



**LUNDS**  
UNIVERSITET

Lund University

Department of Sociology

BIDS

### **On the Verge of Adulthood**

A case study of formal and informal social protection for young people with intellectual disabilities  
in Central Java

Author: Signe Stevnhoved Rasmussen

Bachelor Thesis: UTVK03

15hp Spring Semester 2016

Supervisor: Lisa Eklund

## **The MFS Scholarship Program**

This study has been carried out within the framework of the Minor Field Study (MFS) Scholarship Program and the Travel Scholarship funded by the Swedish International Development Cooperation Agency (Sida). The MFS Scholarship Program gives Swedish university students the opportunity to carry out fieldwork in low- and middle income countries, or more specifically in the countries included on the DAC List of ODA Recipients, in relation to their Bachelor's or Master's thesis. Sida's main purpose with the Scholarships is to stimulate the students' interest in, as well as increasing their knowledge and understanding of development issues. The Minor Field Studies provide the students with practical experience of fieldwork in developing settings. A further aim of Sida is to strengthen the cooperation between Swedish university departments and institutes and organizations in these countries. The Department of Sociology at Lund University is one of the departments that administer MFS Program funds.

## **Abstract**

Young persons with intellectual disabilities in Indonesia face difficulties living up to the financial and social independence criteria of social adulthood. Many will need care- and livelihood support throughout their adult lives. This case study aims to examine how formal and informal social protection for persons with intellectual disabilities is organized in a semi-urban city in Central Java. Social protection here being understood as coverage of care- and livelihood needs. Empirical data was collected through a 10-week minor field study. Ethnographic qualitative methods were applied through participant observations and semi-structured interviews with parents and guardians of young persons with intellectual disabilities and several key informants. The empirical data was analyzed by means of several theoretical concepts appropriate for theorizing barriers to social protection and organization of formal and informal social protection. Apart from these concepts, the care diamond (Razavi, 2007) was applied to organize strategies of social protection into the four welfare sectors of: family, not-for-profit, state, and market. The findings of the study show that, although various actors are involved, social protection for persons with intellectual disabilities is primarily informal and provided by members of the nuclear family. Further research is suggested to develop theories on the coverage of care and livelihood needs of adult persons with intellectual disabilities in developing countries.

*Keywords: care diamond, Central Java, formal and informal social protection, Indonesia, intellectual disability, social adulthood, stigma*

## **Acknowledgments**

Although my name is the only one that figures as author, many people have taken part in the process leading up to the final result of this thesis. Their support and contributions should not go unnoticed. First, I would like to thank my research assistant Arif Dwi Purnomo, who with his persistence and kindness paved the way for many fruitful interviews and eased my workload by spending many hours transcribing and translating interview recordings. Secondly, I would like to thank my supervisor Lisa Eklund, who pushed my critical thinking and provided valuable advice during my field work. Thirdly, this thesis would not have been possible without the willingness of research participants to answer my numerous and often sensitive questions. I truly appreciate the time and trust they placed in me. At last I would like to thank my Indonesian host family for their warmth and hospitality during the 10-weeks the field work took place. Returning to a loving home every day after struggling with frustrating bureaucracy was invaluable.

# **Contents**

<b>1 Introduction.....</b>	<b>1</b>
1.1 Significance.....	1
1.2 Aim and research questions.....	2
1.3 Disposition.....	2
<b>2 Background.....</b>	<b>3</b>
2.1 Definitions of intellectual disability.....	3
2.2 Javanese family structure and social change.....	4
2.3 Indonesia as a familialistic welfare regime.....	5
2.4 The situation of PwIDs in Indonesia.....	6
<b>3 Previous research.....</b>	<b>7</b>
3.1 Formal and informal social protection in developing countries.....	7
3.2 PwIDs and their guardians in developing countries.....	8
<b>4 Theoretical framework.....</b>	<b>9</b>
4.1 Theorizing barriers to social protection.....	9
4.1.1 Social adulthood and role transitioning.....	9
4.1.2 Stigma and stigma by association.....	10
4.2 Theorizing organization of social protection.....	10
4.2.1 Formal and informal social protection.....	10
4.2.2 Social protection actors in a familialistic welfare regime.....	11
<b>5 Methodology.....</b>	<b>12</b>
5.1 Field setting.....	12
5.2 Ethnographic qualitative method.....	13
5.3 Sampling.....	14
5.4 Semi-structured interviews.....	15
5.5 Participatory observation.....	15
5.6 Literature reviews.....	16
5.7 Coding and data analysis.....	16
5.8 Ethical considerations.....	16
5.9 Limitations.....	18
<b>6 Findings and analysis.....</b>	<b>19</b>
6.1 Disabling barriers for young PwIDs transitioning into social adulthood.....	19
6.1.1 Stigmatization.....	19
6.1.2 Social and behavioral barriers.....	20
6.1.3 Barriers to special education and vocational training.....	21
6.1.4 Barriers to livelihood.....	22
6.1.5 Poor access to information about intellectual disability and public services and programs.....	22

6.1.6 Disabling barriers result in social and economic dependence.....	23
6.2 Strategies of formal and informal social protection.....	24
6.2.1 Family.....	24
6.2.1.1 The nuclear family as the main provider of social protection.....	24
6.2.1.2 Care and financial support from relatives.....	25
6.2.1.3 Marriage: social protection by extension of family.....	26
6.2.1.4 Absence of family commitment.....	26
6.2.2 Not-for-profit.....	27
6.2.2.1 The double role of neighbors.....	27
6.2.2.2 Support from religion and religious organizations.....	27
6.2.2.3 Support from the independent parents' group.....	28
6.2.3 State.....	30
6.2.3.1 Improving skills through public education and vocational training.....	30
6.2.4 Market.....	31
6.2.4.1 Integrating private services in family care.....	31
6.2.4.2 Accessing paid work in the formal and informal labor market.....	32
<b>7 Concluding Discussion.....</b>	<b>33</b>
7.1 Suggestions for further research.....	36

## **Bibliography**

## **List of Figures**

Fig. 1 Care diamond.....	11
Fig. 2 Actor map.....	34
Fig. 3 Coverage of social and financial needs.....	36

Appendix A: Table on case studies

Appendix B: List of key informant interviews

Appendix C: Semi-structured interview guide

### **List of Abbreviations**

AAIDD = American Association Intellectual and Development Disabilities

DPO = Disabled Peoples Organization

NGO = Non-Governmental Organization

PwD = Person with Disability

PwID = Person with Intellectual Disability

SLB = Sekolah anak Luar Biasa (Special education school)

UNCRPD = United Nations Convention on the Rights of Persons with Disabilities

WHO = World Health Organization

### **Indonesian and Javanese vocabulary**

Asrama = Boarding house

Bapak/Pak = formal/informal word for father or a polite title for men

Ibu/Bu = formal/informal word for mother or a polite title for women

Utang budi = a debt of gratitude

## **1 Introduction**

Every night we are thinking about their future and every night we pray to God “God, we pray that we won’t die before our children”

(Interview with Bu Desi, 03-03-2016)

These are the words of Bu Desi, a mother of three young persons with intellectual disabilities (from here on referred to as PwIDs). She and her husband pray that their children will die before them out of fear of what will happen to their adult children once they pass away. This quote reflects how families of PwIDs in Central Java carry a life-long responsibility for the wellbeing of PwIDs. In most cultures it is a commonly accepted practice that parents take care of their children until they grow up and are able to take care of themselves. But what happens with young people and adults who do not live up to the independence criteria of social adulthood? How will the PwID achieve social protection in his or her adult life? In many developed countries adult PwIDs and their families can rely on support from government institutions to cover the needs of the PwIDs but such reliable formal social protection support is inaccessible for a majority of the Indonesian population. Instead they rely primarily on informal measure of social protection such as family networks and community-based organizations (Sirojudin & Midgley, 2011).

### **1.1 Significance**

There is no “consistent and reliable data” on PwIDs in Indonesia. It is unknown how PwIDs overcome or mitigate disabling barriers to social protection in their adult lives which makes the development and improvement of existing social protection systems very difficult (Adioetomo, Mont & Irwanto, 2014:4). It is therefore crucial that research is undertaken to explore how informal and formal social protection for PwIDs is organized. This study attempts to do such research by conducting a case study on young PwIDs and their parents and guardians in a semi-urban city in Central Java.

This thesis is limited in scope and scale and cannot claim to cover all aspects of social protection for the PwIDs included in this study. First, the qualitative data for this research was collected through interviews with parents and guardians of PwIDs, rather than interviews with the PwIDs themselves. This approach was deemed most appropriate, as confidently representing the views of PwIDs requires much time and expertise, due to PwIDs various limitations in communication. Furthermore, parents and guardians play a major role in determining the social protection measures of adult PwIDs and will often be responsible for implementation of these measures. Secondly, I decided not to focus on

the issues of intergenerational care in terms of how parents' social protection in old age might be negatively affected by the PwIDs' difficulties in providing for them. Although relevant for this study, it would have required another strategy to confidently analyze this issue. Finally, as so little research has been done on the organization of social protection for adult PwIDs in developing countries, I have prioritized to conduct a broad research that examines the system of social protection for PwIDs rather than a detailed research that for example only focused on informal familial social protection.

## **1.2 Aim and research questions**

Previous studies have established a link between disabilities and poverty, indicating that PwIDs and their families face severe disabling barriers to achieve social protection. Research on measures of formal and informal social protection in developing countries is still rather scant and research on PwIDs in developing countries even more scarce (Palmer, 2013). In this thesis I aim to further the understanding of disabling barriers to social protection for PwIDs in a familialistic developing country. Furthermore, I will analyze the various measures taken to overcome and mitigate these barriers. This research aims to answer the following questions within the context of the case study:

- 1. Which disabling barriers to social protection do PwIDs face in their adult lives?*
- 2. How is formal and informal social protection for persons with intellectual disabilities organized?*

## **1.3 Disposition**

This thesis is based on empirical data collected during a 10-week minor field study in Central Java. Data was collected by means of participant observation and qualitative semi-structured interviews with parents and guardians of PwIDs and key informants. The field data was supported by secondary data collected from literature reviews. The data will be analyzed by theoretical concepts deemed suitable for examining disabling barriers to social protection and strategies for formal and informal social protection. The thesis will end with a concluding discussion on how social protection is organized for young PwIDs in the field setting and by providing suggestions for further research.

## 2 Background

To familiarize the reader with the context of the thesis topic this section will describe how intellectual disabilities are defined internationally and locally, the Javanese family structure, Indonesia as a familialistic welfare regime, and the known situation of PwIDs in Indonesia.

### 2.1 Definitions of intellectual disability

The term ‘intellectual disability’ covers a diverse group of people with various intellectual impairments, which has resulted in much debate about how intellectual disability should be measured and thus defined. According to the American Association on Intellectual and Development Disabilities (AAIDD, 2013), intellectual disability is biologically defined by the following three criteria: “significant limitations in intellectual functioning, significant limitations in adaptive behavior, and onset before the age of 18” (AAIDD, 2013). This thesis defines intellectual disability in terms of the social model of disability which has been promoted by many disabled people’s activists’ groups (Barnes, 2012). According to the social model a PwID has long-term intellectual impairments “which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (UNCRPD, Article 1). In other words, the person with intellectual impairments only becomes ‘disabled’ when facing barriers to full participation in society. Disability according to the social model is therefore seen as a social construction.

In Indonesia, issues related to disabled people are under the responsibility of the social ministry. The social ministry classifies persons with disabilities as:

‘Penyandang Permasalahan Kesejahteraan Sosial’ (persons with social problems). Such persons are considered unable to fulfil their basic needs (mind, body and socially) in an adequate and proper way due to difficulties or disturbances.

(Colbran 2010:12)

This classification clearly indicates how the Indonesian government perceives the disabling barriers facing PwIDs as inherent to their impairment and not as the result of their interaction with society. Special schools in Indonesia are called “Sekolah anak Luar Biasa” (SLB) which translates to “school for extraordinary children”. The word ‘extraordinary’ has a double connotation of disabled people being people with special abilities while also being people that deviate from the societal norm. When a PwID enters a special school he or she will go through a test that places them in either C1 (low level

intelligence) or C (middle level intelligence) (YPAC webpage, 2016). These definitions might not be either medically correct or representative of the abilities of the PwIDs but they do show how institutions and the broader society classify PwIDs. Although the social model of disability is applied in the analytical section of this thesis it has been necessary to include the school definition of middle- and low-level intelligence. This classification partially determines what kind of education and vocational training PwIDs will receive and thus their abilities to overcome disabling barriers to social protection.

