from God, the existence of a child with a disability may be a source of deep shame for the parents and family of that child. According to Groce and Zola, parents who are in this situation sometimes keep their children “tightly behind the door of their home” (1993). In a situation like this, the parents will be less likely to access the early intervention services that are needed to support their child.

As shown in Chapter 6, some mothers still feel badly about the disability of their child. This may also impact the attitude of medical professionals who have contact with a child with autism. For some mothers, the initial acceptance that their child has a disability can be difficult because the mother’s concept of disability equates with ‘physically disabled’, and this does not seem to apply when they look at the body of their child. The mother’s lack of knowledge about autism is the cause of this misunderstanding. An example from medical professionals is that they may still prescribe a medicine for a child, despite knowing that a child with autism will not be healed by that medicine. Medical professionals know that what the child requires is therapies, treatments, and an appropriate education. For example, Mandell & Novak (2005) state that there is an “array of treatments for children with autism including various behaviour, cognitive, vitamin and diet therapy”. However, even some medical professionals still do not know how to help a child with autism.

For some mothers, particular those who live in urban areas, visiting a doctor or medical person are a priority. According to these mothers, a medical person is the best person to ask for good advice. However, as seen in Chapter 6, even for those mothers, their first contact with the medical person was when they took their child to a general

practitioner due to a normal childhood sickness such as a high fever. From the consultation with the medical person, they understood that there is something different in the development of their child. This study shows that the communication between the mother and the medical person is an important part of the journey of caring for their autistic child. The process of communication aims to transfer information to parents by the medical person. The information the parents need from the medical person is crucial; it includes understanding the problems of the child, how they themselves can help their child at home, and what services are available for their child.

In the context of Indonesia culture, the communication between a doctor and patients is often largely ‘one-way’ communication (Claramita et al. 2013) rather than interactive. This study shows that in the communication between doctors and mothers of children with autism, the doctors had a dominant role. In addition, this study also shows a lack of equal communication between medical personnel and mothers of children with autism. As well, it shows that this unequal communication affected the extent to which parents gained appropriate information from the doctors. As a result, parents often visit multiple doctors to gain the information they feel they need. Culturally, in Indonesian communities a doctor is high in the social hierarchy (upper-middle class), and would expect their health advice to be obeyed by patients. However, patients and their families may be reluctant to accept all health advice from doctors. As shown in Chapter 6, mothers said that doctors did not understand either them or their child’s condition, and that information obtained from the doctor did not always explain well what has happened to their child. Based on the mother’s experiences in this study, when making medical visits in person, mothers wanted a clear understanding of what had happened to their child. They viewed the medical professional as a person who

knows best about the health of others. This creates burdens for some medical professionals, as they also may not understand how and what the disorder of autism is. Medical professionals who have limited knowledge of autism will be of limited help to parents of an autistic child. In this circumstance, the parents may feel as helpless as the child. Even where doctors do have knowledge of autism, the lack of a clear explanation of its causes can make communication and trust between mothers and doctors difficult.

Based on the mothers' experiences when they interacted with the professionals, it is recommended that the government compose a program intending to encourage the professionals to understand better autism amongst young children. The programs can disseminate additional knowledge and information for them. The programs could include attending seminars, workshops or conferences about autism and other behavioural and communication disabilities intended for the professionals in the area of health. By joining conferences, it will help the professionals to understand better on particular issues. It is also recommended to the government to create a joint task force with the non-government organizations concerning disability services to perform some training for the professionals.

Chapter 6 shows that mothers sometimes attended first one professional and then another in their attempt to obtain a fuller, clearer diagnosis, as well as the best advice about treatment for their child. Sometimes, seeking a diagnosis for their child, they contacted a paediatrician, or a child psychiatrist. Unfortunately, the health care system in Indonesia does not provide an integrated system of early intervention services for children with suspected autism. In addition, there is still a lack of coordinated services in Indonesia for children with autism.

However, as a mother who lived in the countryside said, contact with a medical professional was not always the first thing they did. Sometimes a mother first made contact with a traditional healer (*dukun*³²) to discuss her child's condition. Two things need to be noted in this situation: was this because of the ignorance of the mother about who to consult, or was she just more trusting of a traditional healer than of a medical professional. Some mothers may see symptoms of autism as a form of mental illness, and are therefore more trusting of traditional healers than medical practitioners. It is not surprising if a mother has this kind of thought; Gerrard (2006) stated that autism was originally viewed as a personality disorder, or a form of mental illness – and an implication of this is that people suffering from it may recover. A mother who visited a traditional healer may have felt this is the best way to help her child be cured. This would allow her to hope that her child would recover from the 'illness'. The mother and the *dukun* might agree that 'evil spirits' has affected the child; however, the 'illness' was hard to be cured by the *dukun* as he performed the removal of demons or evil spirits from the body of the child. As shown in Chapter 2, children with disabilities are hard to cure unless they get suitable treatment or rehabilitation that improves their skills and abilities. For children with autism, what is needed is therapy and special classes at school.

It is recommended that traditional healers should be trained by government, or by a suitable agency, so that they can help people with disabilities and/or their carers.

³² Besides modern health professionals, there are also '*traditional doctors*' who are active in the field of health in Indonesia. They have different terms that are depending on the region and the culture in which they live. Very common is the term '*dukun*', but other names are also used for those who heal using traditional herbs and also by contact with the spirits, '*roh-roh halus*' (Drewes, nn). The technical term is '*tou pa urato*' in West Sumba. In Batak culture it is '*sibaso*', and '*balian*' in Bali, and many more. The term *dukun* originated in Javanese culture, and Bahasa Indonesia has adopted it as the term for a traditional healer.

Indonesia already has a program that trains traditional healers to help women in labor (*dukun beranak*³³); this program has been implemented in rural and regional areas. It educates the traditional healer to assist a local government-employed midwife. Workshops in this training emphasize knowledge about the need for cleanliness, and about the tools of labor, newborn care, and prenatal care, early detection of high-risk mothers and babies, family planning, as well as birth and death records.

This model might be relevant for improving services to people with a disability. As some people still believe in using a traditional healer, government could develop a program to involve them with disabled people. In rural areas, a traditional healer is a trusted key figure that people will communicate with about their health problems. By involving them in training workshops, as it did for women-child care services, the government could encourage parents of children with disabilities to interact with medical professionals as early as possible about their child's health problems.

Once mothers decide to visit a medical professional, obtaining an appropriate diagnosis for their child is their main goal (see Chapter 6). This process has a core: mothers feel relieved when they start interacting with service providers, including medical professionals and educators. In this section, I focus on how they interact with medical professionals at two stages: before they receive a diagnosis for their child, and after the diagnosis.

For some mothers, seeking an appropriate diagnosis for their child is difficult as they are still struggling to find the best person to diagnose their child's problem(s). Due to

³³ Traditional midwife.

inadequate availability of information about the signs of autism in children, the diagnosis is often very late; when the mother first sees symptoms in their child, the child may already be 6 or 7 years old. This delay may be because parents go from one professional to another looking for a 'best' diagnosis, and for proper understanding and advice on how to bring up and deal with their child (Peeters 1997). They were seeking an appropriate and trusted diagnosis for their child. But the lack of information about who could best provide this diagnosis constrained their ability to build a relationship with appropriate medical professionals.

This study indicated that mothers tended to feel relief after gaining the diagnosis of autism for their child. However, their relief would be greater if the diagnosis was given as early as possible. This finding is consistent with Nissenbaum, Tollefson and Reese (2002), who found that parents who suspected autism had the most positive reaction, such as relief, to diagnosis. These researchers said that diagnosis provided parents with an explanation for themselves and others as to why their children exhibited unusual behaviours. Another benefit of the diagnosis is that it can support the parents in their search for an appropriate service for their child. This study found that a referral letter from a hospital or other institution as proof that diagnosis assessments have been completed could be a pivotal point for all mothers for obtaining services.

Mothers in this research stated that the use of simple language could help parents understand the process of diagnosing their child. They highly valued getting information directly from an autism expert, and the value was greatest when it was given clearly. Chapter 6 shows that mothers sometimes had difficulty understanding medical terms the doctor used. Ordinary people who have no knowledge of medical

terms found it hard to accept the process of diagnosis and the diagnosis results when the communication between them and the doctor is unequal. Visiting a doctor can help parents obtain a deep understanding of what of what is happening to their child. However in practice, some mothers did not receive adequate information about the real health condition of their child from the health experts they consulted. Thus, information that mothers needed and desired is not always available at this stage, particularly when there is unequal communication between the mother and the health experts.

7.5. Education

Article 26 of the United Nations Convention on the Rights of Child defines education as a universal right. Indonesian's Education system is aimed at establishing a universal standard of education in the life of every citizen, at guaranteeing the right of all children to education. It has two aspects: access to education, as well as equity in education. Both equity and access to education are required for all children regardless of race, beliefs, background; education is supposed to be required for all children, whether or not they have a disability. The UN Convention on the Rights of the child states:

A mentally or physically disabled child has the right to a full and decent life in conditions that ensure dignity, promote self-reliance, and facilitate active participation in the community. The state should provide special care free of charge and ensure that the disabled child receives education, training and services leading to individual development.

The United Nations recognizes that children with a disability, whether mental or physical, have the right to access education – a right that is equal to that of children without a disability. In order to make this possible, the state should provide services to

children with a disability; including special education services. Special education means instruction that is specifically designed to meet the needs of children with a disability. ‘Inclusive education’ is rooted in the principle of “*normalization*”, and children with a disability have a right to the same opportunities that children without disabilities have.

The Indonesian education system is decentralised. The frameworks decentralize significant responsibilities to sub-national governments such as Provincials and Districts or Municipalities. This has been implemented since Indonesia’s decentralization policy in 2001. However, the funding of education services is mainly derived from the national government, through the school services assistance scheme (BOS³⁴). As stated in Chapter 5, the scheme is granted to all children, whether they are disabled or non-disabled, who are attending class at a private or a public school. Significantly, however, early childhood education services are not part of the scheme, so they are still the responsibility of families. The government requires compulsory school attendance from Year 1 to Year 9 only. So this scheme does not support pre-school services, and the burden of financing these falls almost entirely on families.

Indonesia officially has recognised the education system for people with disability since 2003 through the implementation of Law Number 20 year 2003 and this has been explicitly included in the Education system regulation stating that children with special needs have the same right to education services as other children have. Chapter 4 shows that Indonesia has policies in place that should be guaranteeing the provision of education for all Indonesian citizens regardless of whether a person is

³⁴ *Bantuan Operasional Sekolah.*

suffering from a disability or not. However, in fact implementation of this policy seems to still face some obstacles that hinder the process of delivering services to pupils. Some of these barriers reducing the success of this system for educating children with disability particularly for children with autism include lack of skills among teachers, lack of facilities and resources, and lack of awareness by parents that their children should attend classes. Together, these barriers limit the effectiveness of regular school classes in meeting the needs of school-aged children with autism.

This is not only a problem in Indonesia, Sharpe and Baker (2007) state that although public school districts in United States are legally obliged to provide a fair and appropriate education to children with autism, the educational programs that are provided are rarely sufficient to address the needs of school-aged children with autism, and also that they are not available to young adults with autism. The education system of Indonesia recognizes that education starts with Playgroup classes (these are optional, but they are available to all families), and progresses to Kindergarten, Primary School, Junior School, and finally High School. In Indonesia, four kinds of educational services are available for children between the ages of 1 and 6 - Kindergarten, Islamic Kindergarten, Playgroups and Childcare Centres (Pradhan et al 2012) - and this system is commonly known as Early Childhood Education and Care programs.

Two parts of these Early Childhood Education and Care programs are well recognized in Indonesia: The Al-Qur'an Learning Centres for Children (TPQ³⁵), and the Early

³⁵ *Taman Pendidikan Al-Qur'an.*

Childhood Education (PAUD³⁶). The TPQ contributes most of the Early Childhood Education and Care in Indonesia - approximately 25% (MONE 2010) - as Muslim parents tend to choose this education service for their young children. The TPQ is a place where children under 7 years can learn, read and do recitation of Al-Qur'an; at the same time, children can also play with peers. TPQ is similar to Playgroup, but is more focussed on teaching Islamic values, and on reading al-Qur'an. The aims of PAUD are similar to those of both the TPQ and Playgroups. Parents can freely choose which system they want their child to attend.

However, none of these systems accommodate children with a disability, including children with autism. According to UNESCO (2007), early childhood education is particularly important for children with a disability because it can help to identify problems early, and so increase the possibility of appropriate treatment for such children. Early childhood 'education and care' is not only about education; it is also about *care* including health, development (both social and emotional), and nutrition. If the system is not able to integrate the needs of all children in its earliest stages, it fails to help parents get early treatment, particularly for vulnerable groups such as children with a disability. Chapter 6 describes how one mother insisted on enrolling her child into a PAUD before getting treatment at a rehabilitation centre. The mother decided to do this because she believed she had no choice about the institution at which her child would be educated because of a misunderstanding about the disability of autism in young children. In fact, the PAUD is adopting and applying the learning process as practiced in kindergarten or pre-schools and could be encouraged to

³⁶ *Pendidikan Anak Usia Dini.*

develop inclusive early childhood services and supported to cater to the needs of children with autism and other disabilities.