## **2.2 Javanese family structure and social change**

The majority of urban Javanese households are ‘nuclear’, meaning that a household typically consists of one family unit of a mother, father, unmarried children and occasionally a domestic worker. Many families are ‘augmented nuclear’ in which grandparents are included in the household (Megawangi, Zeitlin, & Kramer, 1995:103). An adult relative might stay in the household for months or years due to migration but these arrangements are rarely permanent. An uncle or aunt might offer to take care of a child if they are more affluent or live in an area with better access to schooling or public services than the child’s biological parents.

Javanese society is predominantly patriarchal, although Javanese women have a favorable position in terms of autonomy in comparison to other Asian countries (Adioetomo, Mont & Irwanto, 2014:2; Megawangi, Zeitlin, & Kramer, 1995:105). Women are responsible for many household decisions but when it comes to large family decisions such as where to live, or women’s activities outside the home, men tend to have the final word (Geertz H., 1961:2, 37; Megawangi, Zeitlin, & Kramer, 1995).

Javanese familial and societal structures have undergone major changes as Indonesia has industrialized and emerged in the global economy. A current general trend in Asia is the increase in nuclear two-generational households rather than three-generational households (‘augmented nuclear’). This change in demographics is threatening traditional systems of familial care as grandparents are not available to take care of young grandchildren and as children are not present to care for their elderly parents (Croll, 2006:475). This presumably also affects families’ capacities to care for adult PwIDs. Traditionally, Javanese families have valued large families but during Suharto’s rule from 1967-1998 a national family planning program was introduced which aimed at reducing birth rates (Megawangi, Zeitlin, & Kramer, 1995:110; Reese, Soedarmadi & Suyono, 1975:104). As a result, fertility rates in Indonesia have stagnated at 2.5 children per woman since 2000 (World

DataBank, 2016). Fewer children also means fewer people to take care of elderly parents and siblings with intellectual disabilities.

Urbanization is another contributor to change in traditional family and community structures. Lianta (1992) argues that increased urbanization and industrialization in Indonesia, has led to PwIDs being more excluded from work activities. Integration of the work of PwIDs in an agricultural setting is more easily accomplished as the work takes place within a family-unit who understands the needs of the PwIDs. In urban settings PwIDs undergo several steps of institutionalization in terms of schooling and work training and have to compete in the labor market with non-PwIDs in order to access formal paid work. This is an unequal competition and many PwIDs are as a result excluded from the formal labour market.

Internal migration from rural to urban areas has also led to increased distance between relatives and in turn decreased the possibilities of relatives providing care and day-to-day financial support for PwIDs. Lianta (1992) does not mean to romanticize the traditional agricultural setting and emphasizes how urbanization and compulsory education (introduced in 1984) has made it more difficult for parents to keep PwIDs at home and hide them from the public. Establishing the foundations of the Javanese family structure is important to further the understanding of the social protection role of the family.

### **2.3 Indonesia as a familialistic welfare regime**

In a familialistic welfare regime the family plays the largest role in welfare provision. As Fahey (2002:52) expresses it: “the welfare and caring responsibilities of households and families (mainly fulfilled by women) are large, and the provision of welfare services by either the state or the market is correspondingly weak”. According to Crossaint (2004:515), familialistic welfare regimes in Southeast Asia, including Indonesia, are dominated by the male bread-winner model in which men are seen as main responsible for the exterior relations of the household, including paid work, whereas women take care of the domestic sphere. Crossaint (2004) further argues that there is a low degree of de-familialization in Indonesia. De-familialization is a process of which either the market or the state unburdens the household of certain “caring responsibilities, reduces the individual’s welfare dependence on kinship, and frees up women for higher levels of labor-market participation” (Fahey, 2002:52).

Sine democratization in the early 2000s the Indonesian government has paid increased attention to formal social protection measures. In 2002 the constitution was amended, stating that all Indonesian citizens have “the right to have access to social security” and the government is required to “develop a system of social security for all people and to empower the weak and incapable” (Rosser & Wilson, 2012:611). The Indonesian government has developed several social protection programs, the latest being a universal healthcare- and employment benefit (BPJS) implemented in 2011. Yet, these programs have been criticized for insufficient coverage, illegal fees, and mis-targeting (Adioetomo, Mont & Irwanto, 2014; Aspinall, 2013; Rosser, 2012a). There is currently no national social protection programs targeting PwIDs in Indonesia and the government expenditure on social insurance and assistance was only 1.2% of the Gross National Product in 2014. This proves that the Indonesian government relies on other sectors in society, in particular families, to provide social protection to PwIDs (von Benda-Beckmann, 2015:327).

#### **2.4 The situation of PwIDs in Indonesia**

Indonesia ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2011. A ratification of the convention means that the government is bound to take immediate steps to fulfill the agreement. Edwards (2014), strongly criticizes the Indonesian government for failing to live up to its responsibilities as defined by the convention. The UNCRPD is based on the social model of disability but Colbran (2010:13) argues that most of the laws and legal terms for disabled people in Indonesia are based on a medical and charity understanding of disability which defines disability as inherent to the disabled individual without consideration of disabling barriers in society. The charity model also entails that disabled people should be pitied and receive alms rather than equal social rights to non-disabled persons. The Indonesian government has implemented several laws to improve the situation of disabled people, such as the Government Regulation No. 43/1998 on Efforts to Improve the Social Welfare of Persons with Disabilities. Still, “there is a general agreement among government and non-government sectors that what disability rights exist in Indonesia remain unenforced” (Edwards, 2014:9). One explanation of the lack of legal rights and effective social program for PwIDs in Indonesia is proposed by Komardjaja (2005:1), who suggests that “people with intellectual disabilities are the most stigmatized [group in society] and the least likely to receive adequate services or funding”. Stigmatization of PwIDs in Indonesia also affects their families:

A person with a disability is seen as a person without capability who will only burden those around them. Disability is also seen by some as a curse or punishment for previously

committed sins of the parents. PwDs are rarely visible in society and are often hidden by their family in shame at home or in an institution

(Colbran 2010:11).

A household survey conducted by the Indonesian National Statistics body (BPS) in 2006 revealed that “only 1.29% of children with disabilities go to school” (Colbran, 2010:31). All data on disabled people from Indonesia should be read with cautiousness as there is no “consolidated and accurate data on the situation of disabled people in Indonesia” (Better Work Indonesia Report, 2011:3). Even though the percentage of children with disabilities attending school might be higher than the survey indicates, it is safe to assume that the vast majority of disabled children in Indonesia are excluded from education. The lack of data on disabled people in Indonesia presents a great obstacle to both disabled people’s interest groups and policy-makers. The first group is hindered in confidently representing and advocating disabled people’s needs whereas the second group cannot plan and execute adequate social policies and programs for disabled people without knowing the size of the target group and their needs.

### **3 Previous Research**

As mentioned in the introduction and background section of this thesis, very little research has been done on how social protection for PwIDs in developing countries is organized. This section on previous research, will introduce the reader to two separate research areas that in combination provide a broader understanding of this issue. These research areas are: ‘PwIDs and their caregivers in developing countries’ and ‘formal and informal social protection for PwIDs in developing countries’.

#### **3.1 Adult PwIDs and their caregivers in developing countries**

Most research on caregivers of PwIDs in the developing world has focused on children with intellectual disabilities (eg. Bailey & Smith, 2000; Einfeld *et al.* 2012; Weldeab & Opdal, 2007) or applied the umbrella term of disability which also includes persons with physical disabilities (eg. Bailey & Smith, 2000; Berman, 2011; Chiu *et al.* 2013). Thus, making it difficult to tease out issues specifically connected to adult PwIDs and their caregivers. This research review will non-the-less introduce the reader to what little is known.

Several studies have established a clear link between poverty and disability (eg. Palmer, 2013; Stone, 1999; WHO, 2011). Intellectual impairments are more prone to occur among poor and deprived people due to malnutrition and limited knowledge about the increased risks of intellectual

impairments among children born of close-relatives and women above 35 (The Arc, 2016; Stone, 1999; WHO, 2011). On a structural level “people with impairments worldwide are more likely to be poor because of the disabling barriers that prevent them from getting an education, a job, access to appropriate support and services, and so forth.” (Stone, 1999:6). Care systems in developing countries are mostly informal, resulting in family-members (particularly female) being main responsible for the care and wellbeing of the adult PwID and thus also at higher risk of living in poverty (Hall & Midgley, 2004; Razavi, 2007; Weldab & Opdal, 2007).

Aside from the economic implications of caring for an adult PwID, “the caregivers of individuals with ID usually face a lifetime of responsibility and, in consequence, great stress (Baxter *et al.* 2000)” (in Chiu *et al.* 2013:1118). In a study on caregivers of children with intellectual disabilities from Ethiopia, mothers felt overwhelmed by the immense task of caring for the PwID and did not receive any significant support from others (Weldeab & Opal, 2007). Furthermore, the mothers in this study expressed experiences of stigmatization as a result of their affiliation with the PwID. Several studies have confirmed how stigma by association can result in stress and decreased quality of life of caregivers of PwIDs (Chiu *et al.* 2013; Komardjaja 2005).

### **3.2 Formal and informal social protection for PwIDs in developing countries**

Most research on welfare systems and social protection has been conducted in the West and as a result has almost primarily focused on formal measures of social protection such as state-run social protection schemes and private services (eg. Esping-Andersen, 1990). The emphasis on formal social protection has also been transplanted to research in developing countries, paying no or very limited attention to local informal systems of social protection (eg. Palmer, 2013; Suryahadi, Fabriany & Yumna, 2014).

Public formal social protection measures are limited in scope and scale in many developing countries and often consist of social insurances and allowance schemes, which “cater primarily to those in regular wage employment, or those living in urban areas” (Hall & Midgley, 2004:234). Such schemes are not easily accessible or sufficient in covering the needs of adult PwIDs and their caregivers, as schemes primarily consist of short-term cash transfers in case of emergencies, which does not necessarily alleviate the long-term care burden of the caregivers of PwIDs. As most caregivers of PwIDs are excluded from formal social protection, they rely on various informal social protection measures. According to Oduro (2010:19) informal social protection is closely tied to social networks and thereby fraught with uncertainty as “family members may not be in a position to provide

assistance at the time that it is required”. Sirojudin and Midgley (2011:17), who have conducted research on social protection in Indonesia, broadens up the familial definition of informal social protection to include community- based social protection institutions. This implies that informal social protection for PwIDs and their caregivers is organized by various actors in the broader society. Informal social protection measures in developing countries, including Indonesia, have primarily been researched by anthropologists (eg. Hüsken & Koning, 2007; von Benda-Beckmann & von Benda-Beckmann, 2008) but in recent years, scholars have begun to pay more attention to how various formal and informal social protection measures interlink and are organized in developing countries (eg. Ochiai, 2009; Razavi, 2007). This thesis aims to further this line of research by analyzing how social protection is organized formally and informally by various intersecting actors. Furthermore, it will attend to an important research gap by analyzing social protection for the academically neglected adult PwIDs and their caregivers.

## **4 Theoretical framework**

The theoretical framework consists of several concepts and theories relevant for the analysis of data with the purpose of answering the research questions. These concepts can be divided into two categories: Concepts intended to analyze barriers to social protection (stigma, stigma by association and social adulthood) and concepts and theories intended to analyze the organization of social protection (formal and informal social protection, care, livelihood, the care diamond and familialistic welfare regime).

### **4.1 Theorizing barriers to social protection**

#### **4.1.1 Social adulthood and role transition**

Adulthood can be conceptualized from various perspectives such as biological adulthood (the age and physical development of a person) and legal adulthood (obtaining legal rights at a certain age). In Indonesia the legal age of voting is 17 and the legal age of marriage is 16 for females and 19 for males (Megawangi, Zeitlin, & Kramer, 1995:109). Biologically and legally the majority of PwIDs included in this study would be defined as adults. Although the PwIDs are biologically and legally adults, they are not necessarily perceived by society as social adults. Social adulthood is only achieved when a person lives up to a set of criteria defined by the “prevailing social norms and values of the particular social context” in which the concept is applied (Westberg, 2004:37). In other words, in this perspective adulthood is socially constructed and differs depending on the context.

When a person transitions to adulthood he or she will also experience one or several ‘role transitions’. A role transition marks a shift in social status and obligations. The concepts of social adulthood and role transition are closely interlinked analytically as social adulthood defines a stage in life and role transition, the change of social roles when reaching this life stage. Social adulthood and role transition are important concepts for this study as they make it possible to conceptualize context-specific criteria of adulthood in Central Java and the disabling conditions that PwIDs face when role transitioning from ‘child’ to ‘adult’.