Another problem is that special schools have long lists of requirements for children with disabilities who wish to attend their classes. The requirements are sometimes applied to all children even if the requirement is inappropriate for the disability of a particular child. A child with autism must perform the same requirement as that of a child with low vision, for instance. This means that a child with autism may be excluded because they are not able to meet the behavioural requirement specified by the school.

There is a transitional education system for students with disabilities, including those who have been diagnosed with autism; they enter a special class to help them adapt to inclusive education. In order to join in Inclusive classroom, the children with disability including the children with autism have to be examined through some required examinations. However, it still is hard to implement due to the hardship for every child with disabilities to perform the skill in the way that is required. Children with autism cannot always compete in general assessments. As a result, the testing system for the children with disability does not work and the government needs to develop a more appropriate testing system aimed to develop their skill and based on their capability to perform, not aimed at excluding them from regular classroom. Therefore, it is recommended that the testing be integrated into student's learning, students with disability should be able to access appropriate services for their learning alongside their peers with non-disability in simple ways. For example, teachers may take them to a shop to teach them how to pay for groceries they want while their

classmate are learning the maths set out in the standard curriculum for their age group.

7.6. Therapeutic Interventions

As described in Chapter 5, after gaining their child's diagnosis of autism some mothers experience a process of moving from shock, to healing or accepting, and this can include feelings of guilt and frustration. However, this situation can also create awareness of how to deal with the problems that arise. For example, as mothers look for appropriate treatments, particularly health treatments and therapeutic interventions, they may find ways to promote the healing process for their child.

A variety of treatment approaches such as ABA³⁷, special diets, and other therapeutics have emerged to help children with autism grow to be independent in their adult life. Because of limited availability of services, it can be hard to obtain appropriate treatments for children with autism. This study found that some mothers have difficulties accessing good and appropriate treatments and therapies for their children with autism.

Regular therapy treatments for children with autism are absolutely essential, and they must start as early as possible. These treatments need to be part of the early interventions for each child. Early childhood intervention is defined as a services for infants and young children to prevent or reduce disability and to promote their development and general well being. Children with autism should be the primary recipients of early childhood intervention along with children with Down Syndrome,

³⁷ Applied Behavior Analysis (ABA) is an evidence-based, intensive education therapy for children with Autistic Spectrum Disorder (ASD). ABA helps children develop their social and behavioral skills needed to interact with others.

cerebral palsy and communication disorders (Albrecht 2006). The age of entry to early childhood intervention services should be between birth and three years; in some western countries, age of entry is from birth to five or six.

To get appropriate treatment, parents need to bring their child with autism to therapy regularly. However, this study found that transport could be a major obstacle for mothers, as can the expense of therapy (because of the way that therapy is funded). Chapter 2 showed that the cost of some treatments for children with autism is high compared with treatments for other children with disabilities (Bebbington & Beecham 2007). A therapy routine or treatment for a young child with autism means their parents have greater regular expenses than do parents of children with other disabilities (or with no disability). It is easier to do for parents who can afford to pay for their child's treatments. However, this study shows that some mothers struggle to continue therapy when they faced financial hardships.

Mothers do have some choices in this situation, including accessing a government scheme that provides free treatments for their children. However, they cannot rely totally on the scheme because it covers only particular services such as the cost of pharmaceutical products; it does not cover all expenses or restricts the availability of some therapies to hospital outpatient department. It is thus important to expand services and reimburse towards expenses covering services provided in a wider variety of venues. As stated in Chapter 4, the Indonesian government has a policy to finance health through the JAMKESMAS or JAMKESDA programs. Indonesian people who live in urban areas recognize this program; however, not all of them understand the procedures they should follow if they intend to use it. This study found

that some parents had very limited knowledge about this mechanism; they even did not know how to go through with the procedures for the scheme. This mechanism is under the authority of the Department of Health which finances health care for poor Indonesians, including families facing financial hardship. Therefore, it is recommended to disseminate information about the procedure of this scheme with simple languages, so the general population can understand better when they need to use the scheme.

Another way to fund treatment for therapy is for parents to pay all treatment expenses themselves ('out-of-pocket'). However, this is very burdensome for some parents. As a result of the 'out-of-pocket', this study shows that parents struggle to divide a family income for daily expenses and the costs of treatment for their children with autism. A family that is facing financial hardship may, for this reason, withdraw their child from treatment. The schemes described in Chapter 4 do not cover the therapy fee for the child charged by a private provider. As well, Chapter 6 showed that even mothers who accessed lower cost treatment from a centre organized by a non-profit organization were desperate as they relied on inadequate family funds to pay the treatment fee; this needs to be paid when mothers start to use the service either through an insurance or reimbursement scheme for families with children with disabilities or directly to approved service providers.

Another burden for mothers of a child with autism is how to bring the child to the place of therapy. According to mothers, the location of these institutions is important, as they face the practical difficulties of bringing their child for treatments. Some of them rely on public transportation, and for them location is particularly important.

However, this creates another burden for some mothers: they may not have any choice in obtaining good and appropriate treatments. For example, if they live in a suburb that is distant from the rehabilitation centre and must bring the child by public transportation such as buses or the *mikrolet*³⁸, this may be inappropriate, as the *mikrolet* does not accommodate the needs of a child with autism. This sometimes results in a distressing journey for the mother, and it could be dangerous for the child. For example, sometimes a child will misbehave uncontrollably during the journey to the therapy centre; not only can this be dangerous, but also the mother can be distressed by the disapproving stares of other passengers. This happens when ill informed lay people question the uncontrolled behaviour of the child. As shown in Chapter 2, lay people may have very limited understanding of children with autism, and so they may assume that the child's 'bad attitude' is a result of parents who do not discipline their child. Consideration should be given to developing transport systems for the disabled or to developing training services for families so that their children can learn to adapt to the transport options used by families.

This study found that treatments for a child with autism aim to help the child become independent. Mothers think that appropriate treatment for their child is the best way to develop this independence. The treatment should meet the needs of their child, and the mothers believe the treatment should be done one-to-one; that is, with only one therapist and one child. This study found that mothers value such a one-to-one approach to treatments for their child. This demand of mothers is in line with Huws and Jones (2010) who said that parents of children with autism have faith in one-to-

³⁸ Mikrolet are small buses or small vehicles. They have a driver as well as a front passenger cabin in the front and a line of seats that face each other in the back. The maximum number of passengers on board is twelve or thirteen people including the driver. The cash fare is paid directly to the driver when the passenger gets off at their destination.

one behavior therapy as the most accurate means of treating autistic behavior. Statements in Chapter 2 show that children who suffer from autism commonly have behavior disorders. For this reason, parents seek behavior therapy rather than other types of therapy for their child. This type of therapy undeniably helps children with autism: Howlin et al. (1973) state that behavioral treatments for children with autism have been used to eliminate a wide range of deviant behavior including self-injury, temper tantrums, and aggressive behaviors. Nevertheless, communications between therapists and classroom settings have a role to play in such behavior change. Developing the skills of educators to be involved in individual treatment programs for the children in their class is something that needs more attention, as is developing parents' understanding of group and classroom settings.