#### **4.1.2 Stigma and stigma by association**

Erving Goffman (1963: Preface) defines stigma as “the situation of the individual who is disqualified from full social acceptance”. Goffman’s definition of stigma should be seen from a social constructivist perspective in which the stigma is relational to the social context. Stigma is thus imposed on a person due to a biological or behavioral deviation from a norm which is perceived as shameful or inappropriate by society. Goffman further develops that stigma is not only affecting the stigmatized individual but can be transferred to people closely engaged with this individual. This form of stigma is called ‘courtesy stigma’ or more recently ‘stigma by association’ (Mehta & Farina, 1988). The concepts of ‘stigma’ and ‘stigma by association’ are highly relevant for this study as stigmatization is often a disabling barrier to the achievement of social protection for PwIDs.

### **4.2 Theorizing organization of social protection**

#### **4.2.1 Formal and informal social protection**

Social protection can very broadly be defined as “protection against vulnerability, risk and unacceptable levels of deprivation through responses which are both formal and informal in nature” (Palmer, 2013:141). In order to make the definition of social protection more specific to young and adult PwIDs in the field setting, I have decided to define social protection as the result of formal and informal measures taken to ensure the care and livelihood needs of PwIDs and their families. **Care** is here defined as the “work of looking after the physical, psychological, emotional and developmental needs of one or more people (Standing, 2001:17)” (in Raghuram, 2012). The concept of care is very important when investigating social protection for adult PwIDs, as many will have life-long care needs. The definition of **livelihood** applied in this study is “the activities, assets and access to resources that jointly determine the living gained by an individual or household” (Hall & Midgley, 2004:xi). The concept of livelihood helps to explain and conceptualize how PwIDs overcome or

mitigate barriers to the economic independence criteria of social adulthood. This study further differentiates between formal and informal social protection. ‘Formal’ is here referring to social protection from the local and national government and officially registered institutions. Forms of formal social protections measures could be social programs and services, and employment in the formal labor market. ‘Informal’ is more difficult to define but refers in this thesis to all measure that do not qualify as formal such as family care and neighborhood support. Distinction between formal and informal social protections has been criticized as the line between ‘formal’ and ‘informal’ is very blurry and many social protection measures have elements of both (Hüsken & Koning, 2007:10). Keeping this critique in mind, the distinction between formal and informal social protection is still valuable for this study as it provides a framework for analyzing gender aspects and reliability of social protection measures as women tend to be more engaged in informal institutions (Newberry, 2010:407) and as informal social protection is more fraught with uncertainty and instability (Oduro, 2010:19).

#### 4.2.2 Social protection actors in a familialistic welfare regime

In order to analyze how formal and informal social protection for PwIDs is organized it is important to get a better understanding of the actors involved in providing social protection and the role they play in a familialistic welfare regime.

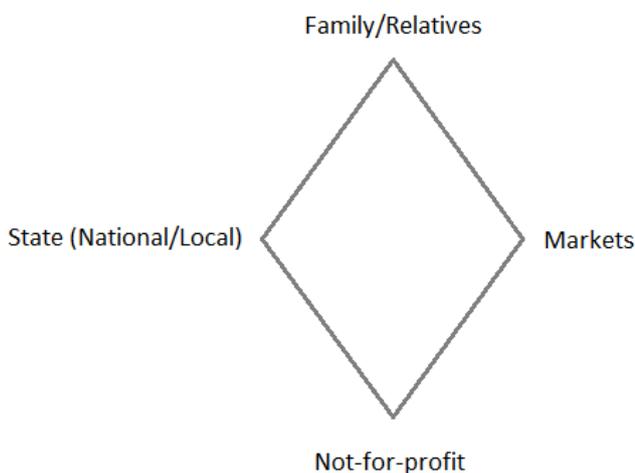


Fig. 1, Care Diamond (Razavi 2007), adapted by author

The care diamond by Razavi (2007), is a model that serves to map out the infrastructures of care in a given society, in other words, the actors and institutional arrangements of care. The model divides care-providers into four sectors: family, state, markets and not-for-profit.

When Ohiai (2009:68) applied the care diamond to the East and Southeast Asian context, she decided to divide the section of family into two analytic units: ‘family’ and ‘relatives’. ‘Family’ in this definition refers to a “nuclear family or a household of people living together” whereas ‘relatives’ encompasses extended family and kins. This analytical distinction will also be applied in this thesis as the type of support that nuclear families and relatives provide will presumably differ. The state refers to both national and local government

initiatives. During democratization after the fall of Suharto in 1997, the Indonesian government decentralized many managerial tasks and funds to local governments and local governments often design local social protection programs (Rosser, 2012b). It is therefore important to differentiate between local and national state actors and institutions. Markets are all privately funded initiatives and services, including the labor market. The final sector, not-for-profit, is the most broadly defined and includes all non-familial and non-statutory actors and institutional arrangements, such as NGOs, neighbours and religious organizations.

It is important to keep in mind that a model will always be a simplification of reality and the sectors in the care diamond may overlap (Raghuram, 2012:163). The care diamond should therefore not be seen as a fixed analytical tool but as an instrument to roughly organize the infrastructure of care. In the purpose of this thesis, the model will not just be limited to look at care provision but will be applied to analyze the infrastructures and organization of formal and informal social protection for the young and adult PwIDs.

## **5 Methodology**

This study was designed as an intrinsic case study. An intrinsic case study is a non-comparative case study where detailed information is sought about the chosen case (Punch, 2014:121). Since the thesis topic is understudied, a desk study would not have sufficed in providing the necessary data to answer the research questions. It was therefore essential that new primary data was collected through a field study. The field study took place during 10-weeks in the spring of 2016. Empirical data was collected through 10 semi-structured qualitative interviews with a core sample group consisting of parents and guardians of intellectually disabled youth aged 16 to 25, participant observation and 17 semi-structured interviews with 14 key informants.

Appendix A provides more detailed information about the 10 case studies of parents and guardians of PwIDs and appendix B gives an overview of the key informants.

### **5.1 Field setting**

The field work took place in a semi-urban city in Central Java, Indonesia. The majority of the population is Muslim and speaks a mix between Javanese and the official language Bahasa Indonesia. The city is located in the outskirts of one of the largest industrial municipalities in Central Java. The city is especially known for textile and garment industries, which employ many low-skilled workers (participant observation).

Participant observation took place at a public school for children with special needs. The school offers education from primary school to senior high school. The school is specialized in education for PwIDs and deaf students. Occasionally blind students and persons with autism are also admitted. It is the only public special school in the entire municipality, which also means that it is the only special school without tuition fee in a municipality with 1.773.905 inhabitants (as of October 2014, Local Statistics Office). There are five private special schools that accept PwIDs in the municipality. The public school was chosen as case, as it was important to include the views and experiences of parents from all economic backgrounds. The public special school, is managed and funded by the provincial department of education. Connected to the school is an 'asrama'. An 'asrama' is a boarding house where students can stay overnight in case they live far away. The asrama is funded partially by the local social ministry and by contributions from parents of students.

The majority of PwIDs included in this case study had recently graduated from the special school and transferred to Temanggung Rehabilitation Centre. Temanggung Rehabilitation Centre is not as the name implies concerned with rehabilitation, but offers vocational training to PwIDs in the age group 15 to 30 years. The centre is funded by the Social Ministry and is the largest (and only) state-run vocational training centre exclusively for PwIDs in Indonesia. There are approximately 150 students at the 'rehabilitation' centre. At the centre, PwIDs will be divided into different courses based on their 'training potential', some will learn basic household tasks and self-maintenance, while others will learn skills with income-generating potential, such as woodwork or sewing (SOCIETA, 2015).

## **5.2 Ethnographic qualitative methods**

Ethnographic research typically entail that the researcher spends a long period of time in the field, learns the local language and applies various semi-structured or unstructured mechanisms of data collection (Hammerslev & Atkinson, 2007:3). From 2010-2011 I lived with a local Muslim family in the field setting while volunteering at the public special school, referred to in this study. I visited the field setting again in the summer of 2015 and spoke to several parents and teachers about the difficulties facing young PwIDs in their adult lives. Through this experience, I have developed Indonesian language skills, cultural understanding, and firsthand experience of the situation at the public special school. It has also led to close relationships with some of the respondents included in the sample group. Ethnographic methods have allowed me to gain a deep understanding of the context of the data and established valuable relations of trust without which this research would have been very difficult.

Qualitative methods were chosen for this study, for the following reasons. First, as the section on sampling below will show, gaining access to parents or guardians of PwIDs is challenging. To uphold standards of validity and generalizability, quantitative studies generally require a large sample size and probability sampling which makes this method unsuitable to answer the research questions (Bryman, 2012:197, 190). Qualitative studies on the other hand tend to engage in purposive sampling and require a smaller sample size as the purpose is not external validity but to construct thick descriptions (Geertz, C. 1973), thereby proving more appropriate for this study. Secondly, since the research topic is of sensitive character, I as a researcher have extensive ethical obligations to my research participants. Feminist scholars have played a big role in developing and promoting qualitative research methods as more sensitive to encouraging and including the perspective of the research participants (Cotterill, 1992).

### **5.3 Sampling**

The core sample group consisted of 10 cases of parents and guardians of young PwIDs. All PwIDs were either in the final grade or recent graduates from the same public special school. As the majority of PwIDs in Indonesia, are kept at home it would have been very difficult to access their parents or guardians without a gatekeeper such as the public special school. Parents and guardians were selected by purposive sampling based on the following variables of the PwID: occupation, gender, and intellectual classification by the public special school. It was important to include both boys and girls with different intellectual classifications and occupations, as the disabling barriers to social protection would likely vary according to these variables. Information on the PwIDs was accessible through a data spread provided by the public special school. Some participants were chosen as they were ‘special cases’. These ‘special cases’ included: Bu Desi, who has three children with intellectual disabilities and the case of Fendy (a young male PwID) who’s paternal uncle and aunt have been caring for him and his twin brother since early childhood.

To contextualize data from the core sample group, 17 interviews were conducted with 14 key informants representing the sectors of state, not-for-profit and market, as defined in the care diamond. All key informants have professional experience working with PwIDs and included five teachers at the special school, two of which also represented a disabled people’s organization (DPO), a staff member of the social ministry, two staff members at Temanggung Rehabilitation Centre, three members of a social business that hires PwIDs, an informal private teacher, and the principal of a private special school. Contact with the key informants was established through snowball sampling.

#### **5.4 Semi-structured interviews**

Interviews with the core sample group were based on the same semi-structured interview guide (see appendix C). These interviews covered the following topics: parents' feelings about having an intellectually disabled child, stigmatization, who they received social and financial support from, their plans and hopes for the future of their child, and how they perceive the quality of education at the special school (in terms of preparing their children for adulthood). As the field study came along minor changes were made to the guide to incorporate new important insights. The method of semi-structured interviews was chosen as it allowed for a high degree of flexibility, while maintaining a structure of conversation that made comparison of cases possible (Bryman 2012:12). Intellectual disability is a sensitive topic in Indonesia and it was therefore important to follow the flow of the conversation and gradually develop trust before asking private and sensitive questions. All interviews with the core sample group were recorded, with informed consent of the participants.

Interviews with key informants were less structured and did not follow a research guide. During these conversations we discussed themes and a few pre-formulated questions, that were relevant to the research aim. At three interviews, several key informants were present. Since the key informants represented a diverse group of respondents from different sectors of the welfare diamond it was impossible to follow a pre-determined research guide for all key informants. Three interviews were recorded while the rest was documented by note-taking.

#### **5.5 Participatory observation**

According to Punch (2014:157), semi-structured interviews should preferably be combined with participant observation to produce descriptive data in ethnographic methodology. During the field study I conducted participatory observation in several settings. I taught part time at the public special school, lived with a host-family on the same street as one of the respondents, took part in neighborhood meetings and gatherings in the mosque, participated in a meeting with an independent parents' committee for high school students and recent graduates from the special school, and joined a family visit to Temanggung Rehabilitation Centre. As very little research has been done on the situation of disabled people in Indonesia it was important to contextualize the information gained during interviews to the public institutions and society that parents of PwIDs engage with daily. Participant observation allows for the researcher to develop a deeper understanding of the lived experience of the respondents which strengthens the analysis of spoken and particularly unspoken data (Bryman, 2012:494). Participant observation was documented by note-taking during the

observation when appropriate and by keeping a detailed field journal in which reflections were documented throughout the field study. I made it very clear in all settings that I was doing a minor field study and that the data would be used in a bachelor thesis.

## **5.6 Literature reviews**

Before and during the field work, several literature reviews were conducted. These reviews aimed at attaining a broad understanding of the research topic while detecting various concepts and theories that could prove useful to answer the research questions. A very broad literature review has the disadvantage that it “can appear rather haphazard” and thus hard to replicate but it is advantageous in the initial stages of the research where keeping an open mind to new concepts and insights is essential (Bryman, 2012:111). During data analysis, focused literature reviews were conducted to get an in-depth understanding of applicable concepts and themes that arose from the analysis.

## **5.7 Coding and data analysis**

Open coding and analysis was first initiated in the field and later intensified during the thesis-writing process. According to Scheyvens (2014:75), qualitative research is ‘iterative’, meaning that the researcher is moving back and forth between data-collection and analysis which allows for the analysis to unfold throughout the research process. Thematic analysis was applied by paying special attention to repetitions of topics, similarities and differences in experiences, theory-related data and ‘missing data’, in other words what the respondents did not talk about and the reasons for this (Bryman 2012:579).

## **5.8 Ethical considerations**

Pretending that race, gender, class and cultural stereotypes would have no influence on the data would be both irresponsible and naïve. When conducting research in a non-native setting it is important to consider positionality and reflexivity. It is very possible that respondents would not share certain things with me as they assumed that I would not have the cultural insight to understand their experience. While it is impossible to change my race, I aimed at mitigating the impact of my ethnicity through my knowledge of Javanese customs, ability to speak Bahasa Indonesia, and experience of working with PwIDs at the public special school. My previous attachment to the field setting created ethical considerations in relation to research participants’ perception of my attachment to the special school, and by negotiations of friendships. Feminist scholars such as Oakley (1981) have encouraged reciprocity in interviews by sharing private information and building up an intimate relationship with

research respondents. Negative aspects of such ‘friendship’ are the downplaying of existing power structures between researcher and respondents and blurry lines between data and information given in confidence. The researcher will always be in a more privileged position as she will leave the field and write the final research paper (Cotteril, 1992:604). On few occasions parents and guardians of PwIDs seemed a bit apprehensive about talking about the conditions at the public special school which might be because they knew I was affiliated with the school. My personal relationship with one of the parents who was an active member of the independent parents’ committee increased the trust between me and other respondents who had no problems criticizing the school. Thereby proving that friendship with research participants, when treated with care, can result in more detailed data.

During the field study, I cooperated with a young local male research assistant who acted as a mediator of language and culture. Although I speak Bahasa Indonesia on a high level it was helpful to be two people when conducting the interviews so that one would be in charge of keeping the conversation on track with the semi-structured interview guide, while the other person could freely emerge in the conversation. During the interviews the male presence did not seem to hinder women from opening up to us and share their views and emotions.

The field setting and all participants in this research have been anonymized except for Temanggung Rehabilitation Centre. Temanggung Rehabilitation Centre is as the only state-run vocational training centre specialized in care and training for PwIDs in all of Indonesia impossible to anonymize. I spoke to several staff members at the centre and they were very welcoming and encouraged me to do the research. The ethical dilemma arises in relation to the anonymity of children of respondents that are currently enrolled at the centre, but as there are 150 PwIDs at the centre and the research setting has been anonymized, they should be very difficult to identify (SOCIETA, 2015:50). In any research there can never be full guarantee that a knowledgeable reader might not identify the research location and some of the respondents. It was therefore very important to clarify this risk to the research participants. Some participants on the other hand encouraged me to use their names openly. Because many participants knew each other very well I decided to provide pseudonyms to all PwIDs and their parents and guardians, in order to ensure the anonymity of those who did not wish to be identified (Scheyvens, 2014:168-169).

Much literature has criticized the lack of representation of the voices of PwIDs in research (eg. Clifford, 2014; Traustadottir & Johnson, 2000). These authors criticize how the autonomy of PwIDs is overruled by paternalism in which “individuals with authority use their power to restrict the

freedom of [PwIDs]” (Brown, 2016:102). Freedom is in this case referring to PwIDs’ possibilities to express their views. This thesis could justifiably be criticized of paternalism for interviewing parents and guardians instead of PwIDs. I chose to interview parents and guardians based on the following reasoning. First, as parents of PwIDs are in most cases also the main care-givers of PwIDs, the future of PwIDs affect parents very much in terms of how much care-work they will engage in and the economy of the household. Their views and proposed strategies for the future of PwIDs are therefore also very relevant to their own lives. Secondly, confidently representing the voices of PwIDs in research takes both time and expertise in order to get to know the PwIDs various limitations in communication and confidently represent their views. I assessed that I had neither the time nor expertise necessary to take on this task.

Another ethical aspect to consider when doing research in non-Western society, is the fact that the majority of theories of social science were developed in the West and have in many cases been transplanted to non-Western societies without consideration to contextual variations. This does not mean that social science developed in the West is necessarily always irrelevant in a non-Western context but Alatas (2001) argues that it is important to test the relevance of theories in different contexts. I will in the analysis and discussion section of this thesis, attempt to criticize the applicability of the care diamond, in the context of organization of social protection for PwIDs in the field setting.

## **5.9 Limitations**

Case studies face limitations in terms of generalization of data and conclusions to a larger context. This case study is no exception. Indonesia is a very large archipelago with around 6.000 inhabited islands and more than 250 million inhabitants (The World Factbook, 2016). It is therefore important to keep in mind that this research is context-specific to the field setting, and not the rest of Indonesia. The majority of the parents included in this study are Muslim. Religious and “cultural beliefs about disability clearly play an important role in determining the way in which the family perceives disability and the kind of measures it takes for prevention, treatment and rehabilitation” (Berman 2011:138). It is therefore important to note that the findings of this thesis are not only geographically limited but also demographically.

Although I have attempted to be inclusive of the views of parents from all backgrounds, the selection of the core sample group from the public special school results in the exclusion of the many parents who keep their intellectually disabled child at home (Berman, 2011). Gaining access to parents of

PwIDs, who do not go to school, would have been an overwhelming task and not possible to accomplish within the framework of a 10-week minor field study.

## **6 Findings and analysis**

The analysis is divided into two main sections. The first section analyzes the disabling barriers facing young PwIDs transitioning into social adulthood. The second part of the analysis examines how formal and informal social protection is organized by focusing on strategies and actors. Disabling barriers, strategies and actors, were detected through a thematic analysis of the field data.

### **6.1 Disabling barriers for young PwIDs transitioning into social adulthood**

According to Priestley (2003:117), children, youth and elderly are to various degrees expected to be recipients of care and financial resources whereas “adults are constructed as independent contributors to the social relations of production and reproduction (e.g. through participation in family work or paid employment)”. This statement is also applicable to the context of Central Java, where the transition from childhood into adulthood entails the role transition from a position of receiving care and support to becoming financially independent and in the long run a provider of care and financial support for one’s potential future children and retired parents (Geertz, H. 1961; Von Benda-Beckmann, 2015). Adult PwIDs, who are excluded from productive and reproductive activities thus enter a stage of limbo caught between being biologically and legally adults but not accepted by society as social adults. During interviews and field observations it was noticeable how both parents and professionals consistently used the term ‘anak’, meaning ‘child’, when they referred to the young PwID’s included in this study. By calling young PwIDs ‘children’, people place them in a permanent stage of childhood which reflects the society’s view of PwIDs being unable to live up to the requirements of social adulthood without significant support.

This section will explore in-depth the disabling barriers that PwIDs face when entering social adulthood. Disability is, as previously mentioned, defined according to the social model of disability which means that individual limitations only become a disability when intersected with structural barriers.

#### **6.1.1 Stigmatization**

Parents and guardians expressed how their intellectually disabled son or daughter had experienced stigma in the shape of bullying from children in the neighborhood, being stared at, and exclusion

from certain social activities. Bagus, who is a young man with an intellectual disability, used to love going to the mosque but after some older boys in the neighborhood hid his sandals after prayer, he refused going to the mosque again, excluding him from a very important socializing institution in Muslim societies (Bu Tri, 13-03-2016). Many parents had also experienced ‘stigma by association’ (Goffman 1963; Mehta & Farina 1988). An interesting example mentioned by middle and upper class parents, was how people would stare at them when they brought their intellectually disabled child to the local mall. Going to the mall is a common leisure activity in Central Java for people of middle and upper class. In a mall parents are confronted with strangers who are uninformed about the conditions of the PwID which might have exacerbated their feelings of being stigmatized and sticking out from the crowd. Bu Laras, a middle class woman, here talks about her initial response to discovering her daughter, Lina, was intellectually disabled:

At first I felt embarrassed and confused, what was I going to do? But after I sent Lina to the special school, I realized that I wasn’t the only one who had a child like Lina. Some parents were doctors, soldiers, professors.. So after that I felt like I didn’t have to be embarrassed.

(Bu Laras, 22-02-16)

Bu Laras’ embarrassment disappeared once she discovered that people in prestigious positions in society also get children with intellectual disabilities. Bu Laras is a middle class woman, and being placed in the same category as people with a high status made her cope better with stigma. The quote of Bu Laras thus reveals that stigma and feelings of embarrassment are related to class. Having a disabled child lowers your status in society, which a teacher at the public special school confirmed by explaining how it is more often ‘noble people’ who have the hardest time accepting the fact that their child needs special education and who will sometimes keep the PwID at home (key informant no.1, 21-01-2016). All parents and guardians in this study had decided to enroll their child in a special school, which shows that they have all, to a certain degree, accepted the condition of their child.

Stigmatization is a disabling barrier which can lead to the social exclusion of PwIDs and their families from public spaces, special education, and welfare services.

### **6.1.2 Social and behavioral barriers**

The social and behavioral difficulties that PwIDs face will differ greatly from individual to individual depending on their personality and intellectual limitations. It is therefore impossible to give a

standardized image of the social and behavioral difficulties they face. Yet, several parents expressed how the PwID experienced difficulties with communication, anger management, and a strong need to stick to routines. Such behavior deviates from the Javanese idealized behavior of non-conflict and self-control (Sutarto, 2006:45). By being unable to live up to the behavioral norms, PwIDs face disabling barriers in interaction with their surroundings. This limits their possibilities for inclusion in society, as people might not know how to interact with them. Young PwIDs therefore need support in developing such skills to their potential and would benefit from increased awareness in society of the behavioral norm deviations connected to intellectual disabilities and how to accommodate these.

Sexuality is a central part of adulthood. Female PwID are “at extreme risk for sexual abuse” (Berman, 2011:138) because they are unaware of their rights or when or how to say no to violating behavior from others. The issue of sexual abuse of female PwIDs came up several times during interviews with parents and key informants. A teacher at the special school told me about a time he had to scream at a man in a bus who was openly violating an intellectually disabled girl, in order to make him stop (key informant no.4, 20-02-16). Several teachers told me about a girl in senior high school who had sold sex to men, who cheated her for the agreed upon price (as money is a very abstract concept for her) and had transmitted a sexual disease to her. Furthermore, the girl did not comprehend the negative social repercussions of having sex with strangers in a predominantly Muslim society that strongly discourages sex before marriage (key informant no.1, 13-01-2016). For female PwIDs social and behavioral difficulties make them more vulnerable to sexual abuse and social exclusion.

### **6.1.3 Barriers to special education and vocational training**

PwIDs have various learning difficulties and need specialized education in order to develop the life skills needed to increase self-reliance and independence in their adult lives. Colbran (2010), has stated how the vast majority of disabled people in Indonesia are excluded from education. The lack of tuition-free special schools in Central Java provides evidence to this claim. Although having accessed a special school it does not mean that the students receive appropriate education. Special schools in Indonesia follow the same national curriculum as regular schools and there are very few adapted text books for PwIDs. Teachers will often write long phrases from textbooks on the blackboard and expect the students to copy the text in their notebooks, disregarding the fact that few students can write and even fewer understand what they are writing (participant observation; key informant no.1, 03-02-2016). Some special schools and so-called ‘rehabilitation centres’ offer vocational training but access to these programs and institutions is limited, resulting in few PwIDs receiving appropriate support to

overcome or mitigate their learning difficulties. Exclusion from appropriate specialized education is bound to mean that many PwIDs do not develop according to their potential which in return negatively affects their abilities to care for themselves and ensure livelihood. The role of special education and vocational training in ensuring social protection for young PwIDs will be discussed more in detail in the second analytical section on ‘strategies of formal and informal social protection’.