Another treatment that mothers seek for their autistic child is speech therapy. This is important because mothers want their child to be able to speak and communicate effectively. Even speaking simple words like *mommy* or *daddy* raise enormous hopes for mothers, so they have high hopes for good outcomes from their child's speech therapy. Chapter 2 showed that children with autism often have difficulties when interacting and communicating with others. So it is not surprising that parents of a child with autism strongly wish for their child to be able to communicate; these parents can place enormous hopes on the ability of speech therapy to help their child communicate with them or with others. Children with autism may experience speech delay, and in some cases they may be completely unable to speak or communicate. They may find words very difficult, even the simplest ones. Children with this condition may create noise or a tone to attract the attention of their parents or others; they may also point their fingers to something that they want. Combining both of

these – a vocal tone, plus pointing fingers - are common forms of communication for a child with autism.

Meanwhile, the effectiveness of the treatments expected by mothers is still debated; that is because the successes of the treatments depend on two things: the involvement of parents, and the availability of experts to provide the treatments. These conditions need to be clearly considered when making plans for the child's therapy. On the former, Sherman et al. (1988) said that parents must be active participants in the treatment process. However, this will be hard to implement if the parents rely on the other person such as a therapist to provide therapy behind closed doors. The child mostly spends their time in the family, instead of outside home. Parents can help their child to continue the detailed program at home by following the guidance the therapist will give them. Collaboration between a child's parents and their therapist is essential if the treatment is to be successful. On this point, mothers need to be active players in the therapy process for their children. In order to do so, there is a need to train the mothers of children with autism to be able to do therapy at home as practiced by therapists at rehabilitation center. Government or the rehabilitation centre itself could do the training for parents or mothers of affected children.

Availability of experts is also essential to the success of treatments. While mothers have a particular concern about the experts who will perform therapy for their child, it is often a lack of experts that is the problem. For example, there may be a shortage of medical experts in the area of psychiatry or neurology (Howlin et al. 1973). Such inadequacies extend to all levels of health professionals in Indonesia there are too few therapist available such as psychologists, occupational therapist and nurse or

disability support workers with expertise in autism and this may result in delayed treatment for the affected child.

Limited finances can also result in a decision to move a child from professional regular therapy into treatment at home by parents. Some mothers decide to withdraw their child from treatment because of the financial hardship caused by fees for treatment. Such a decision has consequences not only for the affected child but also for the mothers. The child's behavior may regress once treatment has ceased. The mothers will now have an additional burden because of their obligation to continue treating the child. In this situation, some mothers themselves become the therapist for their own child at home. Sheinkopf and Siegel (1998) called such mothers a 'co-therapist', and suggest that a co-therapist is the best way to support a child at home, with parents who are active participants in the process of treatment. However, it can be difficult to implement if the mother has no guidance, as the mother (co-therapist) needs some skills if she is to treat her child. This study found insufficient supports in the system that helps mothers be co-therapists. As well, in Indonesia it is unusual for a therapist, either occupational or behavioural, to make home-visits to a child with a disability. The reality is that parents always bring their children to a rehabilitation centre or public hospital to receive therapy.

This study indicates there is a strong willingness from parents to secure appropriate care for their children with autism. In fact, the medical professionals recognise their willingness, and they as experts of medical care often gave some suggestions to the parents. The suggestions should and sometimes do console mothers empowering them to help their child develop in the best way possible. However, some professionals

advised the mothers not to have hopes that their child will grow up normally or to be able to live an independent life. Such information given to parents by medical professionals should not crush all hope. As Berger (2013) states medical professionals significantly underestimate the quality of life of people with disability compared to the assessment of disabled people themselves. They, the professionals, are oriented towards medical treatment that mean a cure usually with medicine and such a cure is not suggested to a person who is suffering a mental or intellectual disability such as person with autism. Medical professionals did suggest bringing their child for therapy. However, some medical professionals need to give more encouragement to families of children with autism because as Chapter 2 showed intensive therapy, particularly behavioural therapy, can yield significant improvements in cognitive development and in behaviour for children with autism. Lovaas (1978) said that intensive treatment of up to 40 hours of therapy per week for at least two years was needed if the child was to experience better wellbeing in the future. However, this study found that such intensive therapy is hard to provide for the child because of financial problems of the family and perhaps it is unrealistic to expect that paid health professionals need to personally provide all 40 hours of such treatments. Such recognition might prompt professionals to situate themselves as the leader and managers of a network of providers of interventions they devise but the family, friends, community and school deliver.

7.7. Recommendations for Improving on Services

There are many possible ways the government could improve services for children with autism and their family as well as carers, as this section will explain drawing together the details discussed above:

1. There is lack of understanding on autism and disability in general among the close kin of person with autism including parents, family members of the affected person, and even communities where the person with disability lives and interacts. The better understanding can contribute to the well being of the affected person. How to make the kin and the Indonesian population in general understand disability and autism is pivotal. The Indonesian government needs to figure out a way to disseminate broad information in order to spread understanding of disability and non-visible disabilities in particular in Indonesia in many ways. It is widely known that there are some established institutions with wide reach into local communities that can help the population understand, and additionally women and local community members are familiar with the role of these institutions. These are the POSYANDU³⁹ (*Pos Pelayanan Terpadu*) and the PKK⁴⁰ (*Pembinaan Kesejahteraan Keluarga*). These two local institutions' work divides households into groups ranging in size from ten to twenty families in neighbourhood (Tejawinata 1997). Mostly the members are women. Each of housewives is a member of the PKK and the *Posyandu*. Based on the works of these institutions, the local and national government can encourage all the members to be active participants as information deliverers. The government authorities could do so by supporting them through training and workshops focusing on disability issues because they already organise

³⁹ POSYANDU stands for Pos Pelayanan Terpadu (The Integrated Services). This work focuses on to inform and to maintain the children health and welfare in neighborhood. This operates similar with the PKKs' works. Mostly the member of PKK is also member of the POSYANDU.