#### **6.1.4 Barriers to livelihood**

An essential part of social adulthood in Central Java, is financial independence and capacity to provide for your elderly parents (in case they don’t have a pension) and potential children (von Benda-Backmann, 2015). PwIDs face severe difficulties when attempting to enter the labor market due to stigmatization and lack of workplaces that are adapted to their behavioral- and learning difficulties. There is a national quota-law in Indonesia that states that private and public employers should employ at least 1 disabled person out of 100 employees (Edwards, 2014). The law was not enforced in the field setting as employers argued that there is no similar law from the local government, and that the law is therefore invalid (key informant no.4, 20-02-2016). This exemplifies how contradictions in local and national governance can hinder pro-disability laws and programs. By, avoiding enforcement of national pro-disability laws, the local government has not taken proper measures to actively integrate PwIDs in the formal labor market.

#### **6.1.5 Poor access to information about intellectual disability and public services and programs**

The majority of research participants discovered that their child was intellectually disabled when they entered kindergarten and could not keep up with the other students. Most parents did not know the exact diagnosis of their intellectually disabled child and had received no or very limited information on how to raise their children according to their intellectual limitations. Through interviews with a key informant it came to my knowledge that there is a targeted cash transfer program from the local government, which supports parents or guardians of adult PwIDs with a fixed amount of money each month during a year (key informant no.4, 20-02-2016). None of the parents and guardians had heard about this program although it had existed for several years. Another example of poor information flows to parents and guardians of PwIDs, is how it took three years after Bu Annisa’s daughter graduated from the public special school before she learned about Temanggung Rehabilitation Centre from a person in her network, who works at the social ministry. Bu Annisa (10-02-2016), who has been working at the ‘asrama’ at the public special school for more than 15years, later found out that several teachers at the school knew about the rehabilitation centre but had not shared the information

with the parents. Bu Annisa's experience shows that information flows through informal social networks rather than through official channels such as the public school.

Poor access to information is a structural disabling barrier to PwIDs as it unnecessarily complicates access to social services and in some cases excludes PwIDs from financial support schemes and special education and vocational training which could have increased their independence from familial support.

### **6.1.6 Disabling barriers result in social and economic dependence**

All members in a society are to various degrees interdependent. Dependence should therefore not be seen as a unique condition for PwIDs but as a variation in degree in which PwIDs are more dependent on certain kinds of support than non-disabled people (Priestley, 2003:120). Priestley further suggests that the emphasis on 'independence' is a typically Western phenomenon correlated with an individualistic model of society. When faced with the question of what their hopes were for their child's future, all parents specifically mentioned the importance of their children being independent, suggesting that the concept of independence is more complicated than Priestley (2003) suggests. Some wished that their child would marry or get a job, but most parents were content with the ability of their children to handle their own care needs, so that they would not be a burden to the siblings or relatives that will take care of the PwIDs once their parents cannot fulfill that role anymore. It is important to note that when parents or guardians talked about independence, they did not refer to economic independence but to the ability to do household tasks and self-maintenance such as showering and handling menstruation. This suggest that the definition of independence in the West and in Central Java differ in the sense that independence in Central Java is perceived as the ability to function independently within a family unit whereas independence in the West is more concerned with living an independent adult life outside of the parental home.

This does not mean that adults in Central Java are not expected to be economically self-sufficient. Economic self-sufficiency is essential in order to fulfill the intergenerational 'contract' of supporting children and elderly in the family. Disabling barriers to earning an income or receiving financial support result in many adult PwIDs being financially dependent and incapable of obtaining a sustainable livelihood. Some PwIDs, depending on their training and intellectual capacities, will be able to handle many care needs on their own but the majority will also need care support of varying degrees throughout their adult lives.

Based on the analysis of the disabling barriers that PwIDs face in being accepted as social adults, it is safe to conclude that the majority of PwIDs will need support to achieve social protection in terms of coverage of care and livelihood needs.

## **6.2 Strategies of formal and informal social protection**

This section will take a closer look at the various formal and informal strategies employed to overcome or mitigate the before mentioned disabling barriers that PwIDs face when attempting to live up to the criteria of social adulthood. Strategies should in this context be understood as plans and actions taken to achieve social protection. It is important to clarify that this section is not an exhaustive analysis of all strategies applied or all actors involved in supporting Central Javanese youth and adult PwID with their livelihood and care needs. It is an analysis of the strategies that the 10 cases of parents and guardians had implemented or were planning to implement, combined with secondary information about how other adult PwIDs in the field setting had addressed the issue of social protection. The analysis will be structured based on the care diamond (Razavi, 2007) by exploring the four sectors of family, not-for-profit, state, and market and how these sectors intersect.

### **6.2.1 Family**

#### **6.2.1.1 The nuclear family as the main provider of social protection**

Out of the 10 cases interviewed, nine households were structured as nuclear and one as ‘augmented nuclear’ and included maternal grandparents and two paternal nephews of the male household head. In familialistic welfare regimes the family is at the center of ensuring social protection for adult PwIDs (Fahey, 2002). It is important to look at the different family members’ role, to get a better understanding of the organization of social protection within a family. In eight out the 10 cases, mothers were the main providers of care for PwIDs. As has been argued previously in this thesis, PwIDs will continue to have various care needs in their adult lives. Depending on the intensity of these extra care needs, caring for PwIDs can make it difficult for both parents to be engaged in paid work outside of the home. In most cases the mother will handle these care tasks and be responsible for the domestic sphere which reinforces the gendered division of labor and the male bread-winner model. Not all mothers felt satisfaction with this division of labor, which was often decided by their husbands. Bu Desi, mother of three young PwIDs, had always dreamed about becoming a civil servant (a high status position in Indonesia) but her husband forbade her from working because “who would then take care of the children?” (Bu Desi, 03-03-2016). Pak Ulum, was the only father out of all

parents interviewed, who defined himself as the main care provider for his intellectually disabled daughter. Hull (1982) has suggested that it has been a sign of status among upper class Javanese to be so wealthy that the wife does not have to work. Pak Ulum is a wealthy man but since he had a very strong emotional bond with his intellectually disabled daughter Elin, he and his wife decided that she would work in their business, while he would stay with Elin in school every day (Pak Ulum, 09-03-2016). Although a single case, it suggests that gender roles in caring for PwIDs are not necessarily as fixed as the literature has suggested.

Family composition plays a big role in terms of the capacity of the family to provide informal social protection for the adult PwID. Rather than relying on intergenerational support the parents in this study emphasized the responsibility of non-disabled siblings to care and provide for the PwID once the parents were incapable of doing so. Bu Desi, who is a mother of four young people out of which the three youngest are intellectually disabled, expressed how the family already relied heavily on the financial support from the oldest son, who was working in a bank. Like most parents she expects the oldest son to take care of his siblings once Bu Desi and her husband cannot do this anymore. The desperation of these expectations shines through in a threat she made to her non-disabled son: “Once I told my oldest son, ‘if you don’t take care of your siblings in a good way (once I die), I will haunt you all the time!’” (Bu Desi, 03-03-2016).

#### **6.2.1.2 Care and financial support from relatives**

As Ochiai (2009) has suggested, most parents made a very clear distinction between the responsibilities of the nuclear family and support one could expect from relatives. Care from relatives is predominantly short-term and most parents only expect relatives to take care of the PwID for one or two days. Some parents fear that relatives will not be able to understand the behavior and needs of the disabled person and are therefore reluctant to ask them for care support.

Internal migration and distance to relatives seems to have a big influence on the kind of support that relatives can offer. Relatives living far from PwIDs cannot help out with daily household activities but can offer financial help in terms of remittances. Some relatives had offered to informally ‘adopt’ the PwID, as they were more affluent and lived in areas with better services for PwIDs. In one of the cases, the paternal aunt and uncle took care of a young male PwID called Fendy. Fendy’s parents were divorced and when his father remarried and had a new child he sent Fendy to his uncle with the words “I leave Fendy with you, if he needs anything just ask me” (Pak Wadi, 10-03-2016). Pak Wadi is neither affluent nor does he live in the proximity of good services. His older brother sent Fendy to

him without much consultation as he saw it as his younger brother's moral obligation to help him. Another respondent, Bu Laras, only has one child and can therefore not rely on siblings to take care of her intellectually disabled daughter once her and her husband grow old. Bu Laras and her husband therefore rely heavily on the willingness of their relatives to take care of their daughter. Bu Laras explained how they often share their fortune with others, especially close family, as they hope that these good deeds will be returned to their daughter Lina. The case of Pak Wadi, and Bu Laras reveal values of *utang budi* translated to 'a debt of gratitude', which entails that if you do good things to people in your close network they will be morally obliged to support you when needed (Mulder, 1994: 106). Although 'utang budi is still very much relevant to people's lives in the field setting, the fact that the majority of parents do not rely on long-term support from relatives suggests that this system of obligation might not be as strong as in the past.

#### **6.2.1.3 Marriage: Social protection by extension of family**

Marriage is an extension of the family and thereby also an extension of an informal system of social protection. None of the PwIDs included in the case studies were married and only about half of the parents and guardians expressed hopes of marriage for the PwID. From secondary sources I learned about several cases of male and female PwIDs who had married with either disabled or non-disabled spouses. Two teachers at the special public school explained how some "pretty girls" with intellectual disabilities got married in return for the husband taking care of them (key informant no. 1 & 2, 13-01-2016). Implying that the criteria of marriage was not based on the female PwIDs' abilities to ensure livelihood of the household but on their abilities to please their husbands with their 'good looks'. I also heard about several cases of male PwIDs that had married. Common for all these men was the fact that they were engaged in paid labor, which confirms the importance of the male breadwinner model in a familialistic welfare regime in which a husband is expected to provide financially for the family.

#### **6.2.1.4 Absence of family commitment**

Not all families are capable or willing to accept the life-long commitment of caring and providing for the PwID. A staff member at Temanggung Rehabilitation Centre explained how some parents would think that their responsibilities as parents were over once their child enrolled at the centre and rarely called or came to visit. It has happened on several occasions that parents have changed their phone number or provided incorrect contact details so that the PwID could not return to their families once their training finished (key informant no.13, 14-03-2016). It is also important to mention here that

PwIDs are not always the recipients of social protection in a family but in some cases they are the providers. A previous student at the public special school works as a parking attendant in order to take care of his supposedly alcoholic father (key informant, no. 1, 13-01-2016). This indicates that strategies of social protection are not always only centered around the family. The following analytical sections will take a closer look at strategies that include non-familial actors.

## **6.2.2 Not-for-profit**

### **6.2.2.1 The double role of neighbors**

According to (Sirojudin & Midgley, 2011:18) “family networks of care and support also extend into the community where many neighbors may in fact be relatives”. It is an important point to keep in mind, as about a third of the respondents had close relatives as neighbors, but for analytical purposes when referring to neighbors in this section I will exclude relatives. As Islam is the predominant religion in the field setting the majority of Muslim respondents interacted daily with neighbors in the mosque (participant observation). Bu Chetna, who is Hindu, did not have a very close relationship with her neighbors which might be exacerbated by their lack of interaction through religious institutions. Section 6.2.2.2 will take a closer look at the role of religion in social protection for PwIDs.

Female respondents expressed how they listened to and tried to follow advice from neighbors in regards to how to best raise and support the PwID in his or her adult life. Many neighbors seem to take genuine interest in each other’s personal matters and discuss it openly with or without the involved party present (participatory observation). Not all comments from neighbors are constructive and Pak Ulum (09-03-2016), expressed how people that are neither close friends nor family will often ‘tease’ PwIDs, including his daughter. Neighbors thereby assume a double role as supporters and stigmatizers. Financial support from neighbors is very limited and mainly given out at special occasions such as funerals, sudden illnesses, weddings etc. (participant observation). Although measures of social protection for PwIDs provided by neighbors are limited, the importance of emotional and symbolic financial support should not be underestimated as it affects how parents cope with stigmatization and decision-making.

### **6.2.2.2 Support from religion and religious organizations**

Out of the 10 cases of parents and guardians of PwIDs, nine families were Muslim and one Hindu. Religion has influence on the strategy of social protection for PwIDs on both a metaphysical level

and through religious organizations. On a metaphysical level, religious beliefs play a big role in how parents cope with stigmatization and economic and social difficulties connected to supporting the PwID. For all Muslim parents, the PwID was seen as a both a challenge and gift from God. Bu Desi expressed it like this: “we think that maybe it is my challenge of this life (to raise three intellectually disabled children). Maybe I will be rewarded in the afterlife. The most important is that I just think positively.” Pak Ulum sees his intellectually disabled daughter, Charika, as a gift from God. She brings him good fortune and he believes that if he and his wife “are patient and take care of her with sincerity, that action will bring us luck and bring us to heaven one day” (Pak Ulum, 09-03-2016). Both Pak Ulum and Bu Desi believe in a reward in the afterlife which makes the struggles in the current life more endurable. For Bu Chetna, a Hindu woman, religion had not only been a source of comfort but had also led to stigmatization:

Some people suggested that I had done something bad. Because Hindus believe in karma. They never said it directly to me [...] It made me reflect about my religion. Maybe I did something bad in my previous life? Why did I get a child like this?

(Bu Chetna, 03-03-2016)

Bu Chetna managed to overcome this stigma when she could scientifically explain her daughter’s chromosome disorder, suggesting that knowledge about disabilities can be a coping-mechanism in overcoming stigmatization.

Berman (2011) has argued that religious beliefs affect parents’ choice in services for PwIDs. The following example supports her claim. The asrama at the special school was originally founded by a Christian organization. At some point the parents and teachers at the school collectively decided to run the asrama with help from the social ministry as Muslim parents feared that the organization was trying to convert the students in the asrama to Christianity (Bu Annisa, 10-02-2016). This religiously grounded skepticism towards social services among Muslim respondents was brought up quite frequently during interviews. Two mothers explained how they were initially apprehensive about sending their children to Temanggung Rehabilitation Centre as they thought it was a ‘non-Muslim organization’. This seems to suggest that for some Muslims, religion plays a major role in choice of social services.

### **6.2.2.3 Support from an independent parents’ group**

Recently, a group of parents of high school students and recent graduates from the public special school formed an independent parents’ group. Although, living far apart, parents had built

relationships through their interaction at the special school. Eight out of the ten cases of parents interviewed in this study were active members of the group. The independent parents' group is the result of informal social organization of a group of parents that face similar challenges on how to ensure care and livelihood for the PwIDs in their adult lives. Although informal in nature, the group seeks to provide its members with information about both formal and informal means of social protection by scouting for workplaces that accept PwIDs and vocational training programs. The group is organized in the form of an arisan. An arisan is a Javanese rotating savings association where the members meet on a regular basis (once a week or once a month) and contribute a fixed amount of money and in turn receive all of the money collected at the meeting. The financial purpose of an arisan is to help its members save up money. Anthropologist Clifford Geertz did extensive research on arisans in the 60s in Java and concluded that an arisan "is commonly viewed by its members less as an economic institution than a broadly social one whose main purpose the the strengthening of community solidarity (Geertz C., 1962:243). This statement is supported by how research participants explained the purpose of the arisan as an institution for "socializing" (participant observation, 28-02-2016).

I participated in the arisan's second meeting since its formation. The meeting took place in a lower class woman's home, who received money from the arisan to provide food and drinks for the participants. 17 parents were present out of which 10 were women and seven men, showing a quite equal gender division. The coordinator of the meeting was a military man who encouraged participants to speak freely in spite of different social and economic backgrounds as they were all in a similar situation. When the official agenda of the meeting was discussed, only a few people of high status spoke out, but during the informal breaks all parents were engaged in conversations regarding matters of their children. Indicating that inclusion of voices of people of low status was best achieved in informal settings. At the meeting a few parents suggested applying for funds and officially registering the committee as an organization (participant observation, 28-02-2016). Pak Ulum, later shared in privacy, that he is skeptical about 'formally organizing' the parents' group as he fears corruption of funds. Hall & Midgley (2004:132), share similar concerns about 'community based organizations' (CBOs) as they "can easily be eroded [...] when CBO's are used instrumentally by powerful community members or for other organizational goals".

Although the independent parents' group provide limited financial support and could be at risk for 'elite capture', the group supports parents in overcoming feelings of stigmatization and increase access to information about ways to achieve social protection for the adult PwIDs.

## 6.2.3 State

### 6.2.3.1 Improving skills through public education and vocational training

None of the parents and guardians interviewed received any care or financial support from the government. The support they did get from the state was tuition-free education at the special school and vocational training at Temanggung Rehabilitation Centre.

Besides opportunities for PwIDs to socialize and make friends, parents did not have many positive things to say about the education at the public special school. Parents felt like the special school has not lived up to its obligation to prepare their children for their adult lives. Some complaints included teachers leaving the students in class, teachers not being educated in special education, and teachers not sharing information about the social and learning progress of the PwIDs. Another issue for parents was that many of them had to stay at the school during school hours, so that they were available to support their children in various care tasks such as going to the toilet or calming them down if they got angry. Teachers feel that such care tasks are beyond their responsibility (participant observations). Spending time at the school makes it difficult for the parent (mothers especially) to engage in paid labor, or do other household tasks which could affect the household economy negatively. At the special school I observed how teachers would take turns to leave classes to sell snacks at a small shop. I found out later that the shop was initially founded with the intention of students selling snacks and earning an extra income but in time teachers took over the business and shared the profits between them (participant observation).

Although the majority of parents are unsatisfied with the conditions at the school few dare to speak up as “we are afraid that if we argue with the teachers, our children will become the target of their revenge” (Pak Ulum, 09-03-2016). Some teachers at the special school were well aware of these issues and would like to improve the conditions but as one teacher explained it:

“If someone is sick, we try to find the cause so we can prescribe the correct medicine. When it comes to the problems in the public sector, people pretend that everything is fine, because they are afraid of insulting the official institutions. But, the society is very sick, the bureaucracy is sick, humanity is sick. In order to find a cure, we need to be brave enough to detect the cause.”

(Key informant no.3, 10-02-2016)

Both teachers and parents are afraid of voicing critique of the public special school out of the negative reflections it could have on their personal and professional lives. This results in lack of accountability and improvement of the conditions at the school.

Seven out of 12 PwIDs included in this case study had recently graduated from the special school and had transferred to Temanggung Rehabilitation Centre. As opposed to the conditions at the public special school, parents seemed very satisfied with the service at Temanggung Rehabilitation Centre and hoped that their children would discover ‘their special talents’ which might enable them to ensure their livelihood. Once PwIDs graduate from the centre, staff will support the ones they find capable in occupying paid work, and offer a cash-transfer for the parents of PwIDs that are deemed incapable of participating in the formal labor market. This cash-transfer lasts for one year and is intended as a starting capital for a small business or commercial livestock (key informant no.13, 14-03-2016). Although perceived as a quality public service by parents, Temanggung Rehabilitation Centre is as the only public rehabilitation centre for PwIDs exclusive, and far from sufficient in covering the needs of the many adult PwIDs around Indonesia.

#### **6.2.4 Market**

##### **6.2.4.1 Integrating private services in family care**

For some parents, the education offered from the state was supplemented by hiring part-time informal private teachers. The comparison of the employment of two such private teachers provides interesting insights into class-differences among parents and the services they can afford. Bu Roni, a lower class woman, hired a psychology graduate with the specific purpose in mind of preparing her son to pass the acceptance requirements at Temanggung Rehabilitation Center. Bu Made, whose husband is a high ranking army man, employed a principal at a private special school while her daughter was still a child, to improve her general academic skills. Although both teachers are providing informal services and improving the skills of the PwIDs, there is a difference in the educational backgrounds of the private teachers and the purpose for which they were hired. This might result in higher quality education for PwIDs of people with sufficient economic funds.

Few parents received help in caring for the PwID from informal private services such as domestic workers and home nurses. Bu Desi and her husband had hired a full time home nurse as one of their intellectually disabled children had suffered a severe brain seizure which had rendered him bedridden and in need of constant support. Hiring a home nurse is very expensive and Bu Desi compared the

cost of providing for her three children with intellectual disabilities, to that of “building 10 houses”, suggesting that the informal nature of family support makes family economies very vulnerable to sudden changes in expenses caused by for example illnesses.

#### **6.2.4.2 Accessing paid work in the formal and informal labor market**

None of the PwIDs included in this study were earning an income so I had to rely on secondary sources about income-generating activities of other PwIDs in the field setting and parents’ hopes and plans for the kind of work that their children could do in the future. It is important to note that PwIDs categorized at the lowest intellectual level (C1) are almost entirely excluded from paid labor (key informant no.6, 11-03-2016; key informant no.3, 17-02-2016).

Very few PwIDs finds work in the formal sector (key informant no.13, 14-03-2016). Bu Dina and Pak Wadi explained how a female PwID had once been employed at the factory they work at but she was fired quite quickly as she could not keep up with the required production targets. Brown and Kessler (2014:95) refer to the placement of PwIDs in regular workplaces without consideration to disabling barriers as ‘dumping’. PwIDs are unlikely to thrive in workplaces where they are expected to perform equally to non-disabled workers and would benefit more from being in a workplace adapted to their needs. During the field work I visited an adapted workplace that employed seven adult PwIDs categorized as having C-level intelligence, who had graduated from Temanggung Rehabilitation Centre. The PwIDs live at the employers’ home which is also where the sewing production takes place. All employers were related and spoke about the business as a family and employers had accepted one of the female PwIDs as their life-long responsibility as she had been abandoned by her family (key informant no.8, 9 & 10, 18-02-2016). I did not hear about other adapted workplaces in the field setting and it should be safe to assume that few adult PwIDs will find such accommodating formal work conditions.

Based on the data collected in the field, PwIDs seem to be more likely to find paid work in the informal sector than in the formal sector. Teachers at the public special school, who still keep in contact with graduates, mentioned two cases of male PwIDs engaged in the informal labor market (key informants no.1 & 2, 10-02-2016). One earns money from busking and the other by working as a parking attendant in front of a supermarket. Both jobs are outdoors and located in the public spheres. Some female PwIDs at Temanggung Rehabilitation Centre received training in domestic work which suggests that this could be a potential informal employment field for female PwIDs. Many parents intended to open up a small shop or production at home where the PwID, with support from the

family, could earn an income. Keeping especially female PwIDs at home makes some parents feel more comfortable as they will be at lower risk for sexual abuse or extramarital pregnancies (Bu Nyana & Pak Rian, 07-03-2016). Another advantage of home businesses is that they “protect family workers, to some degree at least, against the kind of risks arising in the wage economy, such as unemployment and loss of livelihood at times of poor health” (Fahey, 2002:52).

## **7 Concluding discussion**

The aim of this thesis was to further the understanding of disabling barriers to social protection for PwIDs in a familialistic developing country and the various measures taken to overcome and mitigate these barriers. More precisely I intended to answer the following two research questions: Which disabling barriers to social protection do PwIDs face in their adult lives? And how is formal and informal social protection for PwIDs organized?

By applying the theoretical concepts of social adulthood and stigma several disabling barriers to social protection for PwIDs in adulthood, were detected. These barriers included stigmatization, social and behavioral barriers, barriers to special education and training, barriers to livelihood, and poor access to information. The second part of the analysis took a closer look at different strategies to achieve formal and informal social protection for adult PwIDs and the actors involved in implementing these strategies. It did so by organizing strategies into the four sectors defined in the care diamond (Razavi, 2007): family, not-for-profit, state, and market. In order to confidently answer how social protection is organized for adult PwIDs in the field setting, it is important to discuss how the different actors involved in implementing social protection strategies interact. I have therefore attempted to create a context-specific actors map (see figure 2).

The model is color-coded so that, blue refers to informal social protection, yellow to formal, and green to a mix of formal and informal social protection actors and strategies. Nuclear families and PwIDs are placed at the center of the actor map. Nuclear families carry the largest responsibility in terms of life-long provision of social protection for the adult PwIDs. The division of labour within the nuclear family was in most cases consistent with the male bread-winner model, except for the case of pak Ulum, where the traditional gendered division of labor had been reversed. Parents will often be in charge of the decision-making process of which non-familial forms of social protection strategies the PwID should engage with and I have therefore chosen to define them as a collective unit.

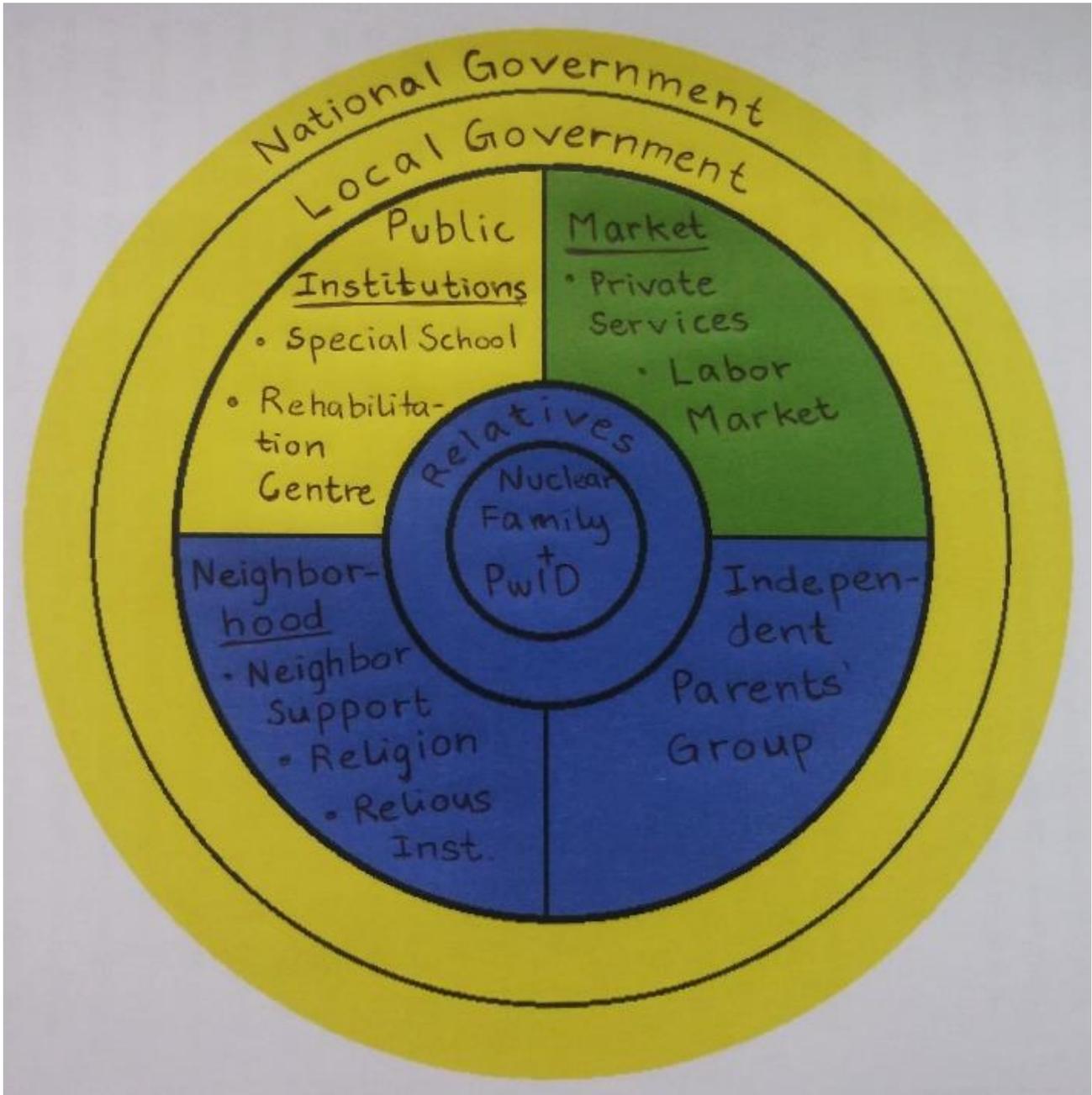


Fig. 2, Actor Map, author (2016)

Surrounding the nuclear family and PwID is a network of informal care and financial support from relatives. Such support is in many cases short-term and often takes the form of caring for the PwID for a few days or sending money in times of crisis. In cases of informal adoptions, support from relatives can potentially be life-long.

PwIDs and their families also engage in strategies of social protection with market, not-for-profit and state actors. Parents have hired informal private services such as private teachers, domestic workers,

and home nurses but such support is dependent on economic status and does not ensure long-term social protection for the PwID. Another strategy was for the adult PwID to engage in paid work in the formal and informal labor market. Most PwIDs are excluded from the formal labour market. PwIDs seem to thrive in work environments that take their disabling barriers into consideration such as in informal home businesses and formally adapted workplaces.

Both neighborhood and the independent parents' group would in Razavi's (2007) care diamond be defined as not-for-profit. Razavi's definition of the concept not-for-profit is too broad to have any real analytical value in the context of this case study. I have therefore decided to display the independent parents' group and neighborhood actors separately in the actor map. Neighborhood support, here defined as support from neighbors, religion, and religious institutions, includes advice on how to ensure social security, metaphysical coping mechanisms in religion, and short term financial support at special occasions. Neighborhood support should not be romanticized as both religion and neighbors have been the cause of stigma for PwIDs and their parents. The independent parents' group, gathers a diverse group of parents in a similar situation to discuss and share means of social protection for adult PwIDs. The group's attempt to overcome class differentiations does not render it immune to inner conflicts and potential 'elite capture' by powerful members. Although the group does not provide notable care or livelihood support, the act of connecting parents of young PwIDs to existing non-familial social protection actors could in the long-run increase social protection of PwIDs and ease the social protection responsibilities of the families.

All of the before mentioned strategies and actors, unfold within the bureaucratic and legal framework of the local and national government. National laws and social protection schemes are not always well integrated at the local level which can result in poor enforcement of pro-disability laws and poor access to social protection schemes.

In conclusion, the social organization of formal and informal social protection for adult PwIDs is complex and includes several actors intersecting different spheres in the care diamond. The nuclear family, and in particular mothers, have by far the largest responsibility in providing social security for the adult PwID. Considering the immense responsibility of families of PwIDs, adult PwIDs without family support are extremely vulnerable and at high risk of living in poverty. The next section will look into suggestions on how further research can ease the immense care responsibility of families of adult PwIDs.

## 7.1 Suggestions for further research

In this thesis I have focused on the organization of social protection for PwIDs by help of several concepts including the care diamond. I am convinced that the care diamond would prove a more powerful theoretical tool in combination with a model that indicates the extent to which strategies, alone or in combination, cover the care and livelihood needs of the PwIDs. Such a model could organize social protection measures according to stability of the support and whether the support is financial or social. I have attempted to organize the social protection measures analyzed in this thesis in such a model:

<p><b>Unstable social support</b></p> <ul style="list-style-type: none"> <li>- Relatives</li> <li>- Private teachers</li> <li>- Independent Parent’s Group</li> <li>- Temanggung Rehabilitation Centre</li> </ul>	<p><b>Stable social support</b></p> <ul style="list-style-type: none"> <li>- Nuclear family</li> <li>- Informal “adoption” of PwIDs by relatives</li> <li>- Marriage</li> <li>- Religion</li> </ul>
<p><b>Unstable financial support</b></p> <ul style="list-style-type: none"> <li>- Neighbourghs</li> <li>- Arisans</li> <li>- Targeted cash-transfer program for families of disabled people</li> <li>- Informal paid work (eg. prostitution &amp; parking attendant)</li> </ul>	<p><b>Stable financial support</b></p> <ul style="list-style-type: none"> <li>- Nuclear family</li> <li>- Marriage</li> <li>- Formal work (with pension scheme)</li> <li>- Home businesses</li> <li>- Adapted workplaces</li> </ul>

*Fig. 3 Coverage of social and financial needs, author (2016)*

Stable support is here defined as predictable support that could potentially last for a life-time. Unstable support does not live up to these criteria and is unpredictable and short-lived. Social support is defined as care, education and emotional support whereas financial support is defined in terms of money contributions and access to paid work.

By placing strategies of formal and informal social protection analyzed in this thesis in the model, it appears that support from nuclear family and extension of family through marriage are the only two strategies of stable social and financial support that could potentially be life-long. Supporting the

conclusion made in this thesis, that nuclear families carry the greatest responsibility in providing social protection for adult PwIDs in the field setting. I cannot claim that the model suggested is exhaustive but it should be seen as an attempt to open up a debate about how we can improve research on social protection of adult PwIDs and their caregivers. It is crucial that more research is conducted which pays attention to how social protection is organized in developing countries, and how well these measures of social protection cover the needs of the adult PwIDs. Such research could potentially increase awareness about the disabling barriers to social protection that PwIDs face in their adult lives and find ways to ease the life-long responsibility of caregivers.

## **Bibliography**

- Adioetomo, S. M., Mont, D. & Irwanto (2014). *Persons with Disabilities in Indonesia: empirical facts and implications for social protection policies*. TNP2K – [National Team for the Acceleration of Poverty Reduction]
- Alatas, S. F. (2001). The Study of the Social Sciences in Developing Societies: towards an adequate conceptualization of relevance. *Current Sociology*, 49 (2)
- Aspinall, E. (2013). *Health Care and Democratization in Indonesia*. Routledge, London
- Barnes, C. (2012). *Re-thinking Disability, Work and Welfare*. *Sociology Compass* 6/6
- Bailey, A. B. & Smith, S. W. (2000). *Providing Effective Coping Strategies and Support for Families with Children with Disabilities*. *Intervention in School and Clinic*, Vol. 35, No. 5 pp. 294-296
- Berman, L. (2011). Integrating Disability into Development in Eastern Indonesia: a case study in theory versus reality. *Health, Culture and Society*, 1(1), 132-145.
- Better Work Indonesia (2011). *Employing Persons with Disabilities: guideline for employers*. ILO, IFC
- Brown, S. (2016). *Mental Capacity and Social Policy* in Evans, T. & Keating, F. ed. *Policy and Social Work Practice*. SAGE Publications, London
- Brown, L. & Kessler, K. (2014). *Generating Integrated Work Sites for Individuals with Significant Intellectual Disabilities*. *Journal of Vocational Rehabilitation* no. 40, pp. 85–97
- Bryman, A. (2012). *Social Research Methods*. Oxford University Press 4th ed.
- Chiu, M. Y. L., Yang, X., Wong, F. H. T., Li, J. H., & Li, J. (2013). Caregiving of Children with Intellectual Disabilities in China: an examination of affiliate stigma and the cultural thesis. *Journal of Intellectual Disability Research*, 57(12), pp. 1117-1129.

- Clifford, S. A. (2014). *A Narrative Inquiry of a Self-Advocacy Meeting: rethinking empowerment from sovereignty to spontaneity*. *Disability Studies Quarterly*
- Colbran, N. (2010). *Access to Justice: Persons with Disabilities Indonesia. Background Assessment Report*. AusAID
- Cotterill, P. (1992). *Interviewing Women: issues of friendship, vulnerability, and power*. *Women's Studies International Forum*, Vol 15, No. 5/6, pp. 593-606
- Croll, E. J. (2006). *The Intergenerational Contract in the Changing Asian Family*. *Oxford Development Studies*, 34(4), 473-491.
- Crossaint, A. (2004). *Changing Welfare Regimes in East and Southeast Asia: crisis, change and challenge*. *Social policy and Administration*, Vol. 38, no.5 pp. 504-524
- Edwards, N. J. (2014). *Disability Rights in Indonesia? Problems with Ratification of the United Nations Convention on the Rights of Persons with Disabilities*. *Australian Journal of Asian Law*, 15(1).
- Einfeld, S. L, Stancliffe, R. J., Grey, K. M., Sofronoffs, K., Rice, L., Emerson, E. & Yasamy, M. T. (2012). *Interventions Provided by Parents for Children with Intellectual Disabilities in Low and Middle Income Countries*. *Journal of Applied Research in Intellectual Disabilities*, Vol.25, pp. 135-142
- Esping-Andersen, G. (1990). *The Three Worlds of Welfare Capitalism*. Princeton, NJ, U.S.A.: Princeton University.
- Fahey, T. (2002). *The Family Economy in the Development of Welfare Regimes: a case study*. *European Sociological Review*, 18(1), 51-64.
- Geertz, C. (1962). *The Rotating Credit Association: a 'middle rung' in development*. *Economic Development and Cultural Change*. Vol. 10, No. 3, pp. 241-263
- Geertz, C. (1973). *The Interpretation of Cultures: selected essays* (Vol. 5019). Basic books.
- Geertz, H. (1961) *The Javanese Family: a study of kinship and socialization*. Reissued in 1989 by Waveland Press, Inc. Illinois (Kindle Version)
- Goffman, E. 1963. *Stigma: notes on the management of spoiled identity*. Simon & Schuster Inc. New York
- Hall, A. & Midgley, J. (2004). *Social policy for Development*. SAGE Publications
- Hammersley, M. & Atkinson, P. (2007). *Ethnography: principles in practice*. Routledge, 3<sup>rd</sup> ed.
- Hull, V. (1982). *Women in Java's Rural Middle Class: Progress or Regress?* In: P.V. Esterik, ed. *Women of Southeast Asia*. Occasional Paper No. 9, Center of Southeast Asian Studies. Dekalb, Ill.: Northern Illinois University.

- Hüsken, F. & Koning, J. (2007). *Between Two Worlds: social security in Indonesia* in Hüsken, F. & Koning, J. ed. *Ropewalking and Safety Nets: Local ways of managing insecurities in Indonesia*,
- Komardjaja, I. (2004). *Independent Living and Self-Determination of Women with Physical Disabilities in Bandung, Indonesia*. Disability Studies Quarterly, Vol. 24, No. 3
- Komardjaja, I. (2005). *The Place of People with Intellectual Disability in Bandung*. Health and Place 11 (117-120), Elsevier Ltd.
- Lianta, D. (1992). *An Indonesian Perspective* in Moss, S. Ed. *Aging and Developmental Disabilities: perspectives from nine countries*. International Exchange of Experts and Information in Rehabilitation
- Megawangi, R., Zeitlin, M. F. & Kramer, E. M. (1995). *The Javanese Family in Strengthening the Family: implications for international development*. The United Nations University Press
- Mehta, S. I., & Farina, A. (1988). Associative Stigma: perceptions of the difficulties of college-aged children of stigmatized fathers. *Journal of Social and Clinical Psychology*, 7(2-3), 192.
- Mulder, N. (1994). *Inside Indonesian society: cultural change in Java*. Singapore: Pepin Press.
- Newberry, J. (2010). *The Global Child and Non-Governmental Governance of the Family in Post-Suharto Indonesia*. Economy and Society, 39:3, pp. 403-426,
- Oakley, A. (1981). *Interviewing women: a contradiction in terms*. In Helen Roberts (Ed.), *Doing feminist research* (pp. 30-61). London: Routledge and Kegan Paul.
- Ochiai, E. (2009) *Care Diamonds and Welfare Regimes in East and South-East Asian Societies: bridging family and welfare sociology*. International Journal of Japanese Sociology, No.18
- Oduro, A. D. (2010). *Formal and Informal Social Protection in Sub-Saharan Africa*. European Report on Development
- Palmer, M. (2013). *Disability and Social Protection: a call for action*. Oxford Development Studies, Vol 41, No. 2, pp. 139-154
- Priestley, M. (2003). *Disability: a life course approach*. Polity Press, UK
- Punch, K. F. (2014). *Introduction to Social Research: quantitative & qualitative approaches*. SAGE Publications, 3<sup>rd</sup> ed.
- Raghuram, P. (2012). *Global Care, Local Configurations: challenges to conceptualizations of care*. Global Networks vol. 12, pp. 155-174, Blackwell Publishing Ltd.
- Razavi, S. (2007). *The Political and Social Economy of Care in a Development Context: conceptual issues, research questions and policy options*. Gender and Development Programme Paper no. 3, UNRISD

- Reese, T. H., Soedarmadi, & Suyono, H. (1975). The Indonesian National Family Planning Program. *Bulletin of Indonesian economic studies*, 11(3), 104-116.
- Rosser, A. (2012a). *Realising Free Health Care for the Poor in Indonesia: the politics of illegal fees*. *Journal of Contemporary Asia* Vol. 42, No. 2, May 2012, pp. 255–275
- Rosser, A. (2012b). *Democratic Decentralisation and Pro-Poor Policy Reform in Indonesia: the politics of health insurance for the poor in Jembrana and Tabanan*, *Asian Journal of Social Science*, Vol 40, pp. 608-634
- Rosser, A. & Wilson, I. (2012). *Democratic Decentralization and Pro-Poor Policy Reform in Indonesia*. *Asian Journal of Social Science* 40 (2012) pp. 608–634
- Scheyvens, R. (2014). *Development Field Work: a practical guide*, SAGE Publications, 2<sup>nd</sup> ed. London
- Sirojudin & Midgley, J. (2011). *Social Protection and Community-based Social Security in Indonesia*. *Social Development Issues* 33 (I), Lyceum Books, Inc.
- SOCIETA (2015). *Majalah Inspiratif Berwawasan Kesejahteraan Sosial* [Inspirational Magazine of Visionary Social Welfare] Edisi Khusus HKSN (original in Indonesian)
- Stone, E. (1999). *Disability and Development: learning from action and research on disability in the majority world*. Disability Press.
- Suryahadi, A., Fabriany, V. & Yumna, A. (2014). *Expanding Social Security in Indonesia: the processes and challenges*. UNRISD, Working Paper No. 14
- Sutarto, A. (2006). Becoming a true Javanese: A Javanese view of attempts at Javanisation. *Indonesia and The Malay World*, 34(98), pp. 39-53.
- Traustadottier, R. & Johnson, K. (2000). *Women with Intellectual Disabilities: finding a place in the world*. Jessica Kingsley Publishers, London
- UN General Assembly. (2007). *Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly*. 24 January 2007, A/RES/61/106
- Von Benda-Beckmann, K. & von Benda-Beckmann, F. (2008). *Social Security Between Past and Future: Ambonese networks of care and support*. LIT Verlag, Berlin
- Von Benda-Beckmann, K. (2015). *Social Security, Personhood and the State*. *Asian Journal of Law and Society*, vol.2, pp. 323-338
- Weldeab, C. T. & Opal, L. R. (2007). *Raising a child with intellectual disabilities in Ethiopia: what do parents say?* PhD Presentation Paper for Refereed Conference of the American Educational Research Association, Chicago, Illinois

Westberg, A. (2004). *Forever young? Young People's Conception of Adulthood: the Swedish case*, Journal of Youth Studies, Vol. 7, No.1, pp. 35-53

World Health Organization (2011). *Summary: World report on disabilities*. WHO Press

### **Web sources**

AAIDD (2013). *Definition of Intellectual Disability*.

<http://aaidd.org/intellectual-disability/definition#.V1g4E75XOt0>, Accessed: 14-04-2016

The Arc (2011). Causes and Prevention of Intellectual Disabilities. [www.thearc.org](http://www.thearc.org), Accessed: 19-05-2016

CIA, World Factbook <https://www.cia.gov/library/publications/the-world-factbook/geos/id.html>, Accessed 11-05-2016

Dinas Kependudukan dan Pencatatan Sipil, [The local statistics office of demographics and registration], Accessed: 29-04-2016

World DataBank,

<http://databank.worldbank.org/data/reports.aspx?source=2&country=IDN&series=&period>,

Accessed 28-04-2016

YPAC – Yayasan Pembinaan Anak Cacat [Indonesian Society for the Care of Disabled Children], Accessed: 21-05-2016

## Appendix A:

	Case 1	Case 2	Case 3	Case 4	Case 5	Case 6	Case 7	Case 8	Case 9	Case 10
<b>Name of parents/guardians</b>	Bu Annisa	Bu Chetna	Bu Desi	Bu Dina & Pak Wadi	Bu Laras	Bu Nyana & Pak Rian	Bu Ria	Bu Suajana & Pak Gunawan	Bu Tri	Pak Ulum
<b>Name of PwID</b>	Ida (f)	Adhira (f)	Dian (f), Putri (f) & Surya (m)	Fendy (m)	Lina (f)	Rani (f)	Aji (m)	Ayu (f)	Bagus (m)	Charika (f)
<b>Relation to PwID</b>	Single mother	Mother	Mother	Paternal aunt & uncle	Mother	Mother & Father	Mother	Mother & Father	Mother	Father
<b>Age of PwID</b>	24	21	22, 20, 20	22	20	18	20	16	20	20
<b>Intellectual Disability</b>	Brain damage, C	Cromosome disorder, C	C, C1, C1	C	C1	Down Syndrome, C1	C	Down Syndrome, C1	C1	Down Syndrome, C1
<b>Occupation of PwID</b>	Temanggung R. C.	Temanggung R.C.	Temanggung R. C, Temanggung R.C, at home	High school student	Temanggung R. C.	High school student	Temanggung R.C.	Temanggung R. C.	High school student	At home
<b>Occupation of female parent</b>	Works in Asrama	House wife	Housewife	Factory worker	Small shop at home	Private company	Housewife	Catering business	At home	Sells meat at market
<b>Occupation of male parent</b>	N/A	Army	Bank employee	Factory truck driver	Pension company	Retired	Police	Professor	Parking attendant	Entrepreneur
<b>Economic status</b>	Low income	Middle income	Middle income	Low income	Middle income	Middle income	Middle income	High income	Low income	High income
<b>Religion</b>	Muslim	Hindu	Muslim	Muslim	Muslim	Muslim	Muslim	Muslim	Muslim	Muslim
<b>Household type</b>	Boarding house	Nuclear	Nuclear	Inter-generational	Nuclear	Nuclear	Nuclear	Nuclear	Nuclear	Nuclear
<b>No. Of children</b>	2	2	4	3	1	2	2	2	2	2
<b>Geographical area</b>	Rural	Urban	Urban	Rural	Urban	Urban	Rural	Urban	Urban	Rural

<b>Ind. parents commitee</b>	Active	Active	Active	Not active	Active	Not active	Active	Active	Active	Active
<b>Main provider of care</b>	Mother	Mother	Mother	Aunt	Mother	Mixed	Mother	Mother	Mother	Father

### Appendix B: List of interviews with key informants

	Gender	Occupation	Recording method	1st Interview	2nd Interview	3rd interview
1	Female	Teacher at public SLB	Handwritten notes	13-01-2016	21-01-2016	03-02-2016
2	Female	Teacher at public SLB	Handwritten notes	13-01-2016		
3	Male	Teacher at public SLB	Handwrit./recorded	10-02-2016	17-02-2016	
4	Male	Teacher at public SLB + DPO member	Handwrit./recorded	10-02-2016	20-02-2016	
5	Male	Teacher at public SLB + DPO member	Handwritten notes	10-02-2016		
6	Male	Principal at private SLB	Recorded	11-03-2016		
7	Male	Social Ministry Staff	Handwritten notes	28-01-2016		
8	Male	Social Business employer of PwIDs	Recorded/Handwrit.	18-02-2016	14-03-2016	
9	Female	Social Business employer of PwIDs	Recorded/Handwrit.	18-02-2016	14-03-2016	
10	Female	Social Business employer of PwIDs	Recorded/Handwrit.	18-02-2016	14-03-2016	
11	Female	Teacher at Temanggung R. C.	Handwritten notes	09-02-2016		
12	Male	Staff at Temanggung R. C	Handwritten notes	09-02-2016		
13	Male	Staff at Temanggung R. C	Handwritten notes	14-03-2016		
14	Male	Informal private teacher	Handwritten notes	13-03-2016		

## Appendix C: Semi-structured interview guide

### 1. Presentation of me and the research

- Student at Lund university
- Purpose of research: to understand the challenges facing the child and family once they finish school.
- Usage: A bachelor thesis to be read by my peers and professors
- Talk about confidentiality
- Participants rights to ask me questions and to end participation in the research at any time

### 2. Quantitative information:

Name of informant:

Age:

Gender:

Occupation:

Educational background:

Economic status (Estimation, eg. look at the house):

Geographical area (rural vs. urban):

No. of people living in the residence:

Relations between these people (eg. uncle, brother etc):

Age of person with intellectual disability:

Who is the main caregiver?: (answers to this could end up being qualitative – a negotiation of responsibilities within the household)

### 3. Qualitative questions:

Introduction:

- Tell me a bit about your family
- What does a typical day for the child look like?

Parents'/guardian's knowledge about disability:

- How did you discover your child was intellectually disabled?
- How did you feel about this?
- How did your family respond?
- Have you received any training/information on how to handle the IDs disability?

- if so from who?

Who has been helpful to the family in relation to the child?

- How?

Community:

- Are you a member of an arisan?
- How does the community respond to your child?
- Do neighbors have any opinions on how you should deal with the child's future?

Social services:

- Did you receive any support from the government?
- Social programs?
- NGOs?

Stigmatization:

- Have you experienced any difficulties?
- What is the opinion of the neighborhood/family about the person with disability?  
(Stigmatization?)

Strategies for the child's future:

- What are your hopes for the future of your child?
- Work?
- Care? From who?
- How could your job of preparing your child for the future be made easier?

4. Give thanks for their participation

5. Do they know any other PwIDs whose families/guardians would be interested in helping me?

6. Give them my contact information and let them know that they are very welcome to contact me at any time about anything.