⁴⁰ PKK stand for Pembinaan Kesejahteraan Keluarga (Empowerment of Family Welfare) is an organization of Indonesian women, particularly the housewives, dedicated to the health and welfare of others. Mostly of the members are women. They dressed in blue Batik uniforms. The women arranged a weekly informal meeting in one of members' home. They shared a knowledge and raise neighborhood issues among the members. The member who agreed to be volunteer has been trained to help improve the welfare of Indonesian communities (Tejawinata 1997).

around issues of basic health care. The women volunteers in these organisations can become the front guard for helping a family who have a child with disability such a child with autism. For example, the Department of Health can build the support programs focusing on training and workshop for the PKK volunteers in terms of how to deliver and to give information about autism to the community. This will foster parents and carers of children with autism as well as the broader community members to understand the disability and this use of peer group education works well for sensitive topic because they know each other due to the neighbourhood relationship. The information could include materials about symptoms of autism, encouraging affected families to contact as early as possible with health professionals, and about where to get appropriate treatments and support. The forms of information disseminations could be communication orally in the monthly meeting or giving written documents such as booklets or flyers to community members and the affected family.

2. As stated at in Chapter 6 mothers of children with autism tend to use Internet for accessing information about autism. However, the quality of information from Internet resources is not sufficient to help parents and carers of children with autism to understand autism and disability. On this point, there are two things that the government could do. The first is the government can help with these problems by improving the capability of public libraries to provide materials about issues of disability and autism. The documented materials could be books, magazines, popular journals concerning autism and disability among children; these resources must be in *Bahasa Indonesia*. Those materials have an advantage as the reader can capture in depth information. This can help parents

and carers of children with disabilities fully understand the information. Another way is, as I state in the discussion section, the importance of developing an official government portal or website explaining the disability and providing information of integrated services for people with disabilities in Indonesia. This should address the information needs of the parents of children with disabilities empowering them from an early stage of their child's development to know what steps to take when noticing something different compared with other children. The website should be designed in such a way that allows parents and carers of children with disability to read complex information in a time-appropriate way.

3. The next point of policy implication is the kinds of government support for the affected children as well as their family and carers. From the mothers' lesson, the lack of financial resources can create irregular treatment and difficulties with securing the appropriate services for their child with autism. In order to avoid the quitting of regular treatments, the government should support the parents of children with autism financially to assist them with maintaining regular treatments such as therapies. As stated in Chapter 4, the Indonesian governments either National or Local have established health care schemes for poor and nearest poor of Indonesia (*The Jamkesmas/Jamkesda*) to support their health care. However, the scheme is not intended to support the expenses of therapies for persons with disability. If the government put the cost of treatments into the scheme, this will help many families who have children suffering with any disability to survive what can be a very tough life. It is widely known that the cost of many treatments for children with autism is high

and will occur throughout their lives. In terms of delivering the scheme, the government needs to provide services free of charge for the families eligible for the *Jamkesmas/Jamkesda* and across the country. As a result, the low-income parents of children with autism could rely on the scheme for obtaining treatments. Middle-income families should also not be neglected and universal health and disability insurance schemes are valuable for this sector. Some of the families of the mothers participating in this study were able to access services for their children with autism because they were voluntary members of health insurance schemes that covered some of their child's therapy costs.

4. The importance of integrated services for children with disability in one place becomes another policy implication of this study. The focus of the integrated services needs to not only be for the affected child but also for the mother of the child. It is widely known that there is an institution focusing on delivery of services for mother and child. The institution is named the *Balai Kesehatan Ibu dan Anak*⁴¹ (BKIA). In this matter, the Indonesian government should strengthen the role of an established institution concerned with assisting mother and child. This institution is familiar among mothers who reside in the city, but it is hard for mothers who reside in rural and regional areas to get services from this centre, as its operations lie mostly in cities. The works of the institution are mostly focused on the prevention of mortality both for mother and child from the period of pre-natal to 5 years old of the child's development. The centre provides services to support mothers and children including monitoring, counselling and checking activities for the health of mother and child during

⁴¹ The Mother and Child's Health Centre.

these periods. In these circumstances, the government can expand the capacity of such organisations to be proactive in providing services for children with special needs such as children with disability and children with autism. The services appertain to early health intervention, pre and post-diagnosis, and continuing treatments for the affected child. This is pivotal for the affected child and their parents/carers as the integrated services in one place can facilitate them in accessing services on a regular basis. If services could be provided on the premises of these highly localised organisations it also will reduce the level of difficulty associated with travelling from home to the therapy. As stated at the discussion section, most mothers of children with autism were feeling anxious and restless when they brought their children to the treatment place due to the lack of transportation system accommodating the disabled person and the consumption of time in the process of accessing treatments.

The government additionally could strengthen the role of local community health centres (the *Puskesmas*) in handling the disability treatments including placing the additional staff that has skills in therapy and special treatments for person and children with any disability. Currently, only public hospitals, rehabilitation centres and private health centres are able to supply therapy activities. Furthermore, the locations of public hospitals are centralised in major cities, which makes it hard for people with disability who live in rural and regional areas to use the facilities on a regular basis. If facilities were available through the *Puskesmas* people could reach them, as the *Puskesmas* are more widely distributed as they lie in the administrative centres of each sub-district and are not restricted to major district capitals. People who lack transportation

tend to visit *Puskesmas* in order to get health care for themselves or their family members. This point is important particularly for mothers of children with disability who are also carers for their family. It is likely that it will be the mother who tends to bring her child or other family member who is sick to a health centre or doctor close to home in order to create a balance of responsibility for the mother who has to look after the home and the sick child. As a result, providing treatments such as speech therapy, behavioural therapy, physiotherapy, psychology and occupational therapy for children or persons with any disability in the local community health centre, or as it is called the *Puskesmas*, close to home, will greatly reduce the burdens on the shoulders of mothers who have children with disability. Additionally, in terms of healthcare funding, the *Puskesmas* can contribute to reduce financial hardship amongst poor people. It also could help the poor family who have a child with disability.

5. In terms of education services, Indonesian governments are still struggling to provide it for persons with disability including children with autism. This study found that, through the experience of mothers who have a child with autism, autistic pupils find it hard to gain acceptance to attend a classroom, even in the special schools. A lack of facilities including funding and the fact that there are very few skilled persons who are performing the task of supporting education services to accommodate children with autism have contributed to this situation where National Government policies are clearly not being implemented. In terms of education funding, the government has built a scheme to help pupils with disability attending school classes with no charge. However, this scheme is not meeting the real needs of the affected pupils since the same amount is

provided for children with and without disabilities. Thus it is recommended the Indonesia government expand the funds for the education of children with disability to cover their real needs and extend access to payments for children with appropriate disabilities to early childhood services. Another recommendation to come up from this study concerned the need to provide skilled teachers including teacher assistants to educate children with autism. The government could very usefully build some programs intended to train teachers in both regular schools and special schools to be skilled in dealing with pupils with autism, and this program could be expanded into building curriculum for students with autism. Furthermore, in the creating of a teacher-to-be, students in university should be trained to accommodate and understand students with disabilities. Masters and other teacher training programs should be offered to increase the skills of teachers after the decision has been made to install them in special schools, or in special classes in regular schools.

7.8. Concluding Remarks

In conclusion, this section draws some points together indicating where the views of mothers of children with autism interviewed for this study have lead us. The aim of this study is to investigate the experience of mothers of children with autism in Indonesia in raising the children and obtaining services for them. It returns to the research sub-questions set out at the beginning of the study: *“How do mothers of children with autism perceive the phenomenon of autism and how do they experience autism services in a regional Indonesian city?”*

7.8.1. How do participants understand autism?

This study found that mothers feel a great deal of confusion in how to look at the disability of their children. Mothers see their child with autism as having good health physically and growing like any normal child. They view disability as synonymous with an impairment appearing on the body of the effected person. For the child with autism, the condition is not visible. As seen in Chapter 5, most of the mothers were confused because they were not aware of any such physical signs of autism in their children. They noticed something different in their child's behaviour when they compared their child with other children (including their own other children). This is in line with Turkington and Anan's (2007) study which found that parents were usually the first to notice unusual behaviour in their child. This brought them to question what happened to the child. Lack of understanding prompted many mothers to develop their own theories about what was the cause of their child's difference. The folk theories developed by these Indonesian mothers were consistent with findings in other studies that show that mothers around the world develop such folk theories and often see the autism of their children as caused by past deeds, or as a punishment. Addressing this information gap would assist families to seek assistance from appropriate health professionals in a more timely manner, and would alleviate some of the stress caused to families by conflicts and stigma originating in such misunderstandings. Moreover, if there was a greater awareness amongst Indonesian mothers of autism and behavioural and developmental disabilities, the mother's knowledge and early observations of the differences in their children could be better used in the early detection of autism in children.

7.8.2. How do participants think about support needs for children with autism?

Mothers in this study lacked sufficient information to enable them to understand what support their children needed or what services were available for them. Information about autism and other developmental disorders emerges from this research as perhaps the most important unmet need among mothers of children with autism. The need for information experienced by mothers is intense, and this encourages many mothers to create themselves as information seekers. They want to understand what is happening with their child, and they see information as a key resource to help them raise their children in the best possible way. Once their child has been diagnosed as autistic, parents want information that thoroughly covers the needs of children with autism, and also the needs of their parents. Next, they particularly want information about services for children with autism. This is particularly important because knowledge about early intervention can make a big difference to the child's future outcomes. However, this study found that many mothers fail to get appropriate services for their child. At the most fundamental level for example, the mothers interviewed did not know where to go when they became worried about the abnormality of their child. If parents or mothers have information about early intervention services for their child, this will positively affect how they react to their child's condition; such information needs to be provided as early as possible. The lack of information is affecting parents of children with disability who, as a consequence, tend to have late contact with experts in early intervention. The mothers interviewed expressed concern about the lack of information they received when they first approached health and education professionals. They hoped that future parents would receive better information about how and where to get

involved in the early diagnosis process, as that will help parents obtain appropriate treatment and education at an early age.

7.8.3. What do participants think of the existing of service delivery for children with autism?

The mothers in this study thought that the aim of treatments for children with autism should be to help the child become independent. They thought that the treatments given to their child should meet the child's individual needs and should be done one-to-one. However, one-on-one therapy is often hard to find as it needs more staff and facilities to support its implementation and there is a shortage of skilled health professionals in Indonesia in areas such as behavioral, occupational and speech therapy, the therapists most sought after by mothers of children with autism. This study indicates there is a strong willingness from parents to secure appropriate therapy for their children with autism. However, this study found that mothers faced financial burden in order to maintain regular treatment for their affected children; even some of the middle income families participating in this study found it hard to afford the appropriate treatments.

In the area of education services, this study found that the implementation of education for all children in Indonesia including children with disability faced problems. Mothers reported difficulties in accessing the education system for children with autism, with considerable behavioral modification through therapy sometimes being expected before schools for the disabled would accept their children with autism. The situation with accessing regular schools was even worse with schools and kindergartens rejecting their children due to their disability. Whilst inclusive

education is the policy of the Indonesian government which is seeking to provide for the education of the disabled by including them in regular school classrooms, this study shows that the implementation of such policies have a considerable way to go. There were mothers who participated in this study who prefer their children were involved in inclusive education at their local schools but such an outcome requires greater resourcing of these schools, access to support for their children whilst at school, and greater expertise amongst teachers in how to incorporate children with autism into their classes and develop appropriate curriculum for them.

7.8.4. What are participants' perspective on the role of government and non-government organization in the delivery of services for children with autism?

Mother in this study generally felt that insufficient funding and other support was available from the government to meet their needs. The Indonesia government has set up some funding to support the general population and children including children with disability in terms of health and education services. The funding that mothers recognize are the *Bantuan Operasional Sekolah* (BOS) and the *Jamkesmas*. However, the funding has not reached the target, especially for those who are diagnosed with a disability. It thus can create a financial burden for the affected family. From the mothers' lesson, the lack of financial support can create irregularly treatment and make it difficult to secure the appropriate services for their children with autism. As stated in Chapter 4, the Indonesian government either National or Local has established the health care scheme for poor and nearest poor of Indonesian (The *Jamkesmas/Jamkesda*) to support their health care. However, the scheme currently does not support the expenses of therapies for persons with disability. If the government put the cost of treatments into the scheme as an extension to the available

assistance funds, this will help many families who have children suffering with any disability to survive their tough life. It is widely known that the cost of many treatments for children with autism is high and will occur throughout their lives. In terms of delivering the scheme, the government needs to provide therapy services free of charge for treatments not only in public hospitals but also in local health centres in communities across the country. As a result, the parents of children with autism would be able to rely on the scheme for obtaining recommended treatments. Meanwhile, this study found that the non-government organizations make pivotal contributions to help the affected family and have been at the forefront of providing services for children with autism. These organizations are well accepted by parents and should be integrated into government service provision for children with autism. This study found that the organizations provide some treatments or therapy for the child with autism, and mothers decided to use the services from the organization. By giving an example, mothers noticed that treatments provided by the organization do not require such a long procedure as public hospitals do. Even they were aware that the scheme is not applied when they use the services for their child in this organization.

7.8.5. What do participants think as mother of children with autism about the impact of service delivery for them?

Mothers deliberated about how existing services impacted on them as mothers of a child with autism and on their autistic child. Impacts were many and varied. Mothers have better understanding about autism and their child. Mothers perceive the treatments their children received have contributed positively to their child's development. The children have better behavior and are able to communicate with

other persons such as parents and other extended family. The mothers also came to better understand and treat their child with autism and were able to develop strategies that worked rather than becoming frustrated and upset when practices that worked for a normal child were not effective.

Additionally, this study found that mothers interviewed have created themselves as experts not only for themselves but also for other mothers. Mothers as services users have a chance to meet with other mothers who have a child with autism, they thus shared similar experiences with others and mothers were not feeling alone or afraid about the future of their children with autism; they have a shoulder to cry on and can lean on each other for emotional support. Meanwhile, this kind of support can help mother to share knowledge and information about autism amongst themselves and with their communities.

7.9. Chapter Summary

In summary, the Indonesian government have formulated many policies in the areas of Education, Health and Social Affairs to assist and to help people with disability for making them empowered as community member and as citizens of Indonesia. However, the experiences of the mothers in this study suggest that the implementation of the policies is still not performing well, especially for the population targeted in this study who are suffering with autism. This study reveals that the mothers' experience in raising a child who is diagnosed with autism is rooted in limited knowledge on autism, limited knowledge on availability of services and limited knowledge on service options. Compounding this is limited availability of the services that are important to their child's development. An important contribution of this

thesis is to show how tapping into the experience of mothers can provide much needed information to policy making and service planners and for policy implementation thereby improving the services for children with autism and their families. An important contribution of this thesis is to demonstrate that accessing the perspectives of mothers of children with disabilities, here mothers of children with autism, will help to improve the system of services for children with autism and children with any disabilities in Indonesia, in particular it will hopefully improve the information about the nature of autism and its appropriate treatment services available to Indonesian citizens.

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Appendix 1. Letter Permission in English

Canberra, 2 February 2011

Letter of Permission

**To: Director of the Office of Special Education
At Barang, East-Java.**

Dear sir/Madam,

I am writing to request permission to collect data from some schools for children with autism at this district as a part of my doctorate research project, "Mother's perspective on service delivery for children with autism in a regional Indonesian city".

The aim of this study is to explore the provision of services for children with autism in Indonesia, to describe the perspective of mother of children with autism about the service delivery and to examine the lesson from the mother's perspective for improving service implementation. The data will be gathered by studying the service delivery for children with autism and by conducting interviews and focus group with mothers of children with autism individually and mothers as part of parenting group member at some schools for children with autism at this district.

I am currently processing the Ethic application from The University of Canberra's Committee for Human Ethic to conduct research with human participants. A copy of the formal approval letter will be forwarded once approval is granted.

The data collection in this research is an important way of learning about the understanding of service delivery for children with autism in Indonesia. I would greatly appreciate the opportunity to conduct research in some autistic schools and look forward to your positive response to my application.

Yours sincerely,

W. Wike
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Appendix 2. Letter Permission in Bahasa Indonesia

Canberra, 2 Pebruari 2011

Surat Pengajuan Ijin Penelitian

Kepada:

Yth. Pimpinan Kantor Dinas Pendidikan Kota Barang

Dengan hormat,

Saya yang bertandatangan dibawah ini bermaksud untuk mengajukan ijin untuk melakukan penelitian di beberapa Sekolah Autis di Kota Barang sebagai bagian dari tugas akademik penulisan disertasi dengan judul, *“Perspektif Ibu tentang pemberian pelayanan kepada anak autis di Indonesia”*.

Tujuan dari penelitian ini adalah untuk mengeksplorasi ketersediaan pelayanan bagi anak autis di Indonesia, guna mengetahui dari perspektif ibu-ibu dari anak autis tentang penyediaan layanan bagi anak mereka, dan bagaimana pengetahuan yang diperoleh dari perspektif ibu-ibu dari anak autis dapat memperbaiki system pelayanan kepada anak-anak autis di Indonesia. Data akan dikumpulkan dengan mempelajari layanan bagi anak-anak autis dan dengan melakukan wawancara secara individual dan melakukan kegiatan diskusi kelompok beserta partisipan yang dalam hal ini adalah ibu dari anak autis.

Saat ini saya sedang memproses surat etik dari Universitas Canberra yang berkaitan dengan penelitian yang melibatkan para ibu dari penderita autis. Salinan surat persetujuan dari komite etik akan dilampirkan jika peneliti sudah menerima hasil akhir.

Pengumpulan data dalam penelitian ini adalah cara penting untuk mengetahui pemahaman tentang pemberian pelayanan kepada anak autis. Saya berterimakasih atas kesempatan yang diberikan untuk melakukan penelitian di beberapa sekolah autis di kota Barang dan mengharapkan tanggapan positif atas permohonan ijin penelitian ini.

Hormat saya,

W. Wike

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Appendix 3. Information Sheet in *Bahasa Indonesia*



LEMBAR INFORMASI

“Perspektif Ibu tentang pemberian pelayanan kepada anak autis di Indonesia”

DESKRIPSI PENELITIAN: Tujuan dari penelitian ini adalah guna mengeksplorasi ketersediaan layanan bagi anak-anak autis di Indonesia, dan untuk menggambarkan sudut pandang dari ibu anak-anak autis tentang pelayanan guna perbaikan terhadap pelaksanaan system tersebut. Data akan dikumpulkan dengan melakukan wawancara mendalam dengan ibu dari anak-anak autis secara individual serta melakukan wawancara kelompok dengan anggota kelompok ibu-ibu. Wawancara semi-struktur akan digunakan untuk mendapatkan pengetahuan tentang sistem penyediaan layanan bagi anak-anak autis dari para ibu yang telah memainkan peran utama dalam membesarkan putar-putrinya. Juga studi ini akan menekankan pandangan para ibu tentang jenis-jenis pelayanan yang ada, kebutuhan akan pentingnya pelayanan bagi anak-anak mereka, dan keluarga mereka.

PENELITI UTAMA: Sang peneliti adalah Wike. Wike saat ini adalah mahasiswa riset doktoral di bidang Kebijakan Publik pada University of Canberra, Australia. Sebelum memulai studinya Wike tinggal di Kota Barang - Indonesia dan bekerja di Universitas B - Indonesia dimana ia akan kembali mengabdikan setelah menyelesaikan sekolahnya.

WAWANCARA: Sebagai peserta dalam sebuah wawancara yang mendalam, Anda akan diminta untuk berbicara dengan peneliti selama satu jam di lokasi yang telah disepakati. Wawancara akan direkam atas izin anda. Dalam wawancara, anda akan diminta untuk merefleksikan pengalaman Anda akan pentingnya dukungan dan pemberian layanan bagi putra-putri anda, keluarga Anda dan diri Anda sendiri. Peneliti akan menekankan pada pemahaman, pengalaman dan pendapat anda yang berkaitan dengan system pemberian layanan bagi putra-putri anda. Pertanyaan-pertanyaan tersebut tidak memiliki jawaban yang benar dan salah. Pertanyaan yang akan diajukan kepada anda adalah untuk membantu peneliti mengetahui tentang sistem pemberian layanan untuk anak-anak autis di Indonesia, bagaimana pengalaman keluarga Anda yang berkaitan dengan sistem tersebut, baik kekurangan maupun kelebihan sistem tersebut, dan bagaimana sistem tersebut dapat diperbaiki.

PARTISIPASI SUKARELA: Partisipasi Anda dalam wawancara ini adalah sukarela sepenuhnya, Anda tidak diharuskan untuk menjawab semua pertanyaan, dan Anda dapat meminta untuk mengakhiri proses wawancara setiap saat. Anda dapat memilih untuk berpartisipasi dalam wawancara, atau untuk alasan apapun, Anda dapat memilih untuk tidak berpartisipasi dalam riset ini. Ini adalah keputusan Anda. Jika Anda memutuskan untuk mengatakan tidak untuk mengambil bagian dalam sebuah wawancara, saya ingin meyakinkan Anda bahwa ini adalah OK. Keputusan Anda untuk mengatakan ya atau tidak tidak akan mengubah layanan yang diterima oleh Anda atau putra-putri Anda.

Jika Anda bersedia untuk dihubungi oleh peneliti guna membahas partisipasi Anda dalam sebuah wawancara, silahkan anda menghubungi saudara _____ (masukkan nama kepala sekolah) di _____ (nomor telepon) dan memberikan izin dari Anda beserta kontak detil Anda untuk diberikan kepada peneliti.

KERAHASIAAN: Wawancara Anda akan digunakan oleh peneliti untuk menulis tentang kebijakan dan layanan untuk anak-anak autisme di Indonesia. Dalam setiap laporan atau artikel, nama Anda beserta nama putra-putri anda tidak akan diidentifikasi. Sebagian besar, informasi yang diperoleh dari wawancara dengan Anda akan digabung dengan informasi dari peserta lain dalam penelitian ini. Namun, tidak selalu mungkin untuk memberikan jaminan lengkap bahwa Anda akan tetap anonim, meskipun nama Anda tidak akan muncul dalam setiap laporan penelitian atau artikel. Hasil dari wawancara ini akan dipergunakan untuk membantu para pembuat kebijakan dan sistem pemberian pelayanan untuk pentingnya memahami kebutuhan dan pengalaman keluarga yang memiliki anak-anak autisme. Terkadang orang-orang dari komunitas/kelompok di sekitar anda akan mampu mengidentifikasi anda dari publikasi informasi ini. Setelah menyelesaikan proses wawancara, anda dapat membaca hasil transkrip wawancara serta anda boleh mengoreksinya, apabila anda anggap hasil wawancara tersebut perlu untuk diperbaiki.

PERSETUJUAN – CARA SETUJU ATAU TIDAK SETUJU UNTUK DIWAWANCARAI OLEH PENELITI.

Ada 3 langkah yang diikuti:

1. Menghubungi kepala sekolah anak Anda, serta memberitahu mereka bahwa Anda setuju untuk kunjungan dari peneliti, Wike. Kepala sekolah kemudian akan memberikan nomor telepon Anda kepada Wike yang akan menghubungi Anda secara langsung untuk membuat janji pertemuan.
2. Wike akan mengunjungi Anda sebagaimana yang telah disepakati, serta membahas informasi penelitian ini dengan Anda. Anda dapat mengajukan pertanyaan kepada peneliti tentang penelitian ini dan tentang proses persetujuan anda untuk menjadi narasumber. Setelah berbicara dengan peneliti, Anda mungkin memutuskan tidak ingin berpartisipasi dalam penelitian, hal itu adalah OK. Tidak ada yang akan tahu keputusan Anda kecuali Wike. Jika Anda memutuskan untuk berpartisipasi dalam penelitian ini, serta anda memiliki informasi yang berkaitan dengan penelitian ini,

maka proses wawancara akan dilaksanakan atas ijin anda.

3. Jika Anda merasa bahwa Anda memahami tujuan penelitian ini dan bersedia untuk diwawancarai, maka anda perlu untuk menandatangani 'Pernyataan Kesediaan'. Hal ini sangat penting bahwa Anda membaca dan menandatangani 'Pernyataan Kesediaan' tersebut sebelum terlibat dalam penelitian ini. Tanda tangan Anda pada formulir ini menunjukkan bahwa anda setuju untuk diwawancarai, dan untuk apa yang Anda katakan dalam wawancara ini akan ditulis oleh peneliti dalam bentuk laporan penelitian. Setelah Anda menandatangani 'Pernyataan Kesediaan', wawancara akan dapat dilaksanakan, atau jika Anda ingin, Anda dapat membuat waktu untuk melakukan wawancara di lain waktu.

Jika Anda ingin mundur dari proses wawancara dalam penelitian ini setiap saat, atau jika Anda memiliki pertanyaan, Anda dapat menghubungi peneliti di University of Canberra.

Peneliti utama:

Wike Wike

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Professional Doctorate in Public Administration

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Pembimbing riset: Dr Anni Dugdale, Dr Dugald Monro

Appendix 4. Informed Consent in *Bahasa Indonesia*



Formulir Persetujuan

“Perspektif Ibu tentang pemberian pelayanan kepada anak autis di Indonesia”

Pernyataan persetujuan:

Saya telah membaca dan memahami informasi yang berkaitan dengan penelitian ini, dan oleh karena itu saya setuju untuk berpartisipasi dalam penelitian ini.

Tandatangan partisipan:

Tanggal:

Formulir Persetujuan

“Perspektif Ibu tentang pemberian pelayanan kepada anak autis di Indonesia”

Pernyataan persetujuan:

Pengambilan gambar atau foto dari para partisipan dalam penelitian ini adalah bagian dari pengumpulan data, dan oleh karena itu saya setuju untuk di ambil foto guna pelaporan dan publikasi penelitian ini.

Tandatangan partisipan:.....

Tanggal:.....

Appendix 5. Informed Consent in English



Statement of Informed Consent

“Mothers ‘Perspective on Service Delivery for Children with Autism in a Regional Indonesian City”

Statement of consent:

The taking of pictures of participants is part of data collection for publication purposes in this research; therefore I agree to be photographed by the researcher.

Signature of participant:

Date: