A multimethod exploration of stigma towards people with intellectual disability in Indonesia

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Declaration: I, Restu Tri Handoyo, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in this thesis.

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Abstract

This thesis aims to explore the stigma associated with people with intellectual disability (ID) in the Indonesian context. The thesis encapsulates a systematic review and three inter-related empirical studies carried out using a multimethod framework to address the aim. The systematic review includes 24 studies, exploring ID stigma in Southeast Asia. A narrative synthesis was performed to synthesise the findings of the reviewed studies. The review highlights the role of cultural factors in shaping the stigma towards people with ID.

Of the remaining three studies, the first explores professionals’ attitudes towards people with ID and their inclusion in Indonesian society. Fifteen professionals i.e. teachers, psychologists, medical doctors, and religious leaders were interviewed. Thematic analysis identified seven themes, namely ‘perceived cause of ID’, ‘use of terminology’, ‘attitudes towards people with ID’, ‘attitudes towards the inclusion of people with ID’, ‘religion and ID’, ‘family-centric support’, and ‘challenges faced by people with ID in wider context’.

The second study adapts a self-report stigma questionnaire, that was developed in the UK, to the Indonesian context. One hundred adults with mild to moderate ID completed the questionnaire. The psychometric properties of the questionnaire and participants’ responses to the final items of the questionnaire were examined. The Indonesian version of questionnaire consists of 11 items with sound psychometric properties.

The third study is a qualitative exploration of experienced stigma and inclusion of adults with mild to moderate ID in society. Fifteen participants were purposively selected from the one hundred participants recruited in the second study. Thematic analysis identified four themes including ‘discrimination and poor treatment‘, ‘reaction to and impact of stigma‘, ‘limited social life and activities‘, and ‘wish for a normal life‘.

Following the multimethod framework, the findings from the three empirical studies were integrated and presented in a stand-alone study. The integration of the findings further highlights the stigma experienced by adults with mild to moderate ID in Indonesian society.

Impact statement

The findings of this thesis suggest that stigma towards people with intellectual disabilities (ID) is present in parts of Indonesian society, which hampers their inclusion. Additionally, cultural factors were suggested as shaping stigma towards people with ID, and professionals generally hold positive attitudes towards people with ID and their inclusion in society. In light of these findings, initiatives are needed to reduce stigma towards people with ID and endorse their inclusion in society. Initiatives to reduce stigma associated with ID should be carried out by considering cultural factors prevalent in targeted communities, and involving specific groups such as professionals—e.g., medical doctors, psychologists, teachers, and religious leaders as they are potential allies in such efforts.

This PhD project has been funded by the Indonesian Endowment Fund for Education (Lembaga Pengelola Dana Pendidikan), a government body under the Ministry of Finance of the Republic of Indonesia that provides postgraduate scholarships and research funds for Indonesian scholars. The findings of this thesis will formally be reported to the Indonesian Endowment Fund for Education, then disseminated to corresponding ministries such as the Ministry of Social Affairs and the Ministry of Health. This thesis is the first to explore stigma towards people with ID in an Indonesian context. As such, it provides important information for the Indonesian government that can improve their policies related to people with ID in order to comply with the Convention on the Rights of Persons with Disabilities (CRPD), ratified by Indonesia in 2011.

Additionally, this thesis has produced a psychometrically sound questionnaire to measure the stigma experiences of adults with mild to moderate ID in an Indonesian context. The questionnaire can be used by the Indonesian government to further investigate the condition of people with ID on a larger scale (e.g. national, provincial, district level). The questionnaire can also be used in future studies exploring stigma towards people with ID and endorse further studies in the field to be carried out in the Indonesian context.

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Preface

In this thesis, I present the findings of a systematic review and three inter-related empirical studies exploring the stigma associated with people with intellectual disability (ID) which was carried out using a multimethod approach. The first chapter provides introduction to this thesis, including its aims and objectives of the three empirical studies. The second chapter provides an overview of the conceptualisation of stigma and ID, as well as background information of ID in Indonesian context. The third chapter reports the results of a systematic review of 24 studies exploring stigma related to ID in Southeast Asian countries. This chapter emphasise on socio-cultural factors shaping stigma of ID which shared between the Southeast Asian countries, including Indonesia.

The fourth chapter presents a qualitative exploration of professionals’ attitudes towards people with ID and their inclusion in society. The aim of this study was to explore attitudes of professionals from multiple backgrounds. Fifteen professionals were included in this study, namely mainstream education teachers, special education teacher, psychologists, medical doctors, and religious leaders (Islam, Catholic, Protestant, Hinduism, and Buddhism). I was interested in exploring this topic due to findings of previous studies suggesting that professionals are the key to successful inclusion of people with intellectual disabilities in society. Religious leaders were included in this study due to the important role of religion in Indonesian society, and that religious-based organisations are commonly providing services to people with intellectual disabilities in Indonesia. The findings are discussed in relation to previous studies as well as the Indonesian cultural context.

The fifth chapter presents an adaptation of a self-report stigma questionnaire, developed in the United Kingdom (UK), into the Indonesian context. I was interested in carrying out the study as it would provide a measure that could be used by future studies exploring stigma in people with ID in Indonesia. The adaptation involved 100 adults with mild to moderate intellectual disabilities, recruited from three service providers. Reliability and common underlying factor structure of the questionnaire were examined to assess its psychometric properties. Additionally, participants’ responses to the questionnaires’ items were examined to explore the self-reported stigma scores and the relationship of stigma with socio-demographic characteristics. Discussion includes comparison of item structure between the Indonesian version of the questionnaire with its UK and South African version.

The sixth chapter presents a qualitative exploration of experienced stigma in adults with mild to moderate intellectual disabilities and the extent of their inclusion in society. The study included a semi-structured interview with 15 adults with mild to moderate ID, purposively selected from the 100 participants in the stigma questionnaire adaptation study (chapter 5). The aim of this study was to obtain an in-depth information regarding stigma which adults with mild to moderate intellectual disabilities experienced in their day-to-day life and how it affects their inclusion in Indonesian society. The findings of this study were also used to complement the quantitative findings obtained in the stigma questionnaire adaptation study.

The seventh chapter presents an integration of findings from the three empirical studies presented in chapter 4, 5, and 6. The quantitative and qualitative findings were compared and contrasted in a matrix, to allow identification of pattern and/or divergence within the data. The aim of this integration is to provide a better explanation of the quantitative findings by utilising qualitative data extracted from the fifteen interview transcripts, as well as to assess validity of findings in the two qualitative studies by comparing interview transcripts of professionals and adults with ID. The integration results were then discussed with findings from previous studies.

In the last chapter, I summarise the findings of the studies and discuss potential implications and direction for future research.

Chapter 1 Introduction

1.1 Rationale

Intellectual disability (ID) is defined as a significant impairment in intellectual functioning and adaptive behaviour that affects three domains – conceptual (for instance, language, reasoning), social (for instance, empathy, social judgement), and practical (for instance, personal care, job responsibilities) – with an onset prior to the age of 18 years (American Association on Intellectual and Developmental Disabilites, 2018). ID is estimated to affect 1.04% of the population globally, but higher rates have been found in low and middle-income countries (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). People with ID are prone to stigmatisation and are among the most excluded populations in society (Ditchman et al., 2013). This stigma affects the functioning and well-being of people with ID and limits their opportunities to be included in society (Werner & Scior, 2016). Stigma is defined as the process of the devaluation of an individual or a group based on particular attributes that distinguish them from others (Goffman, 1968). Furthermore, stigma is associated with limited employment opportunities as well as access to housing and healthcare (Ditchman et al., 2013).

Initiatives to reduce the stigmatisation of people with disabilities have been implemented globally, following the United Nation (UN) Convention on the Rights of Person with Disabilities (CRPD) (Scior et al., 2015); however, people with ID continue to be under-represented in society, including in the disability rights movement (Scior et al., 2016). An international study exploring stigma towards people with ID and the initiatives taken to tackle this stigma noted that pejorative terminology, stigmatising beliefs, and exclusion of people with ID is evident in many parts of the world, including Asia; therefore, there is a critical need to increase awareness of ID and tackle the stigma related to it (Scior et al., 2015).

Indonesia ratified the CRPD in November, 2011 (United Nations, 2018), following which the Indonesian government established a new national disability law – the Law No. 8 Year 2016 – to deliver the aims of CRPD (Indonesia Disability Convention Team, 2017). Since then, efforts to improve the situation of people with disabilities have been made at several levels, including the local governments' efforts across Indonesia (International Labour Organization, 2017). However, the government's efforts to promote the inclusion of people with disabilities has faced challenges. Despite the national law and CRPD, people with disabilities in Indonesia continue to face barriers with regard to attaining equal status and access to services such as healthcare, education, and employment (Australia Indonesia Partnership for Economic Governance, 2017; Irwanto, 2010). There are several reasons for barriers to inclusion, the primary reason being the prevalence of stigma towards people with disabilities in society. In some contexts, such as education, people with ID are subjected to discrimination even when compared to people with other disabilities (Hadis, 2005).

Discrimination against people with ID is reportedly prevalent in the Indonesian society, as cases of institutionalisation by families – hiding family members with ID to avoid shame – are common (Komardjaja, 2005). Hadis (2005) reports that schools do not admit students with ID into inclusive classrooms, leaving them with the sole option of special schools for education. Such incidents are alarming; therefore, efforts to reduce stigma against ID are urgently required. Unfortunately, information and evidence related to stigma towards people with ID in the Indonesian context are scarce.

A systematic review conducted as part of this PhD project found five studies carried out in Indonesia that provide relevant information, such as parental attitudes towards the independence of children with ID (Anisa & Muliasari, 2018), attitudes regarding the sexuality of people with ID (Winarni, Hardian, Suharta, & Ediati, 2018), placements in special institutions (Komardjaja, 2005), and caring experience (Endriyani & Yunike, 2017; Erawati & Keliat, 2018); However, none of them specifically explore the stigma against people with ID. Further studies are required to inform the key stakeholders – the government and policy makers – about the need to increase awareness about, reduce stigma towards, and endorse the inclusion of people with ID in the Indonesian society.

1.2 Project aims and objectives

This PhD project was funded by the Indonesian Endowment Fund for Education (*Lembaga Pengelola Dana Pendidikan*), an education-funding body run by the Indonesian government. It aims to explore the stigma against people with ID and their inclusion prevalent in the Indonesian society. The findings of this project will be reported to the corresponding authorities in Indonesia, namely the Ministry of Social Affairs and the Ministry of Health. The findings of this project are expected to fuel the public policies related to people with ID in Indonesia. The project design comprises a systematic review and three empirical studies carried out through a multimethod research framework. The aims and objectives of the studies are outlined in the next section.

1.2.1 Systematic review: The stigma towards people with intellectual disability in Southeast Asia

The aim of the review is to carry out a systematic evaluation of the studies pertaining to stigma towards people with ID in Southeast Asia. The following questions will be addressed in the review:

- Is stigma towards people with ID present in Southeast Asian countries? If yes, how is it manifested in the society?
- Do cultural factors affect the stigma towards people with ID? If yes, which factor(s) affect this stigma? How do they influence the expression of stigma towards people with ID?

1.2.2 Qualitative exploration of professionals' attitudes towards people with intellectual disability and their inclusion in the Indonesian society

The aim of this study was to obtain insight into the stigma towards people with ID in the Indonesian context. In order to accomplish this, five groups of professionals were recruited into the study – teachers (mainstream, special education), doctors, psychologists, and religious leaders. These professionals were chosen as the focus group due to their authority over the management of people with ID, including making decisions in place of people with ID in certain services such as inclusive education.

In this study, religious leaders were considered as professionals due to their authority over the management of people with ID; such authority is offered to religious leaders due to the importance of religion in the Indonesian society. Religious leaders are often sought for advice regarding treatment, and religion-based institutions providing services to people with ID are commonly found in Indonesia.

The questions addressed through this study are as follows:

- What attitudes are held by professionals towards people with ID in the urban context of Indonesia?
- What are their attitudes towards the inclusion of people with ID into the Indonesia society?

1.2.3 Adaptation of a self-report stigma questionnaire and exploration of stigma experience in adults with mild to moderate intellectual disability in Indonesian context

The aim of this study was to adapt a self-report stigma questionnaire designed and developed for people with mild to moderate ID in the UK to the Indonesian context. The process includes translating the questionnaire's items into the Indonesian language and changing the pictures accompanying each item to those appropriate to the Indonesian context. Psychometric properties – reliability and common underlying factors – were examined. Additionally, the stigma scores and participants' responses on the items in the final questionnaire were examined to explore the relationship between the experience of stigma and socio-demographic characteristics. The questions addressed in this study are as follows:

- What is the test–retest and internal reliability of the Indonesian version of the self-report stigma questionnaire?
- What is/are the common underlying factor(s) of the Indonesian version of the self-report experience stigma questionnaire?
- What is the average of the stigma score among adults with mild to moderate ID in Indonesia? Are socio-demographic characteristics related to the experience of stigma?

1.2.4 Qualitative exploration of stigma and inclusion of adults with mild to moderate intellectual disability in Indonesian context

The study aims to explore the experience of stigma in adults with mild to moderate ID and the extent of their inclusion in the Indonesian society. Fifteen participants were purposively selected from the participants included in the questionnaire adaptation study and were interviewed. The following questions were addressed in this study:

- Do adults with mild to moderate ID living in the Indonesian society experience stigma? If yes, what is the nature of their experience?
- To what extent are adults with mild to moderate ID included in the Indonesian society?

1.2.5 The integration of quantitative and qualitative components

This study aims to integrate the qualitative and quantitative data obtained through the three aforementioned empirical studies. Two data integration approaches – 'following a thread' and 'mixed method matrix' – were used to identify patterns and contrasts across the data. The following questions were further explored:

- What is the experience of stigma among adults with mild to moderate ID living in an Indonesian society?
- To what extent are they (adults with mild to moderate ID) included in the society?
- What is the relationship between socio-demographic characteristics and the experience of stigma among the participants (adults with mild to moderate ID)?

Chapter 2 Overview of principal concepts

2.1 Intellectual disability

2.1.1 Terminology

Intellectual disability (ID) is the currently preferred term that refers to a condition previously known as mental retardation (Schalock et al., 2007). The terms referring to ID have changed over the last few decades, as these terms became pejorative and stigmatising labels (for instance, mental handicap, feeble-mindedness, and mental deficiency) (Bhaumik et al., 2016; Schalock et al., 2007). Other than ID, various locally agreed-upon terms are also in use in different parts of the world. For instance, the term 'learning disability' is widely used in the UK to refer to ID, which can often be confused with specific learning disorders such as dyslexia (Bhaumik et al., 2016).

In light of the Convention on the Rights of Persons with Disabilities (CRPD), which specifies ID as a form of disability, the term ID has been increasingly used over other synonymous terms (Bhaumik et al., 2016). In Indonesia, for instance, the term *disabilitas intelektual* – a direct translation of intellectual disability in the Indonesian language – was officially endorsed following the ratification of the new national disability law, the Law No. 8 Year 2016, derived from the CRPD, which was ratified in 2011. Changes were then made in the nomenclatures of governmental institutions providing services to people with ID in Indonesia. Schalock et al. (2007) explained that the term intellectual disability is preferred due to its compatibility with the general conceptualisation of disability. The term highlights the ecological perspective of disability and highlights that providing support could help the functioning of people with this disability (Schalock et al., 2007)

2.1.2 Definition and diagnostic criteria

ID is characterised by the impairment of cognitive functioning that affects and limits adaptive functioning, and its onset occurs prior to the age of 18 years (American

Association on Intellectual and Developmental Disabilites, 2018). Adaptive functioning is described as the ability to perform daily activities and includes three main skills: (1) conceptualisation (for instance, using language, reading, writing, and computing as well as memory, reasoning, and general knowledge); (2) socialisation (for instance, empathy, social judgment, and interpersonal communication); (3) everyday practical skills (for instance, managing money, securing employment, personal hygiene, and fulfilling their role in school or work). A cross-cultural meta-analysis conducted by Maulik et al. (2011) suggests that ID affects approximately 1% of the global population.

2.1.3 Clinical assessment and level of severity

The American Psychiatric Association (2013) suggests that the diagnosis of ID requires both clinical assessment as well as standardised testing of intelligence. It also prescribes that the level of severity should be based on the assessment of adaptive functioning and intelligence using standardised measures. Intellectual impairment is determined when the individual's intelligence quotient (Abdi & Valentin) is approximately two standard deviations or more below that of the population, which means an IQ score of 70 or less (American Psychiatric Association, 2013; World Health Organization, 2016).

American Psychiatric Association (2013) divides the severity level of ID into four categories – mild, moderate, severe, and profound – and defines them based on the individual's adaptive functioning that is divided into three domains – conceptual, social, and practical domains. American Psychiatric Association (2013) emphasises that the severity level of ID should be determined on the basis of adaptive functioning instead of IQ, as IQ scores do not indicate the level of support required by the person with ID. Moreover, IQ measures have lower validity when used to measure the population at the lower end of the IQ range. Regardless, set ranges of IQ scores are still frequently used to help determine the level of severity. The following is the classification of ID based on IQ score ranges as stated in the ICD-10: 50–69 (mild), 35–49 (moderate), 20–34 (severe), and under 20 (profound). Due to the varying range of severity levels among people with ID, it is essential to keep in mind that ID terminology represents individuals with a diverse level of functioning and abilities (Bhaumik et al., 2016).

2.2 Stigma

2.2.1 Conceptualisation

The term stigma originated from the ancient Greek word reflecting a mark of shame or degradation (Hinshaw, 2009). The term was then re-conceptualised by Goffman (1968) in his seminal work, wherein stigma was defined as a profoundly discrediting attribute that reduces the worth of the individual bearing the attribute, and that defines the relationship between an attribute and a stereotype. Drawing from Goffman's works, the development of stigma models flourished (Stuart, 2008). Two prominent stigma models, proposed by Link and Phelan (2001) and Corrigan and Watson (2002), are described in the following paragraphs.

Link and Phelan (2001) conceptualised stigma by dividing the term into key components and explaining the relationship between these elements – labelling, stereotyping, separation, status loss, and discrimination. Drawing from previous work (Link & Phelan, 2001), the component of emotional responses was later added to the conceptualisation (Link, Yang, Phelan, & Collins, 2004). The stigma process, according to this conceptualisation, follows a pattern: first, a particular characteristic of a person is distinguished and used to label the person as different (labelling). Subsequently, the labelled difference is associated with negative attributes perceived by the cultural beliefs prevalent in the society (stereotyping). The distinguishing characteristic is then used to distinguish the person from the others (separation). Fourth are the emotional responses associated with the processes of stereotyping and separation, such as anger, pity, or fear (emotional reaction). The fifth component describes the loss of status and discrimination as a consequence of the previous components of the process. The last component emphasises on the presence of a power (i.e. social, economic, and political) as well as the relationship between the stigmatised and the stigmatising parties that make stigma possible.

Corrigan and Watson (2002) provide another framework of stigma that comprises three components – stereotypes, prejudice, and discrimination. A stereotype is a knowledge structure that is learned and agreed upon by most members of a social group that generates impressions and expectations of the people who belong to a stereotyped group. However, being aware of a set of negative stereotypes regarding a group does not mean that the person agrees with them.

On the other hand, people having prejudice agree with and endorse negative stereotypes. A prejudice is described as a cognitive and affective response that leads to discrimination, the behavioural component of stigma. For instance, a stereotype of 'dangerousness' would generate the emotional response of fear, which then causes the person affirming the stereotype to avoid the stereotyped person (discrimination) (Corrigan & Watson, 2002)

Corrigan and Watson (2002) further divided stigma into two categories – public stigma and self-stigma. Public stigma refers to the reaction of the general society towards the people being stigmatised, while self-stigma refers to their perspective as they apply the stigma components (stereotype, prejudice, and discrimination) to themselves.

2.2.2 Stigma towards people with intellectual disability

The field of ID currently lacks a systematic conceptualisation of stigma despite the fact that people with ID are among the most excluded and marginalised populations in the society (Ditchman et al., 2013). Although few studies have explicitly explored the stigma of ID, Ditchman et al. (2013) draw information regarding the stigma related to ID from the available references, including those exploring attitudes towards the ID population. The studies suggest that attitudes towards people with ID are negative, and the following characteristics are frequently associated with them: dependent, childlike, vulnerable, and pitiable. This frequently leads to emotional reactions such as pity, discomfort, and fear (Ditchman et al., 2013).

However, the characteristics associated with people with ID are not always negative. For instance, people with Down's Syndrome are often regarded as 'warm' (Fiske, 2012). The nature of the disability influences the stigma of people with ID (Avramidis & Norwich, 2002). They are more prone to be stigmatised due to their lifelong condition (permanently disabled) (Ditchman et al., 2013). On the other hand, people with ID tend to receive a more positive affective response, because the disability is perceived as a given and out of the control of the person (Ditchman et al., 2013).

The efforts to explore and understand stigma are further complicated by the diversity of the level of functioning across different severity levels (mild, moderate, severe, and profound) (Ditchman et al., 2013). People with profound ID have significant limitations in their functioning, such as communication and mobility, which creates an overwhelming barrier (Ditchman et al., 2013). Furthermore, people with profound ID are unable to hide their disability, adding a characteristic of being 'visible', which may not be experienced by people with milder forms of ID (Ditchman et al., 2013). Due to their cognitive difficulties, people with ID are often thought to be unaware of the stigma directed at them. However, studies have suggest the contrary – people with ID are aware of the stigma related to their disability and face the consequences of the same in their day-to-day lives (A. Ali, Strydom, Hassiotis, Williams, & King, 2008; Jahoda & Markova, 2004).

2.3 Social inclusion

2.3.1 Conceptualisation

Social inclusion is an important concept in the field of disability, as it is considered as a logical strategy to battle stigma in society (R. Carter, Satcher, & Coelho, 2013).

Therefore, it is deemed as an important factor in improving the well-being of people with ID (Buntinx & Schalock, 2010). Despite its importance, the concept of social inclusion has always lacked clarity, which makes it interchangeable with other synonymous concepts, such as community participation, social integration, and social network (Simplican, Leader, Kosciulek, & Leahy, 2015). The absence of a generally accepted definition for social inclusion has been noted as one of the challenges of social inclusion initiatives (Hayes, Gray, & Edwards, 2008).

Atkinson (1998) proposed three main elements in conceptualisation of social inclusion and exclusion, namely: (1) social exclusion is relative to norms and expectation prevalent in society at a particular time frame; (2) social exclusion is a result of an individual act, group or institution—that one can decide to exclude him/herself, or the decision of exclusion was made by others; (3) the consequences of social inclusion are not limited to one's current situation, but also to his/her future (for instance, reduced opportunity of future housing or employment).

Drawing from previous works, Hayes et al. (2008) added important points on the conceptualisation of social inclusion/exclusion: (1) that manifestation of social exclusion is not limited to individual level, and therefore, may also be manifested at a community level; (2) Social exclusion is multidimensional, containing mixtures of interrelated variables; and (3) Social exclusion should be seen as a process rather than a result, and exploring the cause of social exclusion of certain individual or group in the community is paramount.

Simplican et al. (2015) offer a model of social inclusion that focuses people with intellectual and developmental disabilities. The model explains social inclusion on two domains – interpersonal relationship and community participation – that capture the structural and functional components of social inclusion. In this model, Simplican et al. (2015) explain that the domain of interpersonal relationship contains three characteristics

– category, structure, and function. Category refers to a group of people in the social network, such as family, staff, and friends.

The structure of an interpersonal relationship includes the length, origin (who initiates the contact), frequency, and location (for instance, home, school, or community) (Simplican et al., 2015). Additional factors considered with regard to structural characteristics are reciprocity, intensity, formality, and complexity (Simplican et al., 2015). Reciprocity refers to the level of mutual support and resources, while intensity refers to the level of emotional closeness. Formality refers to the institutional source of relationship, and complexity can be defined as the number of functions the relationship serves. Simplican et al. (2015) further explain that an interpersonal relationship can be measured along four characteristics – size, homogeneity, geographic dispersion, and density. Homogeneity refers to the similarity of demographic characteristics among network members, such as age, race, and disability status. Geographic dispersion refers to the members' location, while density refers to the degree to which the network members know about each other and interact.

Simplican et al. (2015) describe that interpersonal relationship function can be divided into three groups, namely emotional, instrumental, and informational. A relationship can provide emotional support, which includes love, care, and trust. Instrumental support includes more perceptible aid and services than those of emotional support, while informational support comprises advice, suggestion, and information.

Simplican et al. (2015) divide the domain of community participation into three characteristics – category, structure, and degree of involvement. Community activities were categorised as leisure activities (for instance, sport and art), political and civic activities (for instance, participation in election and community gathering), productive activities (for instance, employment and education), consumption (for instance, access to goods and services), and religious and cultural activities (for instance attendance at religious congregation or wedding ceremony).

Simplican et al. (2015) further classified community participation in three categories: segregated, semi-segregated, and integrated settings. Segregated activities involve people with ID and paid staff, and they take place in segregated facilities such as sheltered workshops and special schools. Activities involving an individual with ID and their immediate family members are also considered as segregated activities.

The activities categorised as semi-segregated are divided into three forms. The first forms involve people with ID and paid staff and/or family taking place in community settings, such as restaurants, arts programs, or theatre groups. The second form of activities involve community members but take place in segregated facilities such as facilitated activity groups manage by volunteers. The third form involves the cyber community. Although Simplican et al. (2015) did not explain this form further due to a limited number of study regarding this area; however, it can be assumed to refer to social interaction in online groups, which includes varying degrees of anonymity and affective attachment (Jensen, Danziger, & Venkatesh, 2007). Lastly, the integrated setting is defined as the mainstream setting of the community.

In terms of different degrees of involvement, Simplican et al. (2015) conceptualised community participation through the aspects of presence, encounter, and participation. Community presence refers to physically being in the community with little to no contact with other people. Encounters refer to meetings between strangers in a community setting that can either be fleeting or sustained, such as interaction with cashiers at a shop or fellow passengers on public transportation. Participation refers to involvement in the community activities that endorse the development of interpersonal relationships. According to the structural category of community participation as mentioned above, participation is further classified as segregated, semi-segregated, and community participation.

Simplican et al. (2015) explains that interpersonal relationships and community participation constitute the main components of social inclusion. The two domains are inseparable and interact with each other. The improvement of a person's social network and interpersonal relationships would increase their level of involvement in the community. Overlaps across domains are to be expected, as the members in social networks are sometimes of the same people.

2.3.2 Social inclusion and intellectual disability

Drawing from previous works, Simplican et al. (2015) provide an elaborate discussion on the social inclusion of people with ID, which will be summarised in this section. People with ID are excluded from society and are known to have limited social lives, since they spend most of their time with family or in the institutions that provide care to them. People with mild to moderate ID prefer to have close friendships with people with disabilities compared to non-disabled peers (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Those with a more severe condition of ID are limited to having relationships only with the family members and staff who provide care to them (Whitehouse, Chamberlain, & O'Brien, 2001)

Endorsing the social inclusion of people with ID would benefit not only them but also the wider society (Simplican et al., 2015). At the individual level, social inclusion has been linked with increased happiness, confidence, self-esteem, mental health condition (Forrester-Jones et al., 2006), opportunities for choice-making, acquisition of adaptive skills and quality of life (Young, 2006); at the societal level, it has been associated with the improvement of attitudes and decrease of stigma (Johnson, Douglas, Bigby, & Iacono, 2009; Power, 2013), and therefore help to overcome social exclusion (McConkey & Collins, 2010).

Initiatives to increase the social inclusion of people with ID have been taken around the globe, stemming from the ratification of the CRPD (Scior et al., 2015), as social inclusion is perceived as one of the focal points of the CRPD (Lord, Suozzi, & Taylor, 2010). Despite the importance of social inclusion and the initiatives taken to endorse it, various factors have hindered the inclusion of people with ID in society, such as negative attitudes towards people with ID, the experience of stigma and discrimination, and restrictions imposed by families (Simplican et al., 2015). However, some studies also noted that social inclusion may induce negative outcomes for people with ID. For instance, broadening the interpersonal relationships of people with ID may lead to negative outcomes such as discrimination in workplace (Hall & Wilton, 2011), abuse (Beadle-Brown, Mansell, Cambridge, Milne, & Whelton, 2010; Ward & Atkinson, 2013) or emergence of negative feelings such as loneliness (Hall, 2005).

Considering the benefits and negative outcomes of social inclusion as well as the barriers in attaining it, the efforts to endorse the social inclusion of people with ID must be made in a careful manner. Most importantly, any effort should be made not only for but also by people with ID who seek such opportunities, as they perceive citizenship as vital (Abbott & Mcconkey, 2006)

2.4 Indonesia

2.4.1 Demographic profile

Indonesia is an archipelagic country consisting of approximately 15,000 islands (BBC Indonesia, 2017) that spans across the equator. Indonesia's main islands (and groups of islands) are divided into seven areas: Java (Jawa), Borneo (Kalimantan), Celebes (Sulawesi), the Lesser Sunda Islands (Bali and Nusa Tenggara), the Moluccas (Maluku), and the western area of New Guinea (Papua) (Encyclopaedia Britannica, 2018a). Indonesia is known as the largest and most populous country in Southeast Asia (Encyclopaedia Britannica, 2018a), and the fourth most populated country in the world (United States Census Bureau, 2018). It is home to an estimated 255 million people (Indonesia Statistics, 2016) comprising over 600 ethnic groups (Arifin, Ananta, Wilujeng Wahyu Utami, Budi Handayani, & Pramono).

Indonesia's ethnic diversity has resulted in the prevalence of over 300 languages spoken across the Indonesian archipelago. The following examples provide a glimpse of the linguistic diversity in Indonesia. Three languages – Javanese, Sundanese, and Madurese – are spoken on Java, while dozens of languages can be found on Sumatra, some further divided into distinct dialects (Encyclopaedia Britannica, 2018a). Another example that can be considered is that of the Torajan people, a relatively small ethnic group that resides on the Celebes Island, who speak several languages among themselves (Encyclopaedia Britannica, 2018a). Despite the linguistic diversity found in Indonesia, most Indonesians use and recognise Indonesian (Bahasa Indonesia) as the national language. In urban areas, Indonesian people speak Indonesian as their first language and retain their ethnic language for domestic use. On the other hand, people living in rural areas predominantly speak Indonesian as their second language, and it is only used during formal occasions.

Diversity can also be found in Indonesian religious life. Although the Indonesian population is predominantly Muslim, most major religions of the world – Christianity, Hinduism, and Buddhism – can be found in Indonesia. Religion is essential for Indonesians, as it is systematically endorsed by the nation. The importance of religion is manifested in the country's national principles, as 'belief in one's God' is the first national principle (Budiyono, 2014). Therefore, Indonesians are endorsed to affiliate themselves with one of the 'state approved' religions – Islam, Protestantism, Catholicism, Hinduism, Buddhism, and Confucianism (Jones, 2005; Woodward, 2011) – or to indigenous faiths that revolve around traditional animism and dynamism.

2.4.2 Disability in Indonesia

There is no accurate data on the prevalence of people with disability in Indonesia due to a poor record of its demographic databases and the changing definition of disability that was used between censuses (Australia Indonesia Partnership for Economic Governance, 2017; Irwanto, 2010). However, based on the information available currently, it can be determined that 4–11% of the population is affected by disabilities (Australia Indonesia Partnership for Economic Governance, 2017). If the lowest approximation of 4% is applied to the Indonesian population, approximately 10 million people in Indonesia can be found to be affected by some form of disability. Disability affects not only the individual with disabilities but also their families and caregivers. In the Indonesian context, women – who are typically assigned the role of caregivers for family members with disabilities – participate less in the labour market. It has also been noted that households with a member with severe disabilities are at higher risk of poverty, making disability an issue that affects numerous people in Indonesia (Australia Indonesia Partnership for Economic Governance, 2017).

Indonesia recently ratified a new disability law called Law No. 8 Year 2016. This law was derived from the CRPD, which was ratified by Indonesia in 2011. The ratification of the new law reflects the commitment of the Indonesian government to ensure the rights of people with disabilities and eradicate stigma and discrimination against them (Australia Indonesia Partnership for Economic Governance, 2017). Despite this, people with disabilities in Indonesia continue to face challenges hindering their inclusion in society. It has been reported that people with disabilities are less represented in the national education systems, experience worse health conditions, and have fewer opportunities to access employment and public services and to exercise their political rights (Australia Indonesia Partnership for Economic Governance, 2017).

Efforts to provide support to people with disabilities in Indonesia have been hampered by multiple challenges, including the scarcity of professional resources and service provision as well as the paucity of information regarding people with disabilities. A World Health Organization (2014) report found that merely 0.29 psychiatrists and 0.18 psychologists are available per 100,000 people, which was further echoed by Diono (2014), who reported that out of 101 people with disabilities, only one has access to disability-related services. Challenges regarding service provision and the availability of mental health professionals in Indonesia are further complicated by the fact that it is an archipelagic country. Professionals and service providers are centralised in the urban areas of the main islands (primarily Java), leaving minimal or no services for people with disabilities in rural areas and more remote Islands. The paucity of information regarding people with disabilities has also been found to hamper the formulation of public policies, especially in terms of the prevalence of disabilities (Irwanto, 2010), the specific barriers towards the inclusion of people with disabilities, and strategies to tackle them (Australia Indonesia Partnership for Economic Governance, 2017).

2.4.3 Intellectual disability in Indonesia

People with ID in Indonesia are addressed by various terms, such as *tunagrahita*, which means a deficiency in thinking, *retardasi mental*, a direct translation of mental retardation, and *cacat mental*, derived from the term 'mental handicap'. Similar to the general field of disabilities, information regarding people with ID is scarce. There is no accurate information regarding the number of people with ID in Indonesia currently, as the information from national surveys and census does not portray the prevalence of intellectual and developmental disabilities (Irwanto, 2010).

Stigma towards people with ID is prevalent in the Indonesian society. A study by Komardjaja (2005) explored the placement of people with ID in the setting of Bandung, a city in the west Java province and found ongoing institutionalisation of people with ID. Furthermore, the study suggests that some families may prefer institutionalisation to hide their family members with ID and avoid the shame associated with having such a relative or family member.

As mentioned in the previous section, people with disabilities face stigma in their daily life. However, people with ID tend to be more stigmatised than people with other disabilities (Scior & Werner, 2015). In the Indonesian context, Hadis (2005) suggests that people with ID are more likely to be excluded from inclusive education settings due to the impairment of cognitive functioning. Similar findings have been reported in other countries in various areas (Australia Indonesia Partnership for Economic Governance, 2017). For instance, in terms of access to employment, people with ID are less preferred than people with other forms of disabilities, such as hearing impairment.

Chapter 3 Systematic review: The stigma towards people with intellectual disability in Southeast Asia

3.1 Introduction

The conceptualisation of stigma points out that cultural beliefs heavily influence stigma (Link & Phelan, 2001). This is borne out in an international study exploring how religion and traditional beliefs influence disability-related stigma, and that the finding has been consistent across diverse cultural contexts (Berry & Dalal, 1996).

As explained in the previous section, Indonesia is a country known for its cultural diversity with around 600 ethnic groups living in the country (Arifin et al., 2015) and more than 300 languages are spoken across its archipelago (Encyclopaedia Britannica, 2018a). Therefore, it is essential to review the cultural factors in order to explore the stigma of intellectual disability (ID) in the Indonesian context. In a broader sense, the stigma towards people with ID occurs across cultures (A. Ali, Hassiotis, Strydom, & King, 2012; Mitter, Ali, & Scior, 2019; Scior, 2011) but the knowledge regarding it is limited; which occurs not only in Indonesia but also across its neighbouring countries in Southeast Asia (Matson, Matson, Lott, & Logan, 2002). Therefore, the systematic review should include a broader geographical context of published research. Any information gleaned by broadening the scope of the review is likely to identify gaps and show similarities and differences within the Southeast Asian countries.

Southeast Asia

Southeast Asia consists of two main regions: the mainland and the archipelago, which consists of eleven countries i.e. Brunei Darussalam, Cambodia, Indonesia, Lao People Democratic Republic (PDR), Malaysia, Myanmar, Philippines, Singapore, Thailand, Timor-Leste and Vietnam (Encyclopaedia Britannica, 2018b). Most Southeast Asian countries are of a lower middle-income (World Bank, 2018) and approximately 648 million people live in the region (United Nations, 2017).

The Southeast Asian region is well-known for its social and cultural diversities, as an enormous variety of ethnic groups and distinct languages are present in the region (Encyclopaedia Britannica, 2018b; Knight & Heazle, 2011). The diversity in ethnicity and language are especially noticeable in some parts of the region, such as the Philippines and Indonesia (Knight & Heazle, 2011). As part of its diversity, the world's largest religions, such as Christianity, Islam, Buddhism, and Hinduism are present and practised in Southeast Asia. Buddhism is predominant in most of the mainland countries, such as the Vietnam, Cambodia, Lao, Thailand and Myanmar, while Islam is predominant in Malaysia, Indonesia and the southern Philippines (Knight & Heazle, 2011). Christianity, in particular Catholicism, is practised in most parts of the Philippines and southern Vietnam, while Protestantism is predominantly practised by the Batak people, an ethnic group that lives in a part of Sumatra Island in Indonesia (Encyclopaedia Britannica, 2018b). A locally predominant religion is also found in one of the Indonesian island, Bali, as its people primarily follow Hinduism (Encyclopaedia Britannica, 2018b). Other than the religions mentioned earlier, animism is practised in some parts of Southeast Asia, particularly in more remote areas, such as the central Borneo, northern Lao and northern Myanmar (Encyclopaedia Britannica, 2018b)

Despite its diversity, Southeast Asia shares common notions in some of their cultural aspects, such as gender, structure of the family and social hierarchy (Encyclopaedia Britannica, 2018b). The countries in the Southeast Asia region share a similar geographical profile, predominantly consisting of rural areas where three-fourths of the population reside in an agricultural oriented society (Knight & Heazle, 2011).

Aims

This systematic review aims to investigate the stigma towards people with ID in the Southeast Asian context and to identify cultural factors which may influence the process of stigmatisation. The findings obtained from the review are expected to report an overview of how the stigma of ID manifests in cultural contexts similar to Indonesia. The following questions were addressed in this systematic review:

- Is stigma towards people with ID present in Southeast Asian countries? If yes, how is it manifested in society?
- Do cultural factors affect the stigma towards people with ID? If yes, which factor(s) affect this stigma? How do they influence the expression of stigma towards people with ID?

3.2 Methods

3.2.1 Search strategies

Two main search strategies were carried out to retrieve relevant references in this review. The first strategy involves searches of five academic databases i.e. PsychINFO, MEDLINE, ERIC, CINAHL, and Web of Science. The searches were not limited by any means (i.e. language, publication time) to ensure an extensive range of coverage of the relevant references. The academic database search was conducted in September 2018 using a keywords list (see Appendix 1), which was derived from two main keywords ‘intellectual disability’ and ‘stigma’ and their truncations. The main keywords were further elaborated to include five key concepts to analyse stigma i.e. ‘belief’, ‘attitude’, ‘stereotype’, ‘prejudice’, and ‘discrimination’ (Link et al., 2004; Rüsch, Angermeyer, & Corrigan, 2005) and alternative terms of intellectual disability (e.g. mental retardation, learning disabilities, mental handicap). The keywords were then combined with the relevant terms referring to the Southeast Asian countries or nationality (e.g. Malaysia, Malay, Thailand, and Thai) to further specify the references generated from the search.

The second strategy comprises the use of Google Scholar® to find relevant grey literature and academic articles not indexed in the five academic databases. Grey literature was sought in this review considering that published academic articles regarding ID in Southeast Asia is scarce (Matson et al., 2002). Google Scholar® is considered a reliable method to search grey literature and to be used as a complementary strategy in a literature review (Haddaway, Collins, Coughlin, & Kirk, 2015). The Google Scholar® search was conducted in August 2018 utilising its ‘advance search’ field, alternatively entering the keywords ‘intellectual disability’ and ‘mental retardation’ in the ‘with exact phrase’ field, combined with ‘stigma’, ‘belief’, ‘attitude’, ‘prejudice’, ‘stereotype’, and ‘discrimination’ in the ‘with at least one of the words’ field, followed by alternatively entering the Southeast Asian countries’ name in the ‘with all of the words’ field. The keywords combination’ generated 22 independent search results. Following the suggestion of Haddaway et al. (2015), the first 200 references in each search were retrieved to optimise the probability of finding relevant grey literature.

A manual search of 23 selected journals was carried out to complement the search strategies. The journals were nominated and selected by the student and another reviewer (AL) by utilising the Scimago Journal and Country Rank website (www.scimagojr.com). The journal was selected based on two criteria: (1) Covering ID topics and (2) Originated from a Southeast Asia country covering relevant fields (i.e. medicine, nursing, psychology, and public health). Journals covering broad topics were selected due to the absence of specific journals covering ID originating from the Southeast Asian countries. The following keywords: intellectual disabilities, mental retardation, and the name of the country were typed in the ‘search’ field available on the website. The final list of selected journals (see Appendix 2) was confirmed after ensuring access to the publication archive and full-text. The manual search of the 23 selected journals was carried out by a second reviewer (AL); the search result was then reviewed by the student. Lastly, the reference list of the included studies was examined to identify relevant articles not included in the previous search strategies.

3.2.2 Inclusion criteria

The inclusion criteria were designed to best address the review questions and therefore, they were designed to be inclusive to allow a broad range of studies. A study is included if it explicitly mentioned stigma, or at least one of its related concepts (i.e. belief, attitude, stereotype, prejudice, and discrimination), specifically related to people with ID and was undertaken within a country identified as part of the Southeast Asia region. Studies exploring stigma towards people with general disabilities, without findings specific to people with ID were excluded. Studies conducted outside of the Southeast Asian countries, including those which involved people originated from the Southeast Asian countries or their descendants were also excluded.

After removing the duplicates, the student and another reviewer (AL) independently screened the combined references retrieved from all the search strategies (i.e. academic database, Google Scholar® search and manual search of selected journals). The screening of references included three phases: title screening, abstract screening, and full-text screening. Excluded references were tagged as ‘not Southeast Asia origin’, ‘not covering ID’, ‘not exploring stigma’ and ‘not an empirical study’. Discrepancies in the screening results were discussed between the two reviewers. One relevant study (Moreira, 2011) which was identified by the student in a previous attempt of a systematic review did not appear during the searches; therefore, the study was included at the end of the search process. Figure 3-1 describes the search strategies and the inclusion of references carried out in this systematic review.

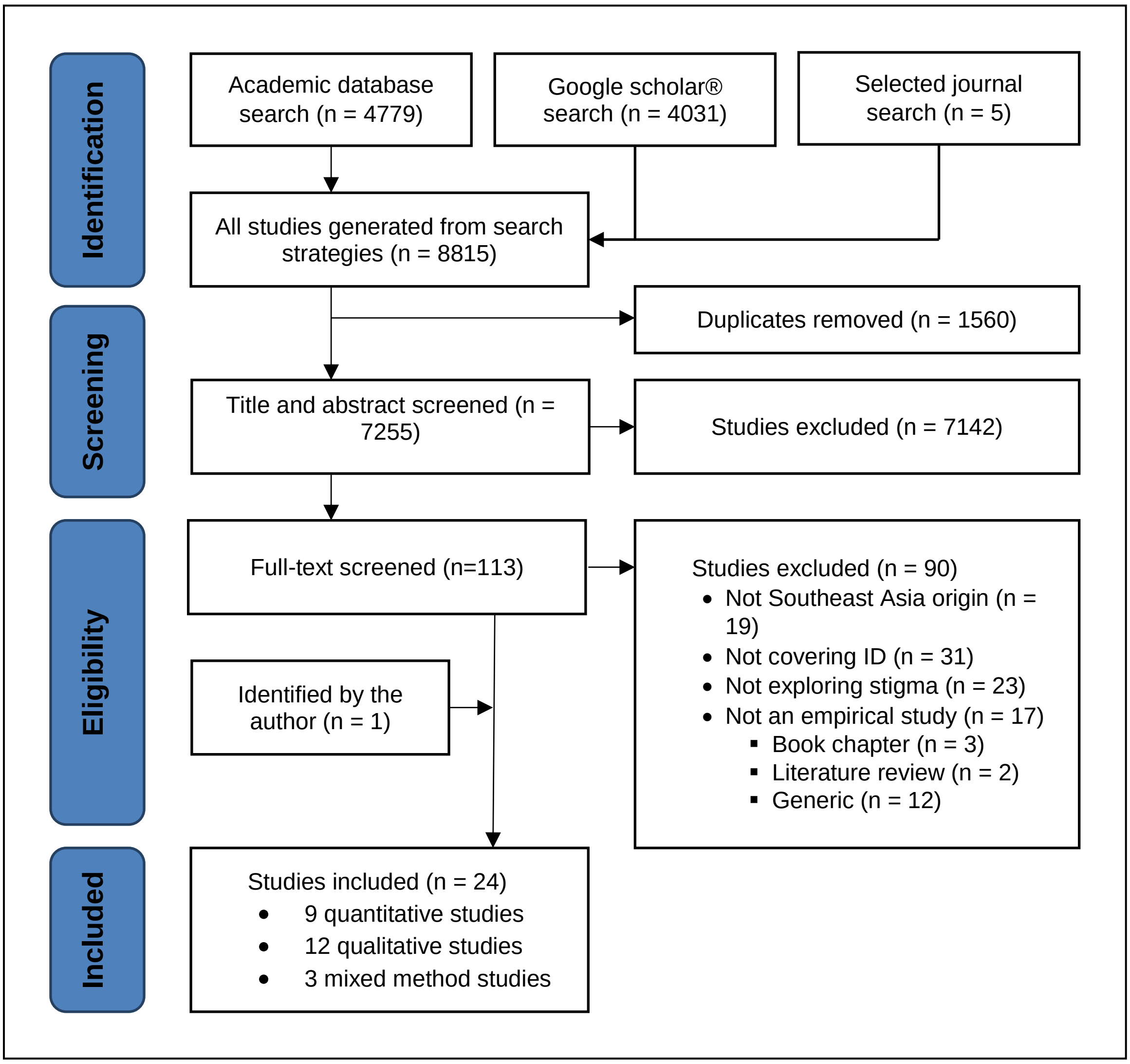

Figure 3-1 Search strategy and studies inclusion

3.2.3 Quality assessment

The included studies were assessed for quality using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). The MMAT was used in this review because of its versatility to appraise studies of various methodologies covering quantitative, qualitative and mixed methods studies and its reliability of use in systematic reviews (Pace et al., 2012; Taylor & Hignett, 2014). The MMAT starts with two screening questions to ensure that the document to be appraised qualifies as an empirical study, as the tools cannot appraise non-empirical studies (Hong et al., 2018). Following the two screening questions, were the five ratings specific to each methodology. The studies were not excluded based on low-quality scores. Instead, the quality scores were reported and considered in the narrative synthesis. Therefore, each study was assigned a MMAT quality score, which ranged from 0 (low quality) to 5 (high quality). The MMAT scores of the included studies are presented in the information extraction table (see Table 1), while the quality assessment form of the included studies is provided in Appendix 3. The quality assessment was performed independently by the student and another reviewer (AL), and the differences between the two reviewers were settled through discussion. In cases where the difference between the two reviewers could not be settled through discussion, the scoring was made by one of the supervisors (AA).

3.2.4 Information extraction

An information extraction form was developed and utilised to record relevant information from each of the included studies. The information extraction form was reviewed and piloted by another researcher (VR) before its use. Data extraction was performed by the student and was reviewed by a second reviewer (AL) for credibility. The feedback from the second reviewer was then used to refine and finalise the data extraction. This process was performed parallelly to the data synthesis, which is explained in the next section (see section 1.2.5), by utilising the NVivo 11. Information regarding the authorship, publication year, country of origin, design of the study, participants, data collection instruments and method of data analysis were retrieved. The information was then copied from the NVivo 11 to the information extraction form (see table 1).

3.2.5 Data synthesis

A narrative synthesis was used as a framework of data synthesis in this review. Popay et al. (2006) described narrative synthesis as an approach of synthesising findings from multiple studies, which emphasise the use of words and text to summarise and explain the results of data synthesis. The narrative synthesis framework can be used in a systematic review, exploring a wide range of questions, such as this review, and it is not limited to reviews which explore the effectiveness of a particular intervention (Popay et al., 2006). This review included various studies with significant methodological variation, which precluded a meta-synthesis of findings and therefore, the narrative synthesis was chosen.

Popay et al. (2006) established four main elements of a narrative synthesis: (1) Developing a theory of how the intervention works, why and for whom (2) Developing a preliminary synthesis of findings of included studies (3) Exploring relationships in the data and (4) Assessing the robustness of the synthesis. The elements were developed for the synthesis of the findings of the studies, exploring the effects of interventions. Therefore, an adaptation of the elements of synthesis was needed to accommodate the current systematic review. The adaptation of the elements of narrative synthesis was exercised in the work of Leamy, Bird, Le Boutillier, Williams, and Slade (2011) which established three elements of narrative synthesis instead of four – excluding the first element i.e. ‘developing a theory of how the intervention works, why and for whom’, which focusses on the synthesis of the findings for intervention effectiveness – to make the framework more relevant to systematic reviews working with non-intervention studies. A similar approach was carried out in this review, which as follows:

3.2.5.1 Element 1: Developing a preliminary synthesis

The preliminary synthesis was established by extracting relevant information under the findings/results and discussion sections of the thirteen studies, which were selected based on the quality of appraisal results. The references included in the preliminary synthesis have all received a minimum total score of four ‘yes’ (out of five) to ensure the quality of the synthesis. Information was extracted from the references by utilising the NVivo 11, following a line by line coding performed by the student. Two pre-established overarching codes (the stigma of ID and cultural factors influencing ID) were used as a guide in the coding process. The pre-established overarching codes were needed to ensure that the synthesis of findings was relevant to the review questions. However, the coding process allows other codes to be established based on the tabulation of codes.

A coding structure (preliminary synthesis of findings) was established at the end of this process.

The second phase of the synthesis was carried out following the preliminary synthesis. References with a total score of less than four ‘yes’ in the quality appraisal were coded in the same fashion as in the preliminary synthesis. However, in the second phase, the coding structure established in the preliminary synthesis was used to guide and limit the coding process by not allowing new codes to be established. The information extracted from the lower quality studies was used to complement the already established coding structure. This two-stage approach was performed to establish a robust data synthesis, which is the focus of the third element of narrative synthesis.

3.2.5.2 Element 2: Exploring the relationship between and within studies

Information from the coding structure and information extraction form were combined in a spreadsheet document. The information was combined thematically by placing the findings regarding specific issues (e.g. attitudes, the experience of caring) side by side with relevant information, which may affect the findings (e.g. participants information, data collection instrument, research setting) to allow the similarities and differences between the studies to be examined. Furthermore, the information in the discussion section of each study was considered in this process to assess the different factors which may affect the findings.

3.2.5.3 Element 3: Assessing the robustness of the synthesis

The robustness of the synthesis was validated during the preliminary synthesis phase by performing an independent coding for the preliminary synthesis and including only good quality references (see section 3.2.5.1). The coding process for the preliminary synthesis was performed independently by the student and a second reviewer (AL). The differences between the coding structures were discussed between the reviewers to finalise the preliminary synthesis (coding structure).

3.3 Results

3.3.1 Overview of the included studies

Twenty four studies were included and reviewed. The studies originated from seven countries of the Southeast Asia: Cambodia (n = 3), Indonesia (n = 5), Lao (n = 2), Malaysia (n = 2), Philippine (n = 5), Singapore (n = 2), Thailand (n = 1), and Vietnam (n = 3). Most of the studies (n = 18) were published or became available after 2010, while the rest of the studies were published or became available before 2010 (n = 6). Among the included studies, one is a doctoral dissertation (Pooh, 2005), two are unpublished study reports (J. Carter, 2009; Moreira, 2011), while the rest of the study are published in peer-reviewed journals. Nineteen studies explored ID-related topics while five of them were looking at their topic of interest in the general disability population or included several types of disability. One study (Anisa & Muliasari, 2018) was written in the Indonesian language. Fortunately, the student is a native Indonesian and the second reviewer, who is a Malaysian national, is familiar with the language.

Twelve studies used qualitative methods, nine quantitative and three used mixed methods. Eight studies explicitly used the term ‘attitudes’ in their title, while differing in operationalisation and focus. For example, studies exploring attitudes among students majoring in dentistry and education operationalise attitudes as ‘level of comfort in treating a patient with ID’ (Ahmad, Razak, & Borromeo, 2015) and ‘preference of having students with ID in an inclusive education’ (Thaver & Lim, 2014). Pooh (2005) divides these attitudes into two categories, namely explicit and implicit attitudes. The two studies explore the relationship of attitudes with other variables, such as parents’ knowledge (Anisa & Muliasari, 2018), psychological problems (Shobana & Saravanan, 2014). They explore attitudes towards the sexuality of people with ID explicitly (Kamapalan & Li, 2009; Winarni et al., 2018), while one study focussed on evaluating a community intervention to change attitudes (Cordier, 2014).

Other studies provide information regarding the stigma associated with ID by exploring the challenges faced by the family's experience of care and the challenges they faced (Alcantara & Castronuevo, 2016; J. Carter, 2009; Endriyani & Yunike, 2017; Moreira, 2011; Persons, 2017; Thoresen, Fielding, Gillieatt, Blundell, & Nguyen, 2017), the folk concept of mental illness (Westermeyer, 1979), traditional treatment (Brolan et al., 2014), health condition of people with ID (Brolan, Gomez, Lennox, & Ware, 2015), restriction of family's social life (Ngo, Shin, Nhan, & Yang, 2012), parental stress (Shin, Nhan, Crittenden, Flory, & Ladinsky, 2006), nursing students experience (Erawati & Keliat, 2018), experience of inclusion among girls and young woman with disabilities (Nguyen, Mitchell, de Lange, & Fritsch, 2015), experience of sexual abuse among adolescents with ID (Terol, 2009), perception towards patients with ID (Sajith, Chiu, Wong, & Chiam, 2017) and placement of people with ID special institution (Komardjaja, 2005).

The included studies were diverse in terms of participants' background i.e. professionals, non–governmental organisation (NGO) staffs, students, parents, and neighbours, while some of the studies recruited more than one group of participants. People with ID were included as participants in five of the studies. One study specifically recruited people with ID as participants (Terol, 2009), while another study recruited them together with people of other disabilities (Nguyen et al., 2015). The remaining three studies included people with ID with non-disabled participants (J. Carter, 2009; Cordier, 2014; Nguyen et al., 2015; Terol, 2009; Thoresen et al., 2017). Four of the studies involve professionals working closely with people with ID, such as head of special institutions (Komardjaja, 2005), resident and non-resident medical doctor in a psychiatric hospital (Sajith et al., 2017), and NGO staff (Kamapalan & Li, 2009). A study involve professionals from various background (i.e., community rehabilitation volunteer, physiotherapist, social worker, medical doctor, occupational therapist, and nurse) (Brolan et al., 2015), while another study did not specify the professionals' back ground in their study (Brolan et al., 2014). Three studies involved students majoring in education (Thaver & Lim, 2014), dentistry (Ahmad et al., 2015) and nursing (Erawati & Keliat, 2018). Seven studies recruited parents and other family members of people with ID (Alcantara & Castronuevo, 2016; Anisa & Muliasari, 2018; Endriyani & Yunike, 2017; Ngo et al., 2012; Persons, 2017; Shin et al., 2006; Shobana & Saravanan, 2014). One study took the perspective of the lay member of the society by conducting an online survey (Pooh, 2005), while six studies involved more than one group of participants, covering professionals, parents, traditional healers, community leaders, faith leaders and neighbours (J. Carter, 2009; Cordier, 2014; Moreira, 2011; Thoresen et al., 2017; Westermeyer, 1979; Winarni et al., 2018). Table 1 presents the extraction form of the included studies, including the information summarised above.

Table 1. Information extraction of the included studies (n=24)

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Quantitative Studies							
Ahmad et al., (2014)	Malaysia	Perception, attitudes and training experience of dental students in special needs dentistry (SND)	Dental students undergraduate (N = 289). Male = 77 and female = 212	• A questionnaire consists of four sections to assess socio-demographic characteristics, the perception of SND, the perception of patients with special health care need and training program for SND.	Regression analysis	• 31.7% of students felt comfortable treating patients with ID. • 56.4% of students reported they would refer patients to a SND specialist if the patient had an ID (attributed to the participants' level of confidence to provide treatment them selves	5
Anisa & Muliasari (2018)	Indonesia	Knowledge and attitude towards the independency of child with ID	Parents of children with moderate ID (N = 53); mother (N = 44) father (N = 9)	• Instruments were not reported.	Chi square to examine the relationship between knowledge and attitudes.	• Most parents (52.8%) have positive attitudes towards their child independency, while the rest (46.2%) hold less positive attitudes.	3
Kamapalan & Li (2009)	Philippine	Attitudes towards sexuality of people with ID	NGO staff recruited from three organisations (N = 82).	• The attitudes to sexuality questionnaire – Individuals with intellectual disability (ASQ-ID)	Descriptive statistics to present demographics. Analysis of variance to analyse relationships between demographics data and attitudes towards sexuality	• Participants hold positive attitudes towards the sexuality of people with ID • Muslims participants show more conservative (negative) attitudes regarding the overt sexuality • Participants with higher education, and more working experience and training were found to have more positive attitudes towards sexuality of ID people.	4

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Pooh (2015)	Singapore	Survey, public attitudes (explicit & implicit) towards people with ID.	333 participants recruited from two universities and from author's contact.	• Two vignettes describing persons with high and low level of functioning. • The attitudes toward intellectual disability (ATTID) questionnaire. • The single test implicit association test (ST-IAT).	Descriptive statistics to present demographics data One-sample t-test to explore attitudes tendencies compared to neutral scale mid-point. Paired sample t-test to compare participants' attitude between level of severity (mild–severe).	• Most participants hold positive explicit attitudes • Participants hold more negative explicit attitudes towards people with severe ID compared to their counterparts with mild ID. • Most participants hold neutral implicit attitudes • Level of ID severity does not affects implicit attitudes.	4
Sajith et al. (2017)	Singapore	Cross sectional survey. Perception of training need and care related to patient with ID	Residents and non-residents at a psychiatric hospital (N = 48).	• A questionnaire assessing clinical experience and training in ID, mental health problems and perceptions on psychiatric care of patients with ID.	Descriptive statistics to analyse the demographic data and participants' responses. Chi square to compare responses between participants.	• Most participants (nearly 90%) perceives people with ID as vulnerable to exploitation by other patients in general wards. • 93% agree that specialised wards would provide a better care for patients with ID. • 97% agree that people with ID should be managed by specialised team. • 15% of respondents agreed with the statement that they did not prefer to see patients with ID. • 83.4% of respondents agreed people with ID were entitled to same level of care as other patients.	4

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Shin et al. (2006)	Vietnam	Parenting Stress of parents of children with ID	Mothers (N = 106) and fathers (N = 93) of children with ID	• The Social Life Scale (SLS) was used to assess the degree to which social life experiences of the families are limited due to the stigma (9-item) • The Scale of Attitudes towards Disabled Persons (SADP) was used to assess general attitudes towards people with disabilities (13-item) and to validate the SLS.	Path analysis was conducted separately between fathers and mothers to examine the mediating roles of social support and stigma-related family experience.	• Stigma was related to parenting stress in both mother and father of children with ID. However, when other confounding variables were considered, stigma was not related to parenting stress.	2
Shobana & Saravanan (2014)	Malaysia	Attitude and psychological problems in mothers of children with developmental disorder	Mothers of children with ID, Autism Disorder (AD), and Down Syndrome (DS) (N = 100)	• The Parental Attitude Scale utilised to measure attitude (40 items with ‘yes’, ‘no’ and ‘cannot say’ as options for an answer).	Analysis of variance was used to analyse the difference in attitude and psychological problem among groups. Regression analysis was used to estimate the relationship between parental attitude and psychological problems.	• Mothers of children with ID were found to have higher negative attitude compared to their counterpart of children with DS. • Negative attitude was found as a significant predictor of psychological problems. • Parents with ID experienced a higher level of psychological problems compared to their counterparts with AD and DS.	3

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Thaver & Lim (2014)	Singapore	Attitudes towards people with disabilities and inclusive education	Pre-service mainstream teachers (student, teacher candidate) N = 1538	• The Attitude towards Disabled People (ATDP-A) (30-items with six-point Likert-type response format). • The Attitudes towards inclusive Education Scale (ATIES) (16-items with six-point Likert-type response format)	Pearson's product moment to examine the relationship between the attitudes towards a person with disabilities and the attitudes towards inclusive education.	• Pre-service mainstream teachers show less favourable attitudes towards the inclusion of students who required academic support, such as those with ID. • Participants' attitude towards inclusive education was ambivalent, bordered on the unfavourable.	5
Winarni et al. (2018)	Indonesia	Cross sectional survey. Attitudes towards sexuality of people with ID	Parents, rehabilitation centre staffs, faith leaders, and community representatives (N = 82)	• Sexuality Questionnaires towards individuals with ID (ASQ-ID). Each participants completes two questionnaires describing both males and female with ID.	Independent t-test of questionnaire's result between demographics characteristics.	• The attitudes towards sexuality in individuals (male and female) with ID was negative. • Attitudes towards sexual right were the most positive. • Compared to other countries, Indonesians have the most negative (conservative) which was attributed to cultural value and Islamic religious beliefs prevalent in indonesian society	2

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Qualitative studies							
Alcantara & Castronuevo (2016)	Philippine	Family experience of caring a child with Down syndrome	Five families having two members each (one parent and one sibling) (N = 10)	• A semi structured interview schedule. Not presented in the manuscript.	Not reported, the results were discussed in themes.	• Generally positive parental attitudes towards the child's ID. They see their child as a blessing and the source of their best experiences. • Most participants report stronger and more open relationships with their family members. • Participants view their families and God as their source of motivation.	4
Brolan et al. (2014)	Philippine	Cultural concepts of ID and treatment options	Professionals working with people with ID (N = 21).	• Questionnaire guided interview, involving an interpreter.	Thematic analyses. Data was coded independently by two authors.	• Attribution of supernatural intervention as the cause of ID is present. • Majority of respondents report the use of traditional treatment by family of people with ID; which can be related to traditional beliefs hold by the family	5
Brolan et al. (2015)	Philippine	The health of people with ID and related factors.	Professionals working with people with ID (i.e., community rehabilitation volunteer, physiotherapist, social worker, medical doctor, occupational therapist, and nurse) (N = 21).	• Questionnaire, assessing views of the health of people with ID, key problems to health care of people with ID, and suggestions on overcoming the challenges	Not reported, authors stated that the data were analysed thematically.	• The health of people with ID are reported to be worse than that of the general population. • Neglect of children with ID was reported, which was atributted to poverty.	4

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Carter (2009)	Cambodia	Exploring challenges faced by children with ID in rural settings and their needs.	48 parents (45 female, 3 male) involved in interview, 69 parents involved in focus groups, 74 NGO staff involved in focus groups, 21 children with various disabilities (was not reported in detail) were involved in a semi-structured interview and 46 children were involved in artistic activities. 29 local authorities were involved in focus groups. 16 other key informants were interviewed.	• 4 questionnaires developed for NGO staff, parents, community members/village leaders and children with ID respectively.	A theme-based analysis was used, no specific analysis method was mentioned.	• Supernatural forces such as karma and spirit possession was attributed as the cause of ID • Most parents report no discrimination towards their child in the community. However, reports from service providers indicated significant discrimination faced by children with ID. • Some form of discrimination was attributed to a lack of understanding (e.g. name calling) • Types of discrimination reported are name calling, the suggestion of euthanasia, and criticism of parents, exclusion and interfamily discrimination. • Children with ID express employment as future aspiration • Parents express burden of care: difficulty in supporting their children in hygene and self-care, and managing challenging behaviour. • Parents express fear or concerns over child’s future.	5

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Cordier (2014)	Cambodia	Community intervention to change attitudes and beliefs of people with ID. Involves a preliminary study exploring attitudes and beliefs related to ID	311 member of poor household in rural Cambodia, including 162 people with ID as intervention target, plus community leaders and representatives of Disabled People organisation (DPO).	• Focus groups discussions and meetings.	Specific analysis methods was not reported. The result section was presented by quoting participants cases/statements to justify finding.	• Children with ID are seen as burden, due to their inability to provide for themself. • Family are forced to choose between assigning a family member to look after the child with ID or to neglect them at home while they go to work. • Concern of the security of people with ID and the possibility of sexual violence directed at girls with ID, when they go out of the house.	2
Endriyani & Yunike (2017)	Indonesia	Exploring mother experience of caring children with ID	Parents (unspecified) (N = 5)	• Not reported	Phenomenological approach	• Some participants express dissapointment and shame of having children with ID • Children with ID receive verbal and non-verbal discrimination and are excluded from the community. • Parents attribute ID as God's trial or gift.	3
Erawati & Keliat (2018)	Indonesia	Nursing students' experience in treating children with ID	Nursing students (N = 7)	• Semi structured interview mentioned as the data collection method. However, the interview schedule was not reported.	The results were presented in thematic way. Specific analysis method was not mentioned.	• Negative views regarding people with ID (i.e. lazy, challanging behaviour, feeling pessimistic) were reported. • Communication was seen as the main challenge in caring people with ID. • Participants reported a change of perception towards ID after interacting and having contact with children with ID.	3

Author and year	**Country**	**Design and scope of study**	**Participant**	**Relevant instrument and data collection**	**Data analysis**	**Relevant findings**	**MMAT Score**
Komardjaja (2005)	Indonesia	The placement of people with ID in special institutions	Head teachers of special schools under study (N = 3)	• Interview. Three main questions were mentioned as a guideline, but were not reported.	No specific analysis method was mentioned. Results were narrated. No quotes of the interview were included to justify findings.	• The institutions are located in a strategic area of the city accessible by public transportation, suggesting no visible exclusion. • A case of neglect of a person with ID whose being left in one of the institutions without being visited for a long time by the family.	1
Nguyen et al. (2015)	Vietnam	Exploring the inclusion of girl and young woman with disabilities	Girls and young women with disabilities (i.e. ID, mobility impairment and other physical impairment (unspecified), age 11–25 years old. (N = 21)	• Data were collected through drawings, photo voice and creating a policy posters. • 21 drawings with captions, 21 sets of photograph with caption, and 7 policy posters were produced by the participants. • Discussions and interviews about the production were conducted.	Data analysis method was not reported. Copy of drawings and captions were presented to justify findings.	• Girls with ID experienced bullying and gender-based violence more frequently than girls with other disabilities involved in the study • Some participants have internalized disability as ‘abnormal,’	4

Author and year	**Country**	**Design and scope of study**	**Participant**	**Relevant instrument and data collection**	**Data analysis**	**Relevant findings**	**MMAT Score**
Persons (2017)	Thailand	Exploring family adjustment and their access to service.	8 participants from 5 families of children with Down syndrome, aged 0-5 years old.	• A genogram instrument exploring 13 areas of family systems was utilised. • Genogram draws by participants were discussed in the focus group discussions (FGD) conducted for 7 sessions. • The FGD was video recorded. • Participants were observed during house visits.	The data was transcribed and analysed using spatial mapping, constant comparison and critical discourse analysis.	• Comments from professionals regarding mandatory abortion of fetus, in response of frequent medical treatment required by children with Down Syndrome. • Verbal discrimination (i.e. feeble minded, taunt in local language 'yaa') by neighbours, which leads to family's withdrawal from the society. • Family exclude their children with Down syndrome in family-related events. • Parents express concerns regarding the future of their children.	3
Terol (2009)	Philippine	Exploring the experience of sexually abused adolescents with ID.	15 participants with mild ID (N = 8) and moderate ID (N = 7)	• Interview guide questionnaire, semi structured interview, Sach's sentence completion test to assess adolescent's perception of their mothers and fathers.	Content analysis	• Most cases (N=12) have familiar person as preparatory (neighbours, in-law) • Sexual abuse as reason for dropping out of school, caused by the fear of sexual predation and discrimination for being sexually abused. • Four participants decide not to disclose case because of threat from the preparatory or fear of rebuke from parents • Poverty was attributed as the cause of abuse and the decision was not to chase the case.	5

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Westermeyer (1979)	Lao	Exploring traditional concepts of mental disorders	Elders and traditional healers, the number was not mentioned. People with psychosis and their families, the number was not mentioned. 13 people labelled as crazy or insane, as a pilot study 35 people labelled as crazy or insane and 242 relatives and fellow villagers 6 people labelled as lost-minded in a pilot study	• Observation-participation, utilising structured and unstructured interviews.	Analysis method was not reported. Findings were narrated and quotes were used to justify findings	• People with ID are referred as Khon Sã or slow person. • Khon Sã is described as people who cannot do many things which they ought to know and did not have the skills which are basic for people in public. • Due to their limited skills, Khon Sã must be supervised in their works, and they require care, protection and guidance from other.	2

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Mixed Method Studies							
Thoresen et al. (2017)	Lao	Identifying the prevalence of people with ID. Exploring experiences of family and service regarding ID people. Describing the experience of people with disabilities and barriers and facilitators to services	Survey: 2469 participants; 939 household Focus groups with stakeholders' representatives i.e. government agencies, DPOs (N = 6) Case study, constructed from data collected through (a) interviews with stakeholders (unspecified), (b) interviews person and/or parents of persons with and without disabilities, (c) participant observation in organisations and communities, (d) examination of physical artefacts e.g. assistive devices, open access buildings and public transport, (e) review of documents provided by the stakeholders	• Focus groups discussion, exploring beliefs and understanding of ID, services available for people with ID, the extent of participation in education, employment and social activities	Data analysis method was not reported. Findings from each elements of study were presented separately.	• Stigma towards people with ID is present in the society, which creates barriers to the provision of support and service. • Limited access to services and job opportunities for children and adults with ID respectively; social and cultural stigmatization towards ID as major barrier. • Children with ID generally not diagnosed, leaving them without access to intervention, support, or treatment services. • Superstitious beliefs, blame on mother due to religious associations to karma and sins in previous lives were reported • The majority of medical support provided by services is for acquired disabilities, which largely excludes people with ID	3

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Moreira (2011)	Cambodia	Cultural perceptions of intellectual disability and challenges faced by families of person with ID.	Families of people with ID (N = 72), triangulated with data from key informants comprises of (a) 13 neighbour and local authorities (b) 10 public school teacher (c) 13 special needs teachers	• Survey and interview. Questionnaires were administered to 72 families of people with ID, followed by an in-depth interview with 8 families. The key informants were interviewed.	Results were presented as a narration, with quotes from the interview included. No specific analysis method was mentioned.	• Karma was attributed as the cause of ID, resulting in discriminatory behaviour such as hiding children with ID, excluded from traditional ceremonies • Most parents present positive feelings (e.g. empathy, pity, hope) towards their child condition, while 35% of them also present negative feelings (e.g. anger, shame, hopelessness). • Some of the negative feelings were associated with parents' cultural expectation of their child (e.g. taking care of parents, marriage, contribution to society). • Only 29% of parents thought that their children receive discrimination because of their condition, which was attributed to lack of knowledge and understanding about discrimination behaviour. • Discrimination was reported i.e. verbal discrimination, blame to mother, rejection and suggestion of euthanasia.	4

Author and year	Country	Design and scope of study	Participant	Relevant instrument and data collection	Data analysis	Relevant findings	MMAT Score
Ngo et al. (2012)	Vietnam	Stigma and restriction of social life of families of person with ID	Parents of children with ID (N = 70, 37 mothers and 33 fathers). 33 parental dyads with 4 mother and 4 father participating without a partner.	• The ABILITIES index was used to assess children's functional ability (19 item, rating 0-5 response format) • The Restriction of Social Life Scale (12 item scale and open-ended follow-up questions).	Generalised Estimating Equations (GEE) Models. Open-ended questions in the Restriction of Social Life scale was analysed for themes.	• Restriction of social life of parents was predicted by the child's level of severity • Qualitative responses revealed themes of individual-level discrimination (N= 24), stigma of being discredited (N= 25), and carers' coping strategies that have elements of discrimination (secrecy, withdrawal, avoidance; N=18).	4

3.3.2 Themes established in the synthesis of findings

The narrative synthesis identified three themes, namely: ‘attitudes towards people with intellectual disability’, ‘the stigma of intellectual disability in traditional community’, and ‘the stigma of intellectual disability and family’. The three themes are described as follows:

3.3.2.1 Attitudes towards people with intellectual disability

The term ‘attitude’ was used and explored in eight studies included in this systematic review. The information relevant to attitudes was also extracted from studies which use synonymous terms, such as ‘view’ or ‘perception’. As mentioned earlier, although eight studies specifically use the term ‘attitudes’, these studies differ in the operationalisation and the measurement of the term. Furthermore, the studies explored attitudes from the perspective of various population groups, such as parents, students, and professionals, which further increase their heterogeneity.

Despite the heterogeneity, the studies generated similar findings as they suggest that the attitudes towards people with ID are generally inclined to be negative. Thaver and Lim (2014) found that the students in training for a teaching position (pre-service teacher) hold less positive attitudes towards the inclusion of students with ID in mainstream settings, such as students requiring extensive academic support. Similar findings were highlighted by Ahmad et al. (2015), suggesting that dental students tend to prefer people with ID to be treated in more specialised services which were attributed to the students’ low level of confidence to provide the treatment themselves. In line with the two studies, Sajith et al. (2017) found that medical doctors (psychiatry residents and non-residents) in a psychiatric hospital in Singapore tend to refer patients with ID to a specialised team and perceived the patients to be vulnerable to exploitation by other patients, if they were to be treated in a general ward. Erawati and Keliat (2018) also provided brief information regarding the initial perception of nursing students towards patients with ID. Erawati and Keliat (2018) mentioned that the students hold negative views towards patient with ID, as the patients are perceived to be lazy and may exhibit challenging behaviours, which made the students less keen to provide care for the patient. However, the students' views were improved after a temporary placement in a rehabilitation centre for people with ID, suggesting that contact is an essential element to improve attitudes towards people with ID (Erawati & Keliat, 2018). It is also important to note that the students perceived establishing communication as the primary challenge in treating people with ID (Erawati & Keliat, 2018).

Studies involving parents suggest a similar trend that parents tend to hold negative views towards their children with ID. Parents consider a child with ID as a burden (J. Carter, 2009; Cordier, 2014; Moreira, 2011), and consequently, express disappointment and shame upon having them (J. Carter, 2009; Endriyani & Yunike, 2017; Moreira, 2011). The mothers of children with ID were found to hold more negative attitudes towards their children, compared to mothers of children with Down syndrome (Shobana & Saravanan, 2014). The difference of mothers' attitudes was attributed to challenging behaviours, which was perceived to occur more often in children with ID (Shobana & Saravanan, 2014).

Parents' attitudes towards people with ID were discussed in association with the burden of care and poverty. Two studies by J. Carter (2009) and Cordier (2014) provide an elaborate discussion of the issue, as they explored the experience of parents from poor economic households in the rural areas of Cambodia. The two studies suggest that parents from poor households were forced to choose between allocating their resources towards caring for their child with ID or to earn an income. For example, in a farmer's family, to look after a child with ID would mean allocating time and human resources, which could otherwise be allocated to work in the fields. Another issue that was discussed along with the burden of care was access to affordable treatment. Parents were found struggling with the expenses of their child's treatment, which must be paid from their small earnings (Brolan et al., 2014; J. Carter, 2009; Moreira, 2011). The burden of care was also portrayed in a mother's views about the passing of her child, who described her feeling as 'relieved' and commented that she now had more time to earn money rather than spending more on her child's health expenses after her child's death (Moreira, 2011).

On the contrary, a study of the parents of children with Down Syndrome in Philipine perceived their child as a gift, which positively affects the family's life by strengthening the bond between the family members (Alcantara & Castronuevo, 2016). Furthermore, Alcantara and Castronuevo (2016) highlighted particular cases where a father willingly resigned from his position overseas to spend more time with the child, and of a sibling becoming more involved in fulfilling the need of their brother/sister with ID. Similarly, a study from Indonesia suggests that the parents hold positive attitudes towards the independence of their children with mild intellectual disability (Anisa & Muliasari, 2018).

Any contradiction of the findings in the studies described above could be explained by considering their participants' backgrounds. Alcantara and Castronuevo (2016) study, which suggested parents' positive attitudes, recruited five families of higher social-economic status, which was described in the study as 'high income' (three families) and 'average income' (two families) groups. On the contrary, studies suggesting negative attitudes towards children with ID describes their participants as families of poor household living in rural settings (J. Carter, 2009; Cordier, 2014; Moreira, 2011), in which poverty and access to service add an extra weight to the burden of care, leading to less positive attitudes towards their caring experience. Another study by Anisa and Muliasari (2018) which mirrors the findings of Alcantara and Castronuevo (2016) did not provide any information regarding their participants' socio-economic status. However, it is known that the participants were recruited from a special school providing support for children with ID. Therefore, it can be argued that the participants included in the study have the capability to attain special services and support, and to some extent alleviate their burden of care, which could not be attained by participants in studies suggesting negative attitudes (Brolan et al., 2014; J. Carter, 2009; Cordier, 2014; Moreira, 2011). Additionally, level of severity could also affects parents attitude towards their children with ID, as Anisa and Muliasari (2018) were focusing their work only on parents of children with mild ID.

Measuring both explicit (consciously accessible and controllable evaluation) and implicit attitudes (underlying automatic and spontaneous evaluation), Pooh (2005) suggested that the public attitudes towards people with ID in a Singaporean context are generally positive. Severity level was highlighted as affecting explicit attitudes, as respondents' attitudes were more inclined to be negative towards people with severe ID. Two studies specifically explored attitudes towards the sexuality of people with ID. Kamapalan and Li (2009) found overall positive attitudes towards the sexuality of people with ID among NGO staffs. However, when religious background was taken into consideration, the study found that participants from an Islamic religious background held more conservative (negative) attitudes. The findings were echoed in a study carried out in Indonesia, a Muslim predominant country (Winarni et al., 2018). The study found that stakeholders (i.e. parents, staff, faith leaders, and community representatives) held a more negative attitudes towards the expression of sexuality of people with ID compared to previous findings which used the same questionnaire (the attitude to sexuality questionnaires towards individuals with intellectual disability). Winarni et al. (2018) note that some of the questionnaire's items address sensitive issues for Indonesian, such as premarital sexual intercourse, masturbation, and homosexual relationship which contradicts prevalent religious and cultural values, and thus the findings were attributed to the Islamic faith common among the participants.

3.3.2.2 The stigma of intellectual disability in traditional communities

The reviewed studies suggested that cultural beliefs, which may arise from religious principles, beliefs of supernatural power and social expectations, are shaping the stigma towards people with ID. For example, traditional beliefs stems from the *karma* principle perceived people with ID as those who committed a sin in previous lives and are being punished in the present life (J. Carter, 2009; Moreira, 2011). The punishments are seen as demerits, which are believed to be transferable to other people, adding an element of 'contamination' in the process of stigmatization (Corrigan & Miller, 2004). Such beliefs have contributed to the exclusion of people with ID from religious activities, wedding ceremonies, and possibly other community activities where pureness and tranquillity are of importance (Moreira, 2011). Rejection from wedding ceremonies comes from the concerns that people with ID could bring bad luck for the newly-wed couple and their future offspring (Moreira, 2011). Adherence to such beliefs have also found to drive families to lock their child with ID in a room, when they are hosting a guest in the house (Moreira, 2011). The act is intended to avoid exposing the child to their guest, which is believed as the proper way to honour the guest (Moreira, 2011)

Supernatural power was thought to be the cause of ID in parts of Cambodia, Philippines, and Lao People's Democratic Republic, where spirits are believed to possess a person with ID (Brolan et al., 2014; Moreira, 2011), or cause other disabling conditions (Westermeyer, 1979). Spirit-related explanation of ID was not only limited to possession but also attributed to an angry spirit which attacks the person with ID (Moreira, 2011). A supernatural explanation of ID has been reported to drive families in seeking help from traditional healers (Brolan et al., 2014; Moreira, 2011).

Cultural beliefs affecting the stigma towards people with ID having its root in social expectations occurs in all levels of society, including the family. In Cambodian communities, children are expected to care for their parents when they reach old age (J.

Carter, 2009; Moreira, 2011). Such expectation potentially becomes the source of disappointment and shame in having a child with ID among parents, which then leads to the exclusion of people with ID. A study carried out in Indonesia, reported a case of institutionalisation of a person with ID due to shame felt by family (Komardjaja, 2005). It is important to note that the study took place in an urban context, which suggests that discrimination of people with ID is not limited to communities living in rural and remote areas.

Another examples of social expectation shaping stigma of ID is portrayed in *Khmer* belief systems, found in the cultural context of Cambodia, in which one's ability to contribute to their family's well being is of the most importance, and the inability to satisfy such an expectation would upset the family and disturb the order of society (J. Carter, 2009). Similar beliefs are present in Vietnam that all individuals of working age are expected to contribute to the community through employment and supporting a family (Moreira, 2011; Ngo et al., 2012). Due to the nature of their disability or the limited opportunity granted to them, people with ID have difficulties in fulfilling such expectations. This leads people with ID to have lack of attainment of 'full-status' within the community, which causes the person to be discredited (Moreira, 2011; Ngo et al., 2012).

Disapproval of people with ID in community was well reflected in the Lao traditional context, where they are referred to as 'slow person' (Khon Sã). The Khon Sã people are traditionally known as those who require supervision in their work, as well as care and protection from others in their daily life (Westermeyer, 1979); a label which strongly emphasises the importance placed on ability to work and to care for oneself. Such perceptions can be detrimental as they can be found behind reasons for removing children with ID from school as they believed that the child would not benefit from education due to the difficulties in learning (Moreira, 2011).

Terol (2009) explores the experience of sexual abuse among girls with ID and provides a thorough discussion regarding the topic. Interestingly, sexual abuse was mentioned in other studies (J. Carter, 2009; Cordier, 2014; Persons, 2017) as a concern among parents of a daughter with ID. Terol (2009) work validates the concerns and confirms that sexual abuse is a real threat for people with ID. Terol (2009) discusses sexual abuse in the context of social adversity including poverty and the lack of support available for the family. The study highlights cases where vulnerable victims were lured with money while being in the community unsupervised. Furthermore, poverty was considered as a barrier for the family to seek justice, as attending court would be costly for the families and take time.

3.3.2.3 The stigma of intellectual disabilities and the family

Families member of people with ID have been reported to be discriminated against due to their relationship. Similar to people with ID, family members were also restricted from community activities such as not being invited to wedding ceremonies (Ngo et al., 2012). Mothers were frequently cited as the main caregivers (Cordier, 2014) and therefore discriminated the most (Moreira, 2011). Mothers were perceived as the person responsible for the child’s condition, as they were blamed for not taking good care of their health during the pregnancy (Moreira, 2011).

Discrimination happens at home with family members as the perpetrator. Restriction on social activities, concealment and institutionalisation of people with ID were reported (Komardjaja, 2005; Moreira, 2011). Discrimination from the family was attributed to the lack of knowledge about such behaviours being considered discriminatory, and such behaviours are perceived in a different way across cultures. For example, parents perceived that derogatory name calling from a neighbour was considered an expression of compassion and pity instead of discrimination (J. Carter, 2009). Furthermore, the lack of understanding and internalisation of traditional beliefs among family members results in a lower rate of discrimination reported by parents compared to those of NGO workers (J. Carter, 2009).

3.4 Discussion

3.4.1 Summary of results

This review synthesises the findings of 24 studies exploring stigma related topics carried out in the Southeast Asian countries. The studies confirm that people with ID experienced stigma in their day to day life. Studies exploring attitudes generally suggests negative attitudes towards people with ID. Cultural beliefs such as *Karma*, spirit-related cause of ID, and social expectations were suggested to endorse negative attitudes and discrimination in some parts of the Southeast Asian countries. Poverty and limited access to service were attributed to negative attitudes and poor treatment of people with ID.

3.4.2 Results in context

This review includes four studies exploring attitudes in professionals and those who are expected to hold such roles in the future. A study explores the perception of psychiatry residence and non-residence towards patients with ID (Sajith et al., 2017), and another three studies explore the attitudes among students majoring in education (Thaver & Lim, 2014), dentistry (Ahmad et al., 2015), and nursing (Erawati & Keliat, 2018). The four studies suggests that professionals holds negative attitudes which manifest in various forms, such as preferences to refer patients with ID to more specialised services (Ahmad et al., 2015; Sajith et al., 2017). This finding is alarming as negative attitudes among professionals has been associated with restriction of access to medical services (Lewis & Stenfert-Kroese, 2010) and inclusive education (Hadis, 2005).

Negative attitudes among professionals were attributed to the lack of training and experience in treating people with ID which creates feelings of incompetence (Lewis & Stenfert-Kroese, 2010). Another explanation regarding preferences to refer people with ID to more specialised services comes from the perception of the said people to be vulnerable of exploitation from another service user if they were treated in the general services (Edwards, Lennox, & White, 2007; Sajith et al., 2017). The importance of equipping professionals with knowledge and skills regarding ID has been addressed by Lennox and Diggens (1999) who identified the key points in ID-related knowledge, skills and attitudes necessary for medical students.

It is critical to discuss the findings regarding professional's negative attitudes in the Southeast Asia context, where, in some of its countries, service provision is centralised in urban areas and often inaccessible for most people. Therefore, findings regarding negative attitudes among professionals reveals an additional barrier for people with ID to access services, aside from the availability of service itself. Further studies are needed to understand better the nature of attitudes towards people with ID among professionals in the Southeast Asia context, and to devise a strategy to tackle problems stemming from such attitudes.

This study suggests that families of people with ID in parts of Southeast Asian countries, perceived discrimination differently from those of professionals; which indicates the role of cultural beliefs in shaping stigma, and the internalisation of such beliefs in family members. Internalisation of discrimination-endorsing beliefs is not limited to family members but also in the broader community member, distorting the border between acceptable and unacceptable behaviour. Studies in this review provide examples of situations where parents hide their child with ID in order to avoid disrespecting their guest or when people with ID are rejected from joining religious ceremonies to avoid spreading demerit. In such situations, hiding and rejecting people with ID were seen as the proper behaviour. In other words, discriminative behaviour is accepted and expected by society. The families and the general member of society may not be aware that such behaviour is unacceptable; and therefore, unintentionally discriminating against people with ID. On the other hand, families has also been reported to experience stigma as the results of their affiliation with their family member with ID. A systematic review has reported and discussed this as affiliate or courtesy stigma which confirms that stigma towards family members happens across cultural contexts (Mitter et al., 2019).

Studies in this review have also noted cultural differences in more subtle elements of stigma, as pity and shame frequently mentioned as an emotional response (prejudice) towards people with ID. In some cultures, expressing pity towards people with disability is considered as derogatory, while in some of the Southeast Asian cultures—as it was mentioned in the studies—it is considered as an expected and positive response (Naemiratch & Manderson, 2009). Shame was also mentioned as the one families' response upon having a child with ID (J. Carter, 2009; Endriyani & Yunike, 2017; Moreira, 2011; Ngo et al., 2012) and was found to drive institutionalisation (Komardjaja, 2005). In the field of the stigma of mental illness, Corrigan and Miller (2004) describe that avoidance is firmly attributed to the sense of shame experienced by the families and that the shamed family may want to hide from the public. This review suggest similar findings where parents tend to avoid exposing their child with ID to society, or to restrict themselves in attending community activities, as the results of undesirable response from the public (Moreira, 2011; Persons, 2017). Corrigan and Miller (2004) describes that relationship between shame and avoidance is complex, as it is unclear whether avoidance is driven by public stigma or self-stigma. Given the relationship between cultural factors and stigma, further studies are needed to better explain the relationship of shame and avoidance in the field of stigma towards people with ID in the culturally diverse Southeast Asian community.

This review suggests that traditional beliefs which endorse sigma of ID are prevalent especially in traditional communities living in rural areas (Brolan et al., 2014; J. Carter, 2009; Cordier, 2014; Moreira, 2011). Eradicating stigma and discrimination in such communities, where stigmatising behaviour is perceived as acceptable, requires efforts to introduce a ‘foreign’ perspective to the member of the communities to redefine the ‘acceptable’ and ‘unacceptable’. Changing prevalent perspectives in local indigenous communities, especially those that come from religions and traditional values, is a complex feat and therefore should be carried out carefully; as religious teachings and traditional values are often the underlying principle of the community’s life which makes it a delicate topic. To refrain from judgement towards certain behaviours or emotional responses could favour the effort to understand how cultural beliefs shapes stigma of ID. For example, the Cambodian studies provide a consistent finding about the acceptability of suggestion to euthanize the child with ID which comes from neighbours who tried to express sympathy and offer solution to ease the burden of parents with child with ID. A suggestion to euthanize a child with ID could easily be recognised as reprehensible were it to occur in the context of western societies. However, when the context of rural Cambodia is to be considered, an alternative explanation could be offered. The prevalent religious beliefs in Cambodia includes beliefs of reincarnation. Considering that the neighbours’ suggestions may come from adhering to such beliefs, the suggestion of euthanasia may come from a hope that the children with ID could have a better condition in their next life. Nevertheless, it is essential to be aware of the potentiality of the suggestion to be converted to actual behaviour.

3.4.3 Strengths and limitations

This systematic review exercises broad search strategies comprising the search of five academic databases and efforts to include grey literature. The search strategy was further complemented by manually search selected journals originating from the

Southeast Asian countries. However, this systematic review could not claim that it has covered all studies related to stigma of ID carried out in Southeast Asia, as the search strategy does not cover studies written in non-Latin based languages such as the languages used in Thailand, Lao and Burmese. Furthermore, given the diversity of culture in Southeast Asia and the limited number of studies included in the review, this study could only provide a glimpse of situations of people with ID in particular context of Southeast Asia; and therefore findings of this review should not be generalised to the broader context of Southeast Asia.

Another limitation of this review comes from the review attempting to address two broad questions which revolve around stigma, a concept which is often defined in a number of different ways. The focus of this review was to find and extract ‘relevant’ information to address the review questions. Determining which information is relevant and which is not, is undeniably a subjective process. Although this systematic review has employed a rigorous process in screening of studies and extracting information, it could be argued that such efforts does not entirely remove subjectivity from the process.

3.4.4 Future studies

This review includes twenty-four studies representing the eleven Southeast Asian countries. Considering the vastness of the region and the diversity of the cultural factors present in the region, the number of the studies is rather limited. However, the synthesis of findings suggests that stigma and discrimination of ID people are present in parts of the Southeast Asian countries. Further studies are needed to provide more information regarding stigma and the situation of people with ID in the Southeast Asia. Future studies should carefully examine cultural factors in shaping the stigma of ID, to provide a basis of stigma eradication plans which can be implemented in culturally diverse communities like those of Southeast Asian countries.

Out of the twenty-four studies, five studies included people with ID as research participants (J. Carter, 2009; Cordier, 2014; Nguyen et al., 2015; Terol, 2009; Thoresen et al., 2017). However, only two of the studies put the experience people with ID as their main focus and provide elaborated findings regarding the topic. Nguyen et al. (2015) included 21 girls and young women with disabilities including people with ID (number was not reported) to explore the extent of their inclusion in society. While, Terol (2009) focuses on exploring experience of sexual abuse by interviewing 15 participants with mild ID. The two studies highlights crucial issues that girls and woman with ID are experiencing gender-based violence and abuse, as well as bullying (Nguyen et al., 2015; Terol, 2009) which needs to be quickly addressed. On the other hand, the other three studies involving people with ID as research participants does not report a detailed findings regarding the lived experience of people with ID (Cordier, 2014; Thoresen et al., 2017), or only provide brief findings regarding employment as their future aspiration (J. Carter, 2009). Furthermore, most of the discussion regarding the stigma process in this review has been built on reports from parents and other stakeholders working closely with ID people (NGO staff, teachers, and faith leaders). Therefore, future studies should further explore the stigma from the perspective of people with ID in order to provide a comprehensive understanding of the stigma process.

3.5 Conclusion

This systematic review provides a synthesis of findings regarding the stigma associated with ID in the Southeast Asia context. The synthesis of findings suggests that ID-related stigma is present in some of the Southeast Asian countries. Cultural beliefs, driven by religious teaching and social expectation, are likely to play an important role in shaping personal and societal attitudes towards people with ID. Stigma related to ID was also found to affects other family members, in particular mothers. Further studies are needed to understand better the stigma towards people with ID in various cultural settings, followed by efforts to reduce the experience of stigma by people with ID and their families.

3.6 Acknowledgement

I thank Ms Amanda Lim for performing the independent screening and quality assessment, as well as reviewing the information extraction form and the initial preliminary synthesis of this study. I also thank Dr. Victoria Ratti for reviewing the information extraction form used in this study.

Chapter 4 Qualitative exploration of professionals' attitudes towards people with intellectual disability and their inclusion in the Indonesian society

The manuscript of this chapter has been accepted for publication in Transcultural Psychiatry (see appendix 4).

4.1 Introduction

People with intellectual disability (ID) are among the most stigmatised and excluded in society (Ditchman et al., 2013). Efforts to increase the social inclusion of people with ID have taken place in many countries following the ratification of the Convention on the Rights of Persons with Disabilities (CRPD) (Scior et al., 2015). Alongside efforts to promote positive attitudes towards people with ID through laws and public policies, it is crucial to explore prevailing attitudes in society, their formation, and the presence of negative attitudes that hamper the inclusion of people with ID in everyday life (Yazbeck, McVilly, & Parmenter, 2004). Understanding attitudes prevalent in society is also relevant in achieving social change and evaluating the effectiveness of public policies in the promotion of inclusive approaches to people with ID (Werner & Scior, 2016). Attitudes toward disabilities are socially constructed and shaped by experience (Tregaskis, 2000). An international study covering countries in Asia, including Indonesia, found significant differences in the degree of inclusion of people with disabilities, which the authors attributed partly to differences in religious beliefs across the countries studied (Berry & Dalal, 1996). Studies in Cambodia also highlight the role of religion in shaping attitudes towards ID (J. Carter, 2009; Moreira, 2011).

Aims

The present study was designed to explore the attitudes of professionals working with people with ID in Indonesian communities. Four groups of professionals were included in this study: medical doctors, psychologists, teachers, and religious leaders. These professional groups were selected as they are often the primary initial contact in the management of people with ID. Medical doctors and psychologists provide a formal diagnosis of ID and recommendations for treatments. Teachers may identify cases of students with ID in their classrooms, make referrals to health professionals, and to more specialised education—sometimes without a formal diagnosis. In the Indonesian context, religious leaders are sought out by their followers for treatment, including for disabling conditions. Participants were recruited from four urban areas in Java Island, namely Jakarta, Tangerang, Bogor and Bekasi. This study aimed to address the following questions:

- What attitudes are held by professionals towards people with ID in the urban context of Indonesia?
- What are their attitudes towards the inclusion of people with ID into the Indonesia society?

4.2 Methods

4.2.1 Ethics statement

Ethical approval was obtained from the UCL Research Ethics Committee, project ID number 8849/001 (see appendix 5). Participant information sheets, consent forms, semi-structured interview schedule and vignettes, which were translated into Indonesian, were reviewed and approved by the committee. Participant information sheet and informed consent form are available in appendix 6. The semi-structured interview schedule and vignettes are available in appendix 7. The study did not undergo another ethical review in Indonesia as the collaborating service providers which helps with participant recruitment were satisfied with the ethical clearance provided by the UCL Research Ethics Committee. Details regarding ethical clearance were presented in the information sheet for participants to read. Furthermore, all participants were made aware that participation in the study is voluntary.

Personal information collected in this study includes age, sex, occupation, religious affiliation, ethnicity, length of professional experience (in year), as well as whether they had contact with people with ID or not. The collected information, along with audio data collected during the interview were stored in UCL Data Safe Haven—a secure data storage and management system provided by UCL—in compliance with the UCL Research Ethics Committee's recommendation. The audio data collected during the interview were transcribed into text documents. Identifiers information such as name and institution's name were removed during the transcription. The audio recordings were deleted after transcription.

4.2.2 Participants and procedure

In total, 18 participants were interviewed, including two medical doctors, three psychologists, two mainstream education teachers, three special education teachers, and eight religious leaders. They were recruited through convenience sampling, using work and personal contacts of the author, as well as those of two collaborating service providers. The participants recruited from work/personal contacts were sent an email containing an invitation and information sheet about the study, whilst those recruited via service providers received the invitation and information sheet from their respective organisations. Participants provided written consent and were interviewed at a time and place of their choosing. Four participants chose to be interviewed by phone. Figure 4-1 depicts the recruitment process of this study.

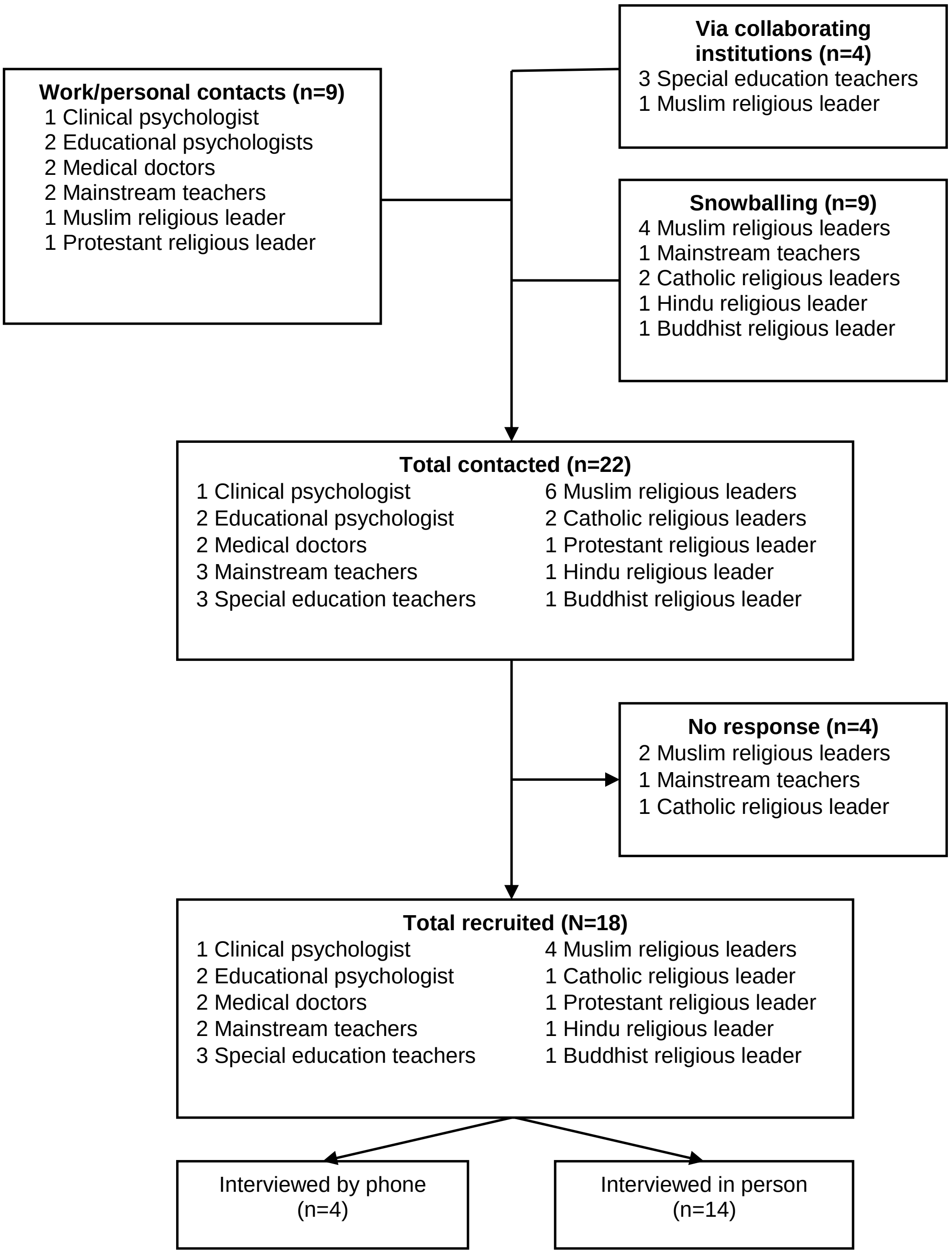

Figure 4-1 Participant recruitment flow

4.2.3 Instrument

A semi-structured interview schedule and two vignettes depicting a person with mild ID and a person with severe ID were utilised in this study (see appendix 7). The interview guide aims to explore participants' perceptions regarding likely causes of ID, attitudes towards people with ID, and attitudes towards the inclusion of people with ID in society. Attitudes towards inclusion were explored in relation to five domains: education, employment, marriage and parenthood, participation in community activities, and living arrangements. The interview guide was developed for the purpose of this study, guided by the literature. For example, questions about causal belief were based on the suggestion of its influence towards attitude (Scior & Furnham, 2016) and questions about participation in community activities such as wedding ceremony and religious service were based on finding that people with ID are excluded in such activities (Moreira, 2011; Ngo et al., 2012). The vignettes were used during the interview to provide a description of people with ID as well as a reference point for participants without any prior contact with people with ID. The vignette depicting mild ID was developed based on Morin, Crocker, Beaulieu-Bergeron, and Caron (2013) work. The instruments were piloted with three members of the professions: a clinical psychologist, a mainstream education teacher and a Muslim religious leader, and were refined based on their inputs.

4.2.4 Data collection process

Interviews were conducted in Indonesian language and audio recorded. The interviews lasted between 35 and 64 minutes, with an average of 48 minutes. The participants were given a chance to read the two vignettes prior to the interview and to refer to the vignettes anytime during the interview. Interviews were transcribed in Indonesian by the student and subsequently translated into English by a translation service. The translated transcription was then reviewed for quality by the student.

4.2.5 Data analysis

Data were analysed after the translation to English. Thematic analysis was used to identify patterns (themes) within the collected data, following the six steps proposed by Braun and Clarke (2006) namely familiarisation with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing reports. Initial familiarisation with data was done by reading each interview transcript several times. The qualitative data management programme NVivo 11 was used to extract information from the interview transcripts and to establish codes and themes. The initial coding structure was made by the student with input from the supervisory panel. The initial coding structure was then independently reviewed by another reviewer (RA) to check its reliability; differences were discussed to establish the final structure. Data saturation was examined in twelve transcripts and determined when no further themes were identified in the next three transcripts (Francis et al., 2010). Data were analysed together across professional groups, with participants' group membership attached to each citation.

4.3 Results

This section present participant's socio-demographic characteristics and themes identified from the interview transcripts.

4.3.1 Participant demographics

The composition and characteristics of the participants recruited to this study are shown in table 2.

Table 2. Participants' characteristics

Characteristic		N	%
Sex	Male	11	61.1
	Female	7	38.9
Age group (years)	20-29	2	11.1
	30-39	11	61.1
	> 40	5	27.8
Religion	Islam	11	61.1
	Catholicism	4	22.2
	Protestantism	1	5.6
	Hindu	1	5.6
	Buddhist	1	5.6
Ethnicity	Javanese	9	50
	Sundanese	2	11.1
	Balinese	1	5.6
	Banjarese	1	5.6
	Bataknese	1	5.6
	Betawi	1	5.6
	Chinese	1	5.6
	Jambinese	1	5.6
	Minangkabau	1	5.6
Profession	Medical doctor	2	11.1
	Clinical psychologist	1	5.6
	Educational psychologist	2	11.1
	Mainstream education teacher	2	11.1
	Special education teacher	3	16.7
	Muslim religious leader	4	22.2
	Protestant religious leader	1	5.6
	Catholic religious leader	1	5.6
	Hindu religious leader	1	5.6
	Buddhist religious leader	1	5.6
Professional experience (years)	< 5	6	33.3
	5 - 10	7	38.9
	> 10	5	27.8
Prior contact	Mild	17	94.4
	Severe	12	66.7

4.3.2 Themes

Seven themes were identified from the analysis, namely: the perceived cause of ID, use of terminology, attitudes towards people with ID, attitudes towards inclusion of people with ID, family-centric support, religion and ID, and challenges faced by people with ID in a wider context. These themes are presented below and illustrated with excerpts from the interviews. Themes reported are limited to those recurring in at least four interviews.

4.3.2.1 The perceived cause of intellectual disability

Perceived causes of ID among participants were divided into three categories, i.e. medical-related causes, religious-related explanations of causes, and lay explanations of causes. The three most frequently reported medical-related causes were malnutrition, accidents, and hereditary factors. Malnutrition was perceived as happening during the prenatal stage and associated with poverty and maternal malnutrition. Participants discussed accidents, e.g. head injuries during early childhood. Hereditary factors were described in a general way as a characteristic that runs in the family or is inherited from one or both parents.

> Maybe the parents' economic condition also affects him, and there was malnutrition during pregnancy (P13/teacher mainstream education)

Religious causes were mentioned by six participants, mostly from the religious leaders' group but also by a clinical psychologist who associated hereditary factors with 'the will of God'.

> I tell parents that it is a test from God, which is meant to dignify them… they need to believe that their condition is an ordeal from the creator (P09/religious leader-Islam)

> …the child's disability may be the results of his/her deeds from the previous life (P17/religious leader-Hindu)

Participants mentioned two causes of ID classified as lay explanations, namely maternal stress during pregnancy and lack of stimulation of the infant/child.

> It is a condition that develops before the child was born… perhaps it is because the mother feels stressed during pregnancy (P06/special education teacher)

> Lack of stimulation… could also lead to becoming a slow learner (P03/clinical psychologist)

4.3.2.2 Use of terminology

Participants stated that the term ‘deficiency in thinking’ *(tuna grahita)* is commonly used to refer to people with ID in Indonesia.

> This is the first time I heard the term intellectual disability… I have heard about mental retardation, but we usually use the term tuna grahita (P08/teacher special education)

Alternative terms that overlap with other diagnoses were also used, e.g. ‘children with special needs’ (*anak berkebutuhan khusus*), learning difficulty (*kesulitan belajar*) and ‘diffability’ (*difabel*) which refers to the concept of ‘differently able’. The term ‘educable’ (*mampu didik*) and ‘trainable’ (*mampu latih*) were used in education setting.

> Rudy (mild ID) can care for himself in eating and dressing; the term for him is educable. Gilang (severe ID) should be trained to care for himself; the term for him is trainable (P08/teacher special education)

Derogatory terms such as ‘idiot’ and mental handicap (cacat mental) were reported to be used among lay people. Among the derogatory terms used to refer to people with ID, some (‘mental disturbance’, ‘madman’) have overlapping meaning with the term used to address people with mental illness, especially psychosis; suggesting a lack of differentiation between mental illness and ID among lay people.

> Unfortunately, they usually use the term ‘mental disturbance’ (gangguan jiwa) or ‘madman (orang gila) to these people (P11/religious leader-Protestantism)

4.3.2.3 Attitudes towards people with intellectual disability

This theme encompasses participants’ attitudes towards people with ID. Four sub-themes were identified; see Figure 4-2.

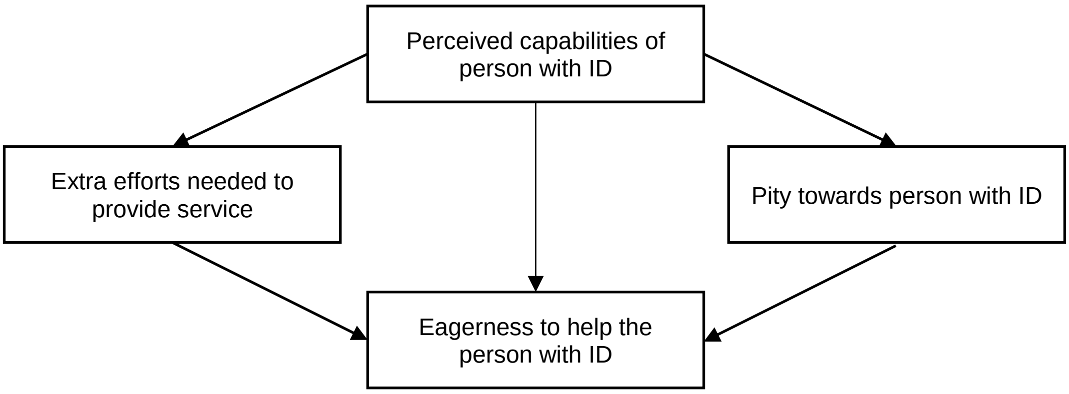

Figure 4-2 Attitudes toward people with ID

Positively perceived capabilities led to positive attitudes towards persons with ID, and as a consequence, people with severe ID received less favourable opinions than counterparts with mild ID.

> In his future, Rudy (mild ID) will stay at home, helping his mother with her kiosk at home. He can do various activities, but is limited to his house… Gilang (severe ID) will be stuck at home until he is old. Maybe he will do nothing but sleep (P13/teacher mainstream education)

In some instances, participants' negative perceptions of the capabilities of people with ID led them to express pity (kasihan).

> I would feel pity (kasihan) (for Gilang, severe ID)… feel pity because I can imagine his future, where he can't be independent and very dependent on his mother (P05/teacher mainstream education)

Participants in all three professional groups anticipated that they would need to make extra efforts to provide services for people with ID as they were perceived as less capable.

> If I had a client like Gilang, I would feel 'oh God, it will take a lot of energy to work with… a lot of things will need to be done for him… not to mention the

> struggle to work with him in person because he only speaks a few words and he cannot read or write'… (P01/educational psychologist)

Despite expecting that they would need to make extra efforts, all participants expressed an eagerness to accommodate people with ID who attended their services. In addition, one participant stated that they felt pity alongside an eagerness to help.

> I would give him support, to bring some confidence to him, to make him feel accepted. Because of his limitation, people in the community tend to exclude him... I would support him and guide him carefully… (P10/religious leader-Islam)

> It feels like I love and take pity on them, but at the same time I must teach and help them… it is sometimes… complicated, a combination of affections, the obligation to provide them with education, and pity (P06/teacher special education)

4.3.2.4 Attitudes toward the inclusion of people with intellectual disability

This theme is comprised of eight sub-themes represent factors influencing attitudes towards the inclusion of people with ID, as seen in Figure 4-3.

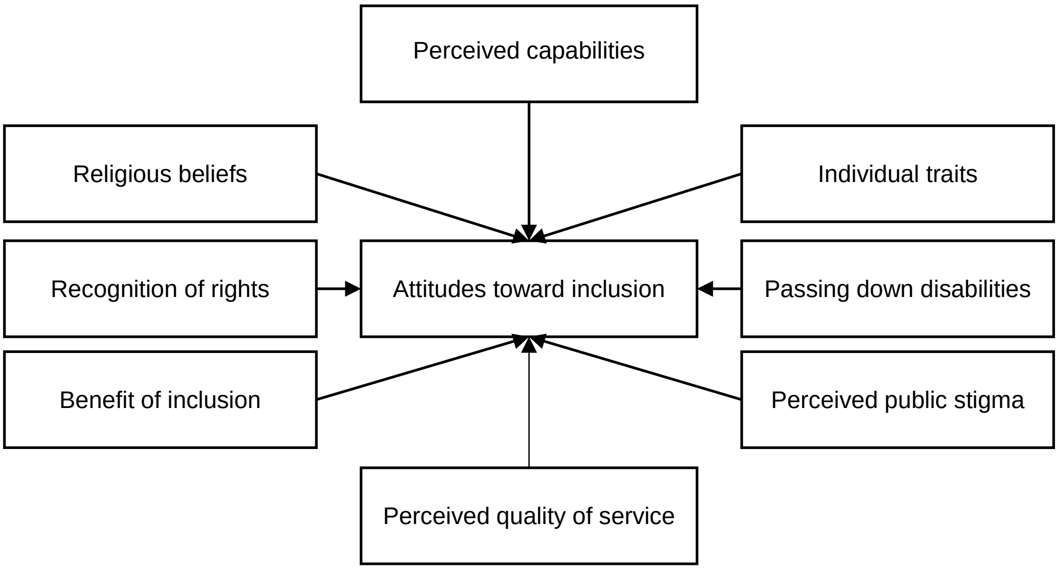

Figure 4-3 Professionals' attitudes towards the inclusion of people with ID

Participants were inclined to a positive attitude towards the inclusion of people with ID in all five domains explored in this study (education, employment, marriage and parenthood, participation in community activities, and living arrangements). However, participants were more favourable towards the inclusion of people with mild ID.

> People like Rudy (mild ID) should live at home with his family if he is single. If he is married, then it is okay for him to live separately… Q: what about Gilang (severe ID)? A: to stay with his family (P05/teacher mainstream education)

They noted the lack of good quality services for people with ID in Indonesia, and the gulf in educational quality between public and private schools, with the latter perceived to be of higher quality yet inaccessible for people of low economic status.

> The quality of inclusive education in Indonesia, especially those run by the government, is poor… if the parent is wealthy, then they can send him to a private, inclusive school, but if the parent is poor… then I prefer to recommend him to go to a special school (P01/educational psychologist)

> If we put him (Gilang, severe ID) in a school, even in a special school, the teachers will not be able to attend the students in a one on one basis... They don't have sufficient human resources… I prefer home-schooling (for Gilang, severe ID) (P11/religious leader-Protestant)

Participants who recognised the benefit of inclusion and the rights of people with ID are more likely to give an inclusive recommendation, including for participation in an election.

> …an inclusive school is the most appropriate… it is to provide him with a chance to socialise with more able people and to improve his communication skills (P05/mainstream education teacher)

> He has the right. In a general election, everyone has a voice, and it needs to be respected (P02/medical doctor)

However, some participants were more hesitant to endorse marriage and/or parenthood of people with ID despite recognising marriage and parenthood as human rights.

> It is human rights… but if you ask my perspective on this issue, I think they should not (marry)… Based on my experience… it will end with disaster (P06/special education teacher).

Hesitation to endorse marriage and/or parenthood among participants is related to concern about the possibility of passing down the disability. A participant went as far as recommending sterilisation as a countermeasure.

> I am worried he might pass his condition to his children. If he is married, he should go for sterilisation, to ensure he will not have a child (P15/educational psychologist)

Religious beliefs were found to influence attitudes towards marriage and/or parenthood among participants from the religious leader group.

> In the Book of Genesis, it is written 'Be fruitful and increase in number; fill the earth and subdue it'. Having a child is a mandate for married people, and it is an expectation from society and religion… (P11/religious leader-protestant)

Participants identified stigma and personal traits as a barrier to inclusion especially in educational settings and participation in community activities.

> There will always be people who perceive individuals with disabilities using derogatory views and remarks, such as ‘give it up’, ‘you don’t understand’, ‘do not even try to get involved (in the activity) … moreover, if the person himself does not like being in a crowd, then he will have a hard time to participate (in community activities)’ (P01/educational psychologist)

Stigma was reported to be internalised by families, leading to limited participation in community activities.

> Some families are ashamed to have children like him. So, they never bring such a child to wedding ceremonies. There are cases of parents hiding their child (P07/special education teacher)

Discrimination such as bullying, gossip, and name calling was reported to be present in the community, resulting in people with ID being marginalised and excluded. Therefore, endorse participants to advise people with ID to less inclusive options.

> But if his (Rudy, mild ID) parents think that it is impossible for the child to go to school because they are worried about bullying. I often hear about children with disabilities being bullied… It is hard for me to say this, but it is the truth. Then the second option is home-schooling (P11/religious leader-protestant)

The younger members of the society were said to more likely discriminate against people with ID.

> We may find children do such thing to them… Adults, I think they would not mind… they (the children) don't have an ill intention; they just want to have fun, to make fun of people with disabilities (P17/ religious leader-Hindu)

4.3.2.5 Religion and intellectual disability

As discussed in the section about perceived causes of ID, religious leaders explained ID as an ordeal imposed by God or a punishment for past sins (karma, hereditary sin). It is important to note that participants saw these concepts as not necessarily stigmatising of people with ID. The Hindu religious leader emphasised that *karma* is a personal process deemed important to purify the soul (*atman*) and that the person receiving his/her *karma* should not be shunned as the punishment has been settled prior to his/her rebirth.

> Because, from our perspective, it had been settled, because the process (of karma) is very personal. What had happened, has been settled... Now the person is born a new (P17/religious leader-Hindu)

The Protestant and the Catholic religious leaders emphasised that the concept of hereditary sin is no longer recognised in the religion, but the Protestant religious leader noted that it is still endorsed by priests of the previous generation, while younger priests tend to hold more positive perspectives of disability.

> … I remember that some priests have a funny perspective on disability. They relate disability with parents' sins… there is a concept of hereditary sin, although, in Christianity, the concept no longer exists (P11/ religious leader-Protestant)

Persons with disabilities are expected to be patient and adhere to the teachings of each religion as included in its holy books. In Islam, although disability is considered an imperfection, all humans are perceived to have some form of imperfection. Therefore, there is no reason to disregard people with disabilities on religious grounds. Treating people with disabilities with respect and honour is an Islamic teaching.

> The Prophet had an acquaintance who also had a disability… he was honoured by the prophet; he was cared for by the Prophet… (P09/religious leader-Islam)

Similar beliefs and teachings were also expressed in an interview with the Protestant religious leader, who cited a parable from the Bible about a person with a disability who was received at a banquet.

> King Saul had a son named Mephibosheth. He was born with a disability… after King Saul died, King David welcomed Mephibosheth to dine at the same table as him (P11/religious leader-Protestant)

All participants from the religious leader group said that they would welcome people with ID at their service. One participant thought that the presence of people with ID at religious sermons would motivate the public to attend more frequently.

> I would feel grateful… with his condition, to attend a religious sermon… he would encourage other members to come and study religion (P09/religious leader-Muslim)

> There are various activities they (people with ID) could be involved in the Vihara (Buddhist monastery). They could go to the Sunday school which we have here (the Vihara) (P16/religious leader-Buddhist)

The Protestant religious leader suggested that people with ID could well play a (simple) role in religious activities, for example as ushers and welcoming worshippers.

> There is a role we call 'usher'. They are the receptionists. We could ask Rudy (mild ID) and Gilang (severe ID) to be the receptionists… we can ask Rudy to say something like 'Happy Sunday' or 'Welcome to the church' (P11/religious leader-Protestant)

4.3.2.6 Family-centric support

Most participants described the family as the central support for people with ID across domains of inclusion explored in this study, especially for living arrangement and lifelong support.

> Gilang (severe ID) can't live independently… he needs other's support and companionship. Q: Whom do you mean by other? A: Well, if his parents are no longer here, then his brother or sister should support him (P10/religious leader-Islam)

In line with this perspective, participants talked about marriage as a supporting system to complement and/or substitute the role of parents and sibling.

> I think having a family is not only about Rudy himself. When he is married, there will be others to help him, his wife, and his parents (P05/teacher mainstream education)

> I think it is important to have a child. And it will also be beneficial to have the children to care for Rudy in his old age (P09/religious leader-Islam)

The Buddhist religious leader mentioned the expectation towards the family of caring for their members with a disability as part of religious teaching.

> …we have a sentence from the holy book, if I may cite, there is the responsibility of parents towards their children, and there is the responsibility of children towards their parents. For example, is to care for children when they are ill… In the future… they could never be left alone, and therefore the parents should take the role (P16/religious leader-Buddhist)

One participant perceived sending people with ID to special institutions or arranging their marriage as an attempt by families to relinquish their responsibilities.

> I don’t recommend them to live there (special institution), because sending them to an institution may… be interpreted as removal of responsibility (from the family) (P04/medical doctor)

4.3.2.7 Challenges faced by people with intellectual disability in wider context

Poverty, as well as a lack of awareness and support from the government, were identified as the main challenges faced by people with ID in Indonesia. Both are associated with limited accessibility, availability of services, and opportunities for inclusion. In addition, adverse socioeconomic conditions mean that the basic needs of persons with ID and their families are often unmet.

> If they come from a poor family, life may be hard for them, because their parents should balance their focus between earning money to meet daily needs and look after their children, which takes a lot of their time (P04/general practitioner)

Participants commented on the government’s lack of interest in or prioritisation of people with disabilities, as well as acknowledging that a prevailing view suggests that people with ID are burdens to society. One participant cited a comment from a member of parliament, expressing this perspective.

> I heard a comment from one Member of Parliament regarding people with disabilities. He said, ‘we can’t afford to care for the handicapped while we still have normal people being left without care’. It is an example of the unsupportive environment faced by people with disabilities (P15/educational psychologist)

4.4 Discussion

4.4.1 Summary of results

The findings suggest that apparent or perceived deficits in adaptive abilities play an essential role in both attitudes toward people with ID and their inclusion in society. Therefore, participants showed more favourable attitudes towards people with mild ID and their inclusion compared to those with severe ID, which reflects the attitudes of the general public (Morin, Rivard, Crocker, Boursier, & Caron, 2013). In line with their attitudes, participants were more likely to advocate inclusive options for people with mild ID and more restrictive ones for people with severe ID in their advice. The finding suggests that the nature and severity of the disability were important drivers behind less favourable individual and public responses to inclusive practices (Avramidis & Norwich, 2002). It is also critical to note that a condition that may influence participants' attitudes towards inclusion is the availability of good quality services (Avramidis & Norwich, 2002). In general, participants perceived that the services currently available for people with ID in Indonesia are underdeveloped and limited.

4.4.2 Results in context

Studies from neighbouring countries (Malaysia and Singapore) suggest similar findings of positive attitudes among professionals. The studies found that teachers hold positive attitudes towards the inclusion of people with disability people (M. Ali, Mustapha, & Jelas, 2006; C. Clarke & Nomanbhoy, 1998; Lian et al., 2008). A study from Indonesia also found that mainstream teachers were eager to use sign language for students with severe ID (Sheehy & Budiyanto, 2014) which again confirmed present findings. However, it is crucial to carefully interpret the findings as this study use hypothetical cases (C. Clarke & Nomanbhoy, 1998) when discussing people with ID and their inclusion. One factor that may influence participants' attitudes in the present study is the extent of exposure. Participants in this study, aside from the three special education teachers, have not had much exposure to people with ID. Stakeholders with less exposure to people with ID are known to have more positive attitudes towards inclusion (Avramidis & Norwich, 2002). In their recommendation regarding community participation and employment, participants seem to have little consideration for social factors such as public attitudes and accessibility to employment that hamper inclusion. It is reported that people with disability in Indonesia have low access to employment (Prasetyo, 2014), and high levels of stigma towards people with ID present in the society (Komardjaja, 2005). Thus, participant’s recommendation may be seen as representing an idealistic point of view, regardless of actual condition. Nevertheless, the positive attitudes found in this study should be regarded as a strength and suggests that opportunities to promote and endorse the inclusion of people with ID in the society.

Hofstede (2001) defines culture as “the collective programming of the mind that distinguishes the members of one group or category of people from another” (p. 9), which includes beliefs, attitudes, skills and values. In this study, three factors that are embedded within the cultural context of Indonesia were found to underpin attitudes towards people with ID in Indonesia: family-centric support, interpretation of religious beliefs, and interpretation of ‘pity’, each discussed in turn below.

The family was cited as the primary source of support for people with ID, which may relate to the limited and underdeveloped services (e.g. daycare, professional provision) discussed earlier. An alternative explanation for this family-centric support may lie with Indonesian cultural values. Indonesian is a collectivist society, in which loyalty to family is paramount (Hofstede, 2001). These values are reflected, for example, in the Indonesian annual custom of ‘homecoming’ (*Mudik*) to celebrate the end of Ramadhan (the Muslim fasting month), which has long become an inclusive custom regardless of ethnicity and religion (Yulianto, 2011). During *Mudik*, millions of people travel from urban areas, where they work and make a living, to rural areas where their families live. Given their loyalty to family, children are expected to care for parents in their old days, as sending them to a care home would be seen as irresponsible or even treason (*durhaka*). In a collectivist society, the family is seen as the source of protection against the hardship of life (Hofstede, 2001). Therefore, the family is expected to hold responsibility for family members with a disability. Due to the family is seen as the primary source of support while professional support is lacking, it is essential to consider families' experience of providing care for their members with ID. Several studies have found associations between caring for a family member with ID with lower quality of life (Brown, MacAdam-Crisp, Wang, & Iaroci, 2006), depression (Olsson & Hwang, 2001), stigma, and social restrictions (Ngo et al., 2012) in caretaking.

Causal explanations of ID which are based on the belief of God’s punishment, ordeals and past sin emerged during the interview with the religious leaders. Such beliefs are known to be related to negative attitudes (J. Carter, 2009; Hubert, 2006; Moreira, 2011; Scior & Furnham, 2016). However, it is interesting that the religious leaders’ attitudes were more inclined towards the positive as it was reflected in the overall finding of this study. This was possible because the religious leaders in this study were interpreting those beliefs in a more positive tone, which allows them to express positive attitudes despite holding such beliefs. Interpretation (or re-interpretation) of religious beliefs and teachings is a privilege held by religious leaders, which could be seen as an opportunity to endorse positive attitudes among the followers.

The majority of participants express pity (*kasihan*) as their emotional response to people with disability. Pity was expressed as the basis of their eagerness to help, including when providing their services as professionals. While pity is generally perceived as a negative and unwanted response within the context of disability, it is arguably considered as positive and expected response in Indonesian context and its neighbouring countries such as Cambodia (Moreira, 2011). The word ‘*kasihan*’, which commonly used as translation of ‘pity’, shares similar meaning to ‘*belas kasih*’ which can be translated to ‘mercy’ or ‘compassion’; it derived from a homonym Indonesian word of ‘*kasih*’ which means ‘love’ or ‘to give’ (Indonesian Language Development and Guidance Agency, 2016). Therefore, the word ‘*kasihan*’ is hardly considered to be derogatory in its literal meaning. In the Indonesian culture, it is almost obligatory to express ‘*kasihan*’ as a response to people perceived to be in needs or facing hardship, while not feeling ‘*kasihan*’ to such people may attribute to lack of compassion or heartless. Therefore, participants response related to pity in the present finding should not be prematurely judged as a negative response, and consideration towards the cultural context of ‘pity’ should be endorsed in the effort to explore attitude across cultural contexts. In parallel, the reaction of people with ID towards ‘pity’ and their expectation of social response should also be further explored and accounted for.

Participants identified stigma as the barrier of inclusion. Stereotypes, derogatory terms, bullying and the idea that sterilising people with ID is acceptable were mentioned in the interviews; similar findings were found in studies conducted in a Cambodian context (J. Carter, 2009; Moreira, 2011). Bullying was reported by participants as happening in educational settings and on the broader community. Bullying in educational settings suggests that more work is needed to target disablist attitudes among children and young people, as well as at the community level. Stigma was associated with a lack of awareness and knowledge, as well as the perspective of disability among community members. The perspective that people with disabilities are a burden on society were reported to be held by politicians in the country, but there is no other evidence to confirm or refute what may be anecdotal conjecture. The perspective that people with disabilities are a burden to society, as reported in this study, must be critically challenged if positive attitudinal changes are to take hold and affect the availability and quality of public services for people with ID in Indonesia. Given that stigma was reported to be present, it is critical to explore the experience and everyday life of people with ID further, as well as the extent to which they are affected by stigma.

4.4.3 Strength and limitation

This study is the first to explore the attitudes of professionals towards people with ID in an Indonesian context. Semi-structured interviews were conducted in this study, thereby offering the flexibility to explore key points and perspectives as they arise. Interviews were conducted by a single interviewer (the student), which provided a standardised process for carrying out semi-structured interviews. The student is a native Indonesian clinical psychologist who has experience working with people with ID in Indonesia. Five domains of inclusion were covered in this study, providing broad perspectives on the inclusion of people with ID in the Indonesian context.

The number of participants in the study was small, and the participants were self-selected. Therefore, participants' perspectives may not represent the wider community of professionals working with ID in Indonesia. Convenience sampling, including the use of student's work and personal contacts, and snowballing utilised in this study, accounted for further sampling bias and issue on representativeness. However, this study took advantage of the flexibility inherent in convenience sampling to gain a wider perspective, seen, for example, in the recruitment of religious leaders from five different religions. As the participants in this study are heterogeneous, differences in their beliefs, values, and knowledge may influence their attitudes towards people with ID and inclusion, which was most evident among religious leaders whose attitudes were influenced by their religious beliefs of piety and unconditional acceptance. Participants were recruited in selected urban areas due to resources available for this study. Therefore, this study may not reflect a more traditional community in rural areas, in which religion may play a greater role. Information on participants' prior contact with people with ID was based on self-reporting, which may not be accurate for participants who are unfamiliar with the characteristics of ID.

Thematic analysis was utilised in this study as it provides a flexible approach which can be modified to accommodate the need of many studies (Nowell, Norris, White, & Moules, 2017), including those with small data sets and heterogeneous samples (V. Clarke & Braun, 2017) such as the present study; while also providing detailed and rich data (Nowell et al., 2017). However, the flexibility of thematic analysis offered as its main advantage can also be a disadvantage, as it may lead to a lack of coherence in theme development (Nowell et al., 2017).

4.4.4 Critical Reflexivity

As this study addressed professionals' attitudes towards people with ID, as well as how religious background affect such attitudes, it is important to convey that the student is also part of the studied population as he is a clinical psychologist working with children with ID and their family as well as being a practicing Muslim. Therefore, it is possible that the student's educational, professional and religious background may have affected the interview process. The student felt that some participants (including medical doctors and psychologists) appeared to be uncomfortable with their answers especially on the questions about the cause of ID. As soon as the interview ended, the participants asked whether they answered the questions in the wrong way, or whether they had made mistakes in answering any of the questions.

The student believes that his religious background could have also affected how he conducted the interviews as well as participant recruitment. For example, due to his prior knowledge about Islamic teaching, the student would ask further questions to non-

Muslim religious leaders when they mentioned a religious-related concept, while under the same circumstances with Muslim religious leaders, the student would use fewer prompts. Furthermore, the student believes that his religious background, to some extent, might have facilitated the recruitment of Muslim participants from his professionals and personal contacts. On the other hand, the student struggled to find participants from non-Muslim religious background. The student had to contact the national representative organisation of the religion in question and asked an acquaintance who worked in a university affiliated with a religious organisation to recruit participants from non-Muslim faiths. The student also experienced rejection from one non-Muslim religious leader who asked the student's religious affiliation, and subsequently refused to take part in the study.

4.5 Conclusion

This study provides information on attitudes towards people with ID and their inclusion in an Indonesian context, as reported by professionals. Overall, the findings are encouraging as professionals generally hold positive attitudes towards people with ID and their inclusion in society. There is an urgent need for greater efforts to reduce stigma and promote the inclusion of people with ID in general Indonesian society.

4.6 Acknowledgements

I thank all the collaborating institutions for their support with participant recruitment. I also thank Ms Ria Dwi Agustina for reviewing the initial coding structure of this study.

Chapter 5 Adaptation of a self-report stigma questionnaire and exploration of stigma experience in adults with mild to moderate intellectual disability in Indonesian context.

5.1 Introduction

The self-report stigma questionnaire was originally developed to be used in the UK (A. Ali et al., 2008). The questionnaire comprises 10 items aimed at measuring the experience of stigma by adults with mild and moderate ID and their emotional response to it. It is written in an easy-to-read format, i.e., each statement is accompanied by a suitable picture to help the respondent understand the statement. The statements are scored through a dichotomous response, wherein participants respond 'yes' or 'no' based on whether they have experienced the situation described in the statement. Although intended as a self-report questionnaire, it is suggested that the respondents be prompted to provide examples of their experiences and justify their response for each of the items to avoid acquiescence bias (tendency to agree with all the items) (A. Ali et al., 2008). The questionnaire has previously been adapted and validated for other cultures, such as in the South African context, and proven to have sound psychometric properties (Kock et al., 2012).

5.1.1 Aims and objectives

This study aims to adapt the self-report stigma questionnaire to the Indonesian cultural context in order to examine the psychometric properties of the Indonesian version of the questionnaire and to examine the self-reported stigma score obtained from this version. In this study, 21 preliminary items of the UK version of the questionnaire were chosen, instead of the final 10 items, in anticipation of the potential cultural differences between England and Indonesia. The following questions were addressed:

- What is the test–retest and internal reliability of the Indonesian version of the self-report stigma questionnaire?
- What is/are the common underlying factor(s) of the Indonesian version of self-report experience stigma questionnaire?
- What is the average of the stigma score among adults with mild to moderate ID in Indonesia? Are socio-demographic characteristics related to the experience of stigma?

5.2 Method

5.2.1 Ethics statement

Ethical approval was obtained from the UCL Research Ethics Committee (UCL REC) in October 2016 (project ID number 8849/001), see appendix 5. The participant information sheets, consent forms, and the questionnaire used in the study were reviewed and approved by the committee. The participants involved in the study were required to provide written consent prior to their participation, and therefore, have sufficient receptive and expressive language ability and be able to express their wishes. The participant information sheet and consent forms utilised in the study were written in an easy-to-read format, with simple text and accompanying pictures to aid the participants' comprehension of the study. Participants who decided not to participate or those who lacked the capacity to do so were not included. Participant information sheet and informed consent form are available in Appendix 8.

Participants recruited in this study were nominated by organisations (Special Olympics Indonesia, a special school and a rehabilitation day centre) which provide services to the participants. Upon obtaining verbal agreement (from the potential participant) to meet the student, staff assisted in arranging a meeting between the student and the potential participant which took place within the premises of the organisation. The student explained the aims of the study by reading the information sheet together with the potential participant, or by reading the information sheet to the potential participant for those with limited reading skills. The student highlighted that decision to or not to participate in this study would not change access to services the participant was currently receiving. Written consent was taken from the potential participant upon receiving his/her agreement to participate in this study. A staff member of the respective institution was present during the meeting, to ensure that the participants had access to support if needed as well as in order to comply with the recommendation from the UCL REC.

The student collected and stored personal (demographic) information including sex, ID level, age, occupation, co-occurrence of Down Syndrome, ethnicity, living area, and religious affiliation, while identifier information such as name were retained by the institutions. Personal information and data containing such information were stored and processed in UCL data haven. Any identifier information was removed from the data (anonymised) prior analysis, so participant could not be identified.

5.2.2 Translation and adaptation

This study follows the stages of the translation and adaptation process carried out in the previous study that aimed to translate and adapt the self-report stigma questionnaire from the UK context to the South African context (Kock et al., 2012). The process comprised the translation and back translation of the questionnaire and involved professionals to provide feedback on the questionnaire and piloting of the questionnaire to people with mild to moderate ID.

The translation and adaptation of the questionnaires follows the sequence of starts with the forward and back translation of the questionnaires. The student translated the initial

21 items of the UK version of the questionnaire into the Indonesian language. He is a native Indonesian speaker with a good proficiency in English and is experienced in working with people with ID, being a clinical psychologist. The translation was back-translated into English by a professional translator to ensure that the questionnaire retained its original meaning. The accompanying pictures in the UK version of the questionnaire were swapped for pictures more suitable to the Indonesian context. The 21 items of the UK version as well as their Indonesian versions are available in Appendix 9. From this point forward, the translated questionnaire will be referred to as the self-report stigma questionnaire Indonesian version (SRSQ-I).

Two professionals, a clinical psychologist and a social worker (both with over 5 years of experience of working with people with ID) provided feedback on the translated questionnaire and examined its suitability for the Indonesian population with ID. The stigma questionnaire was refined with the help of their comments. For instance, the wording of some items was changed to a simpler structure (see appendix 10). The stigma questionnaire was examined in a discussion group involving three adults with mild (n=2) and moderate (n=1) ID to ensure its utility and clarity. The discussion group was facilitated by the student and attended by a staff member of the organisation from which the respondents had been recruited. The staff member was invited to attend the discussion to provide support to the participants, such as to better explain the meaning of the items and the topics of discussion when needed.

The questionnaire was piloted with three other respondents with mild (n=2) and moderate ID (n=1) to further examine the readability of the items. The piloting was carried out to determine whether the people with mild to moderate ID could complete the questionnaire independently or if they needed assistance, and if yes, the level of assistance they needed. A staff member was present during the piloting as well to provide assistance when necessary. No amendments were made after the piloting, as the respondents with mild ID were able to complete the questionnaire independently, while the participants with moderate ID were able to complete it with minimal assistance in the reading and comprehension of some items. The student provided assistance by reading the items to the respondents and prompting examples to ensure that the participants responded.

5.2.3 Test–retest reliability

5.2.3.1 Participants

This study involved 100 participants with mild or moderate ID. The participants were recruited from three organisations providing services and support to people with ID – a special school, a rehabilitation centre, and an NGO. The inclusion criteria were (1) adults aged 17–55 years (2) mild or moderate ID, and (3) no comorbid conditions such as autism spectrum disorder (ASD), ADHD, and psychosis. The lower limit of the age range of the participants was determined on the basis of the definition of adults in the Indonesian context. At the age of 17 years, an Indonesian individual receives a national identification card and is granted full citizenship, including civic rights to vote. Therefore, a 17-year-old person is considered as an adult. The upper age limit of 55 years was based on the pensionable age as stated in the Indonesian pension law. The inclusion criteria in this study is related to the qualitative study that explored the stigma of adults with mild to moderate ID (see chapter 6), since both are carried out in a multimethod study. The qualitative study aimed to explore stigma along with the extent of inclusion in the society, including current employment experience. Therefore, the upper age range was based on the pension law, excluding those of retirement age.

The potential participants were referred by their respective organisations based on the inclusion criteria stated above after the organisations ensured their eligibility and obtained verbal consent from each individual to meet the researcher. The diagnosis of

ID and severity level were confirmed by the organisation based on the relevant information in their database. However, one organisation could not provide information about the severity level, as this was not included in its database. To compensate for this, a screening assessment was carried out by two psychologists (including the student) for all individuals referred by collaborating organisations to determine the severity level. A questionnaire based on the characteristics of mild and moderate ID as stated in the Diagnostic and Statistical Manual of Mental Disorder, 5th Edition (DSM-V) (American Psychiatric Association, 2013) was utilised for the screening. The questionnaire is available in Appendix 11.

5.2.3.2 Procedure

The participants were asked to complete the SRSQ-I on two occasions that were scheduled two weeks apart to balance the risk of respondents recalling their previous answers with the possibility of encountering new stigmatising experiences. The student individually administered the questionnaire to each participant to ensure that all the participants filled it correctly and to provide assistance when needed. A staff member of the organisation from which the participants received services was also present in all the administration sessions to provide support and assistance, such as ensuring the comfort and safety of participants as well as to comply with the administration procedure suggested by the UCL Research Ethics committee. The SRSQ-I administration was carried out within the premises of the collaborating organisation in a room provided by the administration of the special school, a sports venue where the collaborating NGO held their weekly practice, and a room provided by the rehabilitation centre. The administration typically took between 15 to 20 minutes. Figure 5-1 describes the recruitment flow of participants in this study.

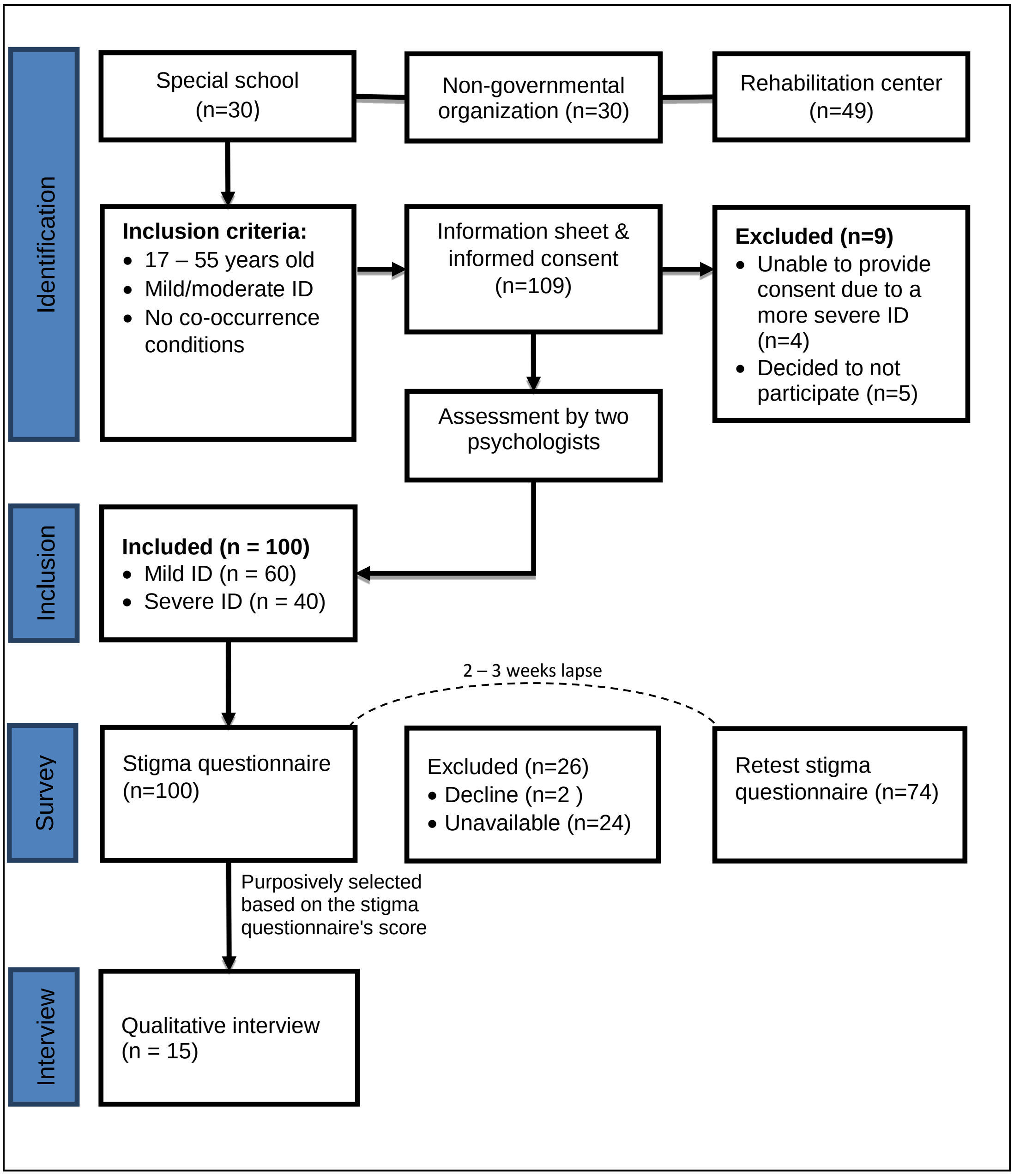

Figure 5-1 Participants recruitment flow

5.2.4 Data analysis

The STATA statistics software package was utilised to analyse the data collected in the study. Response distributions, tetrachoric correlation, multiple correspondence analysis, and Cronbach alpha were calculated to examine the psychometric properties of the SRSQ-I. Based on the result of the response distribution analysis, items with little variation in response distribution (≤20% or ≥80%) were removed, as they would be less likely to differ in a person with low experience of stigma than another with high experience of stigma (A. Ali et al., 2008; Kock et al., 2012). Due to its binary ('yes' or 'no') response format, tetrachoric correlation was used to examine the test–retest reliability of the questionnaire (Long, Berry, & Mielke Jr, 2009). The correlation coefficients of the items were examined, and items with a correlation coefficient less than .4 were removed (A. Ali et al., 2008; Kock et al., 2012).

Multiple correspondence analysis (MCA) was conducted to identify and represent underlying structures in the SRSQ-I to estimate the construct validity of the questionnaire. MCA can be used as an alternative to the principal component analysis, given that the data to be analysed are categorical (Abdi & Valentin, 2007). Lastly, Cronbach alpha was calculated to examine the internal consistency of the SRSQ-I, i.e., how closely related a set of items are as a group. It is considered to be a measure of scale reliability. Descriptive statistics were used to present and examine the total stigma score obtained from the final items of the SRSQ-I. The chi-squared test and multiple regression were computed to examine the relationship between the stigma score and socio-demographic characteristics of the participants.

5.3 Results

5.3.1 Response rate and questionnaire administration procedure

The participants were recruited between 4 November 2017 and 13 March 2018; 109 people with ID were initially referred to this study. Five individuals decided not to be included in this study after reading – or hearing, as it was read out – the information sheet of the study, while four were considered ineligible due to a more severe level of ID, as they did not fulfil the inclusion criteria. The 100 participants included in the study completed the first administration of the questionnaire. Although all the participants consented to complete the questionnaire for the second time, only 74 participants were available to do so. Two participants withdrew from completing the questionnaire for the second time, while 24 were unavailable (either could not be contacted or did not attend the organisations' weekly meeting). Although a two-week interval between the test and retest had been initially planned, 19 participants completed the retest within three weeks of the first completion due to their availability.

Of the total participants, 63 participants were able to complete the questionnaire with minimal assistance, while the remaining 37 participants required assistance in reading the questionnaire items and providing examples of the situations reflected by the items. Minimal assistance implies helping the participant to read the items, as some participants possessed elementary level reading despite belonging to the mild ID category. In these cases, the student helped read the items while prompting examples from the participant to ensure his/her understanding of the item. Participants categorised as 'needing assistance' were those who required to be repeatedly prompted and/or needed to be given examples of the situations addressed by the items.

5.3.2 Socio-demographic characteristics

Out of the total sample, 60 participants (60%) had mild ID, 40 (40%) had moderate ID, and 12% had Down syndrome. The ages ranged between 17–44 years (M = 24, SD = 7.11). The majority (68%) fell between the ranges of 17–25 years, while 21% were 26–35-years-old, and 11% were 36–45-years-old. A majority of the participants were Javanese (61%), followed by Chinese (18%), Betawi (8%), Padang (4%), and Bataknese (2%) populations. The rest of participants (7%) belonged to the seven other ethnic groups (Balinese, Manado, Sundanese, Banten, Banjar, Talaki, and Palembang). Most of the participants (75%) practised Islam, 11% practised Catholicism, 9% practised Protestantism, 4% practised Buddhism, and 1% practised Hinduism.

The participants in this study were mostly trainees in a rehabilitation centre (54%), and only one participant had full employment. Over half (54%) of the participants lived in their family homes, and a majority (56%) were recruited from urban areas (see Table 3 for details).

Table 3. Socio-demographic characteristics

Characteristic	N (%)	Characteristic	N (%)
Sex		Down syndrome	
Male	65 (65)	With	12 (12)
Female	35 (35)	Without	88 (88)
ID level		Ethnicity	
Mild	60 (60)	Javanese	61 (61)
Moderate	40 (40)	Chinese	18 (18)
Age		Betawi	8 (8)
17-25	68 (68)	Padang	4 (4)
26-35	21 (21)	Bataknese	2 (2)
36-45	11 (11)	Others	7 (7)
Occupation		Living area	
Student	24 (24)	Urban	(56) 56
In training	54 (54)	Rural	(44) 44
Sheltered employment	15 (15)	Religion	
Unemployed	6 (6)	Islam	(75) 75
Full employment	1 (1)	Catholic	(11) 11
Housing		Protestant	(9) 9
Family home	54 (54)	Buddhism	(4) 4
Institution	45 (45)	Hinduism	(4) 1
Supported housing	1 (1)		

5.3.3 Psychometric properties of the 21-items stigma questionnaire

5.3.3.1 Response proportion

The proportions of responses for each item are described in Table 4. Three items (items 3, 7, and 9) were answered 'yes' by fewer than 20 participants, while three other items (items 11, 14, and 16) were answered 'yes' by over 80% of participants. These six items showed little variation in response and were considered less useful in identifying people with differing levels of stigma. Therefore, these six items have been removed from the analysis and depicted in shaded areas in Table 4.

Table 4. Response distributions SRSQ-I, 21 items, English, (n=100)

No	Item	'Yes' response (%)
1	People talk down to me	56
2	People think I am not as good as them	52
3	The police has treated me badly	3
4	I think I am the same as other people	43
5	The way people talk to me makes me angry	48
6	People make me feel embarrassed	44
7	Doctors and nurse have treated me badly	8
8	People on the street make fun of me	32
9	People on the street have hit me	13
10	People on the street look at me in funny way	25
11	People like to talk to me	82
12	People make fun of my family	21
13	No one bothers me when I use buses, trains or taxis	78
14	I feel welcome in shops or restaurants	85
15	People laugh at me because of the way I look	22
16	People are nice to me	87
17	People treat me like a child	26
18	I keep away from other people because they are not nice to me	40
19	People laugh at me because of the way I talk	36
20	I worry about the way people act towards me	44
21	People make fun of me about going to the special school	47

5.3.3.2 Item test–retest reliability

Table 5 depicts the tetrachoric correlation of each item in the questionnaire. The items with rho coefficient less than .4 were eliminated. Therefore, items 10 and 19 were eliminated. At this stage, 13 items remained.

Table 5. Test–retest reliability tetrachoric correlation

No	Item	rho (p≤0.05)
1	People talk down to me	0.402*
2	People think I am not as good as them	0.723*
4	I think I am the same as other people	0.670*
5	The way people talk to me makes me angry	0.665*
6	People make me feel embarrassed	0.730*
8	People on the street make fun of me	0.759*
10	People on the street look at me in funny way	0.351
12	People make fun of my family	0.755*
13	No one bothers me when I use buses, trains or taxis	0.802*
15	People laugh at me because of the way I look	0.552*
17	People treat me like a child	0.513*
18	I keep away from other people because they are not nice to me	0.532*
19	People laugh at me because the way I talk	0.258
20	I worry about the way people act towards me	0.641*
21	People make fun of me about going to the day centre	0.743*

5.3.3.3 Multiple correspondence analysis (MCA)

This study used MCA to identify the underlying factors of the questionnaire. Initially, exploratory factor analysis (EFA) was attempted to be used as the analysis method to identify underlying factors, as it has been used in previous studies (A. Ali et al., 2008; Kock et al., 2012). Upon performing the Kaiser–Meyer–Olkin (K–M–O) test on the tetrachoric correlation matrix in STATA to examine the data suitability for factor analysis, an error message indicated that the correlation matrix was singular, which indicates that the matrix has rows or columns that are linearly interdependent, violating one of the assumptions in EFA. Attempts to remove the linear interdependent rows or columns (in this case, items) resulted in a K–M–O value of less than .5, which indicated that factor analysis would not be very useful for the current dataset. Therefore, MCA was used as an alternative method to identify the underlying factors, especially since the data being analysed are categorical ('yes' and 'no' responses) (Abdi & Valentin, 2007).

MCA found that the first factor explained 73.1% of the total inertia (variance), while the remaining four factors explained only 6.2%, 3.1%, .03%, and .01% of the variance, respectively (see Table 6). Therefore, one-factor solution was deemed preferable for the SRSQ-I.

Table 6. Multiple correspondence analysis, principal normalization

Dimension	Principal Inertia	Percent	Cumul. Percent
dim 1	0.0291122	73.12	73.12
dim 2	0.0024699	6.2	79.33
dim 3	0.0012417	3.12	82.45
dim 4	0.0000108	0.03	82.47
dim 5	1.99E-06	0.01	82.48
Total	0.0398128	100	

The MCA plot (see Figure 5-2) was observed to examine the items' response pattern. The responses of items were clustered together, except for item 4 that formed its own pattern, indicating that the item is incompatible with the other items. Therefore, it was removed.

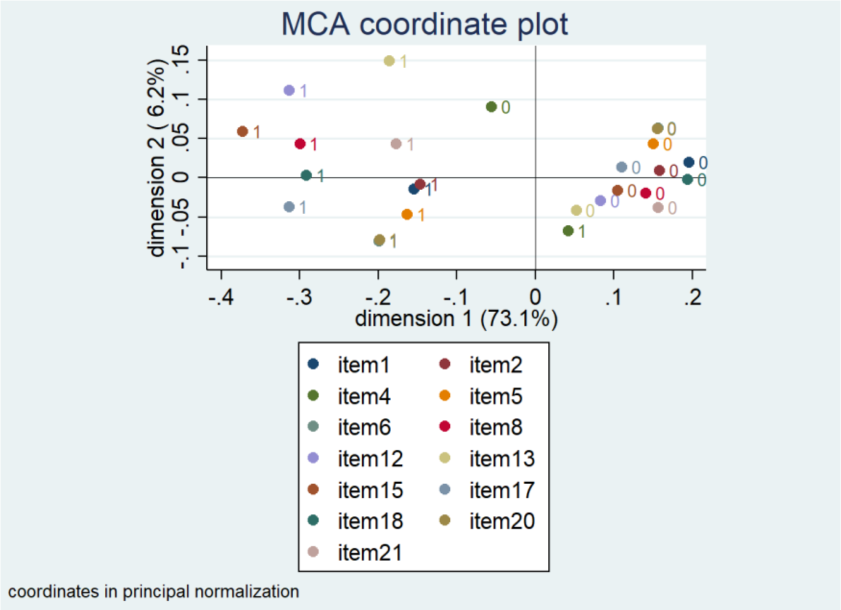

Figure 5-2 Multiple correspondence analysis coordinate plot

5.3.3.4 Internal reliability and total score test–retest reliability

Cronbach's alpha was used to examine the internal consistency of the items in the questionnaire. Item-rest correlation found that all items, except item 13, had a good correlation with the other items, with *r* ranging from .308 to .527. Subsequently, item 13 was eliminated, making the alpha of final questionnaire .727 (see Table 7).

Table 7. Internal reliability, item total correlation, and alpha coefficient

No	Item	Item-rest correlation	Alpha if deleted
1	People talk down to me	0.364	0.703
2	People think I am not as good as them	0.318	0.709
5	The way people talk to me makes me angry	0.308	0.711
6	People make me feel embarrassed	0.351	0.705
8	People on the street make fun of me	0.430	0.694
12	People make fun of my family	0.315	0.710
13	No one bothers me when I use buses, trains or taxis	0.179	0.727
15	People laugh at me because of the way I look	0.391	0.699
17	People treat me like a child	0.381	0.701
18	I keep away from other people because they are not nice to me	0.527	0.680
20	I worry about the way people act towards me	0.350	0.705
21	People make fun of me about going to the special school	0.348	0.705

Test–retest reliability between the total stigma score and the final 11 items of the SRSQ-I was calculated. The results showed that the SRSQ-I has a test–retest reliability of .779 for the total stigma score and a range of .402–.759 for each item in the questionnaire (see appendix 12).

5.3.4 Exploration of participants' responses to the final 11 items of the SRSQ-I

5.3.4.1 Response distribution

A total of 100 participants completed the questionnaire. The majority answered 'yes' for two items: 'people talk down to me' (56%) and 'people think I am not as good as them' (52%). Over 40% of the participants responded with a 'yes' to five items: 'the way people talk to me makes me angry' (48%), 'people make me feel embarrassed' (44%), 'I keep away from other people because they are not nice to me' (40%), 'I worry about the way people act towards me' (44%), and 'people make fun of me about going to special school' (47%). A smaller percentage of participants responded with a 'yes' to the remaining four items: 'people on the street make fun of me' (32%), 'people make fun of my family' (21%), and 'people laugh at me because of the way I look' (22%). Table 8 presents the distribution of the participants' responses.

Table 8. Distribution of response 11-items SRSQ-I

No	Item	Response (%)	
		Yes	No
1	People talk down to me	56	44
2	People think I am not as good as them	52	48
3	The way people talk to me makes me angry	48	52
4	People make me feel embarrassed	44	56
5	People on the street make fun of me	32	68
6	People make fun of my family	21	79
7	People laugh at me because of the way I look	22	78
8	People treat me like a child	26	74
9	I keep away from other people because they are not nice to me	40	60
10	I worry about the way people act towards me	44	56
11	People make fun of me about going to the day centre	47	53

5.3.4.2 Analysis of responses by socio-demographic characteristics

The chi-squared test was calculated to examine the proportion of responses between socio-demographic groups that were classified into two categories (dichotomised) – age group (aged 17–23 years versus 24+ years), sex (male versus female), Down Syndrome (with versus without), ethnicity (Javanese versus non-Javanese), religion (Islam versus other religions), housing (home versus institution), and occupation (employed versus unemployed). Table 9 presents information about frequency of responses (f) and expected frequency of responses (expected f) on eight items of the SRSQ-I that have significant ($p < .05$) results in terms of the relationship between response to the items and the socio-demographics characteristics being considered – religious and ethnic background, age, employment status, and living area. The result of the chi-squared test for the 11 items of SRSQ-I is available in appendix 13.

Table 9. Chi-squared table, stigma, and socio-demographic characteristics

Item	Socio-demographic groups		Response		Total
			Yes	No	
People talk down to me	Islam	F	37	38	75
		Expected f	42	33	75
		Row %	49.3	50.7	100
	Non-Islam	F	19	6	25
		Expected f	14	11	25
		Row %	76	24	100
	Pearson chi (1)		5.41		
	p		0.02		
People make me feel embarrased	Employed	F	3	13	16
		Expected f	7	9	16
		Row %	18.7	81.2	100
	Unemployment	F	41	42	84
		Expected f	37	47	84
		Row %	48.1	51.2	100
	Pearson chi (1)		4.93		
	p		0.03		
	17–23 years old	F	30	25	55
		Expected f	24.2	30.8	55
		Row %	54.5	45.4	100
	24–25 years old	F	14	31	45
		Expected f	19.8	25.2	45
		Row %	31.1	68.9	100
	Pearson chi (1)		5.52		
	P		0.02		

Table 9. Chi-squared table, stigma, and socio-demographic characteristics (continue)

Item	Socio-demographic groups		Response		Total
			Yes	No	
I worry about the way people act towards me	17–23 years old	F	30	25	55
		Expected f	24.2	30.8	55
		Row %	54.55	45.4	100
	24–25 years old	F	14	31	45
		Expected f	19.8	25.2	45
		Row %	31.11	68.9	100
	Pearson chi (1)		5.52		
	p		0.02		
People on the street make fun of me	Urban	F	23	33	56
		Expected f	17.9	38.1	56
		Row %	41.1	58.9	100
	Rural	F	9	35	44
		Expected f	14.1	29.9	44
		Row %	20.4	79.5	100
	Pearson chi (1)		4.81		
	p		0.03		
People treat me like a child	Urban	F	19	37	56
		Expected f	14.6	41.4	56
		Row %	33.93	66.1	100
	Rural	F	7	37	44
		Expected f	11.4	32.6	44
		Row %	15.91	84.1	100
	Pearson chi (1)		4.16		
	P		0.04		
People make fun of my family	Javanese	F	8	53	61
		Expected f	12.8	48.2	61
		Row %	13.1	86.9	100
	Other ethnicity	F	13	26	39
		Expected f	8.2	30.8	39
		Row %	33.3	66.7	100
	Pearson chi (1)		5.86		
	p		0.01		
People laugh at me because of the way I look	Javanese	F	9	52	61
		Expected f	13.4	47.6	61
		Row %	14.7	55.2	100
	Other ethnicity	F	13	26	39
		Expected f	8.6	30.4	39
		Row %	33.3	66.7	100
	Pearson chi (1)		4.78		
	p		0.03		

Table 9 demonstrates that participants belonging to minority religious backgrounds were found to be more likely to respond with 'yes' to the item 'people talk down to me' (76%) than participants following the Islamic faith (49.3%). The relationship between religious background and responses to the item 'people talk down to me' are statistically significant, as X^2 (1, N = 100) = 5.41; *p* = .02. It can also be seen that participants with no employment were found to be more likely to respond with 'yes' (48.1%) to the item 'people make me feel embarrassed' than participants with employment (18.7%). This relationship between employment status and response to the item 'people make me feel embarrassed' is statistically significant, as X^2 (1, N = 100) = 4.93; p = .03. Similarly, participants belonging to a younger age group (54.5%) were found to be more likely to respond 'yes' to the item 'people make me feel embarrassed' than participants from an older age group (31.1%). The relationship between the age group and response to the item is statistically significant, as X^2 (1, N = 100) = 5.52; p = .02.

As depicted in Table 9, a relationship between age groups and response was found with regard to the item 'I worry about the way people act towards me'. Younger participants (54.5%) were found to be more likely to answer 'yes' than their older counterparts (31.1%). This relationship between age group and response is statistically significant, as X^2 (1, N = 100) = 5.52; p = .02. Participants living in urban areas (41.1%) were more likely to answer 'yes' to the item 'people on the street make fun of me' than their counterparts living in rural areas (20.4%). The relationship between living area and response to the item was statistically significant, as X^2(1, N = 100) = 4.81; p = .03. Participants living in urban areas were also more likely to answer 'yes' (33.9%) to the item 'people treat me like a child' than their counterparts living in rural areas (15.9%). The relationship between living area and response to the item is statistically significant, as X^2(1, N = 100) = 4.16; p = .04

Table 9 depicts that participants belonging to minority ethnic groups (33.3%) were more likely to answer 'yes' to the item 'people make fun of my family' than Javanese participants (13.1%). This relationship between ethnic groups and response to the item is statistically significant, as X^2(1, N = 100) = 5.86; p = .01. Similarly, a relationship between ethnic groups and responses was also found in the item 'people laugh at me because of the way I look', where participants belonging to minority ethnic groups were more likely to respond 'yes' (33.3%) than Javanese participants (14.7%) , and X^2(1, N = 100) = 4.78; p = .003.

5.3.4.3 Descriptive statistics of the stigma scores

The stigma score mean was found to be 4.32 (SD = 2.711), ranging from 0 to 11. The skewness and kurtosis were analysed to examine the distribution of the total SRSQ-I score. The analysis shows skewness = .208, p > .05 and kurtosis = 2.362, p > .05. The stigma score is normally distributed, confirmed using the Shapiro–Wilk test of normality, where W = .977, p > .05, as presented in Table 10.

Table 10. Descriptive statistics stigma scores

Variable	Range	Mean	SD	Kurtosis	Skewness	Shapiro-Wilk	
						W	*p*
Total stigma	0–11	4.32	2.711	2.362	0.294	0.977	0.0723

The skewness and kurtosis scores indicate that the stigma score is positively skewed, implying that more participants scored lower in the questionnaire. This indicates that the tails of distribution are a little too thick and, consequently, a little too flat in the middle, as depicted in Figure 5-4.

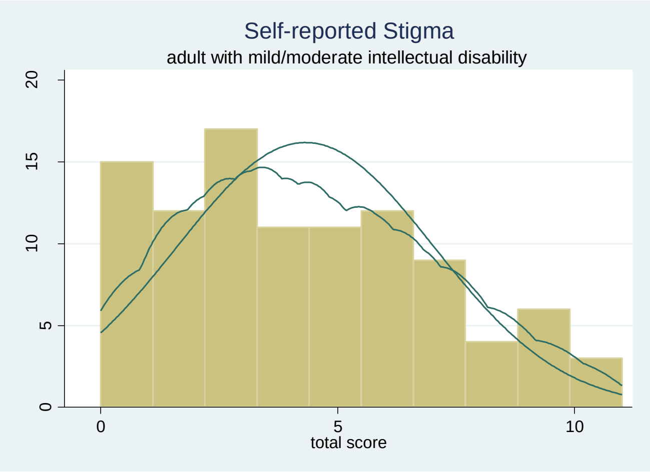

Figure 5-3 Histogram, stigma score

The frequency of total stigma score was further examined (see Table 11). In the sample of 100 people, only nine scored '0' on the SRSQ-I, which indicates that the stigma is common for participants, as most participants (81%) experience stigma to some extent.

Table 11. Frequency, stigma score

Score	Frequency	Cummulative %	Score	Frequency	Cummulative %
0	9	9	6	12	78
1	6	15	7	9	87
2	12	27	8	4	91
3	17	44	9	6	97
4	11	55	10	2	99
5	11	66	11	1	100

5.3.4.4 Socio-demographic characteristic as a predictor of stigma

A regression model including dichotomised socio-demographic characteristics – sex, age, ID level, Down Syndrome, ethnicity, religion, housing, occupation, and living area – explains 12.5% of the variance in the stigma experience of adults with ID in Indonesia, *F* (9,90) = 1.42, *p* = .190. The model suggests that 'age' has a moderate and statistically significant effect, β = -.273, *p* = .021, while none of the remaining socio-demographic characteristics have a statistically significant effect. Table 12 presents the results of the multiple regression analysis.

Table 12. Multiple regression, total stigma score, and socio-demographic variables

Characteristics	Coef.	t	p	β
Sex	-0.507	-0.84	0.405	-0.090
Age	-1.481	-2.35	0.021	-0.273
ID level	-0.337	-0.53	0.596	-0.612
Down syndrome	0.346	0.36	0.720	0.042
Ethnicity	0.721	1.00	0.318	0.130
Religion	-0.041	-0.05	0.961	-0.007
Housing	5.039	1.79	0.076	0.929
Occupation	-0.213	-0.23	0.817	-0.029
Living area	-5.530	-1.90	0.060	-1.017
_constant	6.925	2.06	0.042	
F (9,90)	1.42			
Prob > F	0.190			
R2	0.125			
Adj R2	0.037			

5.4 Discussion

5.4.1 Summary of results

The final version of the SRSQ-I consists of 11 items. The questionnaire was found to have good test–retest reliability with Spearman's rho, ranging from .402 to .759 for the 11 items, and good internal consistency of alpha .727. One underlying factor labelled 'experienced stigma', was identified. The examination of the total stigma score obtained from the final 11 items found a mean of 4.32 (out of 11). Furthermore, only nine participants (out of 100) scored zero in the SRSQ-I, which suggests that stigma is a common experience among participants. This finding supports previous studies that suggest that people with ID experience stigma in their day-to-day lives (Jahoda & Markova, 2004; Scior et al., 2015).

This study suggests a relationship between the participants' responses for particular items in the SRSQ-I and their socio-demographic characteristics. The chi-square analysis suggests that participants belonging to the younger age group, those living in urban areas, those who were unemployed, and those who came from minority ethnic and religious groups were more likely to respond affirmatively on particular items, suggesting that they are more likely to experience the stigma portrayed through the items. A regression model, considering socio-demographic characteristics as independent variables and the total stigma score as the dependent variable, suggested that 'age' is a predictor of stigma. This finding consistently suggests that participants belonging to a younger age group are more likely to experience stigma than those belonging to older age groups.

5.4.2 Results in context

The SRSQ-I retained a different set of items than its previous versions (the UK and the South African version). The SRSQ-I has one extra item that is not included in the other two versions, which only have 10 items. Apart from the number of items, the item structure of each version of the questionnaire also differ. The UK version contains two items not included in the SRSQ-I while sharing eight items. On the other hand, the SRSQ-I has five items not included in the SA version while sharing six items (see Table 13 below). Given that the item structure of each version of the questionnaire was different, it was not possible to compare the results of the studies.

Table 13. Item comparison – Indonesia, UK, and SA versions of self-report stigma questionnaire

Items	I	UK	SA
People talk down to me	✓	✓	
People on the street make fun of me	✓	✓	✓
People laugh at me because of the way I look	✓	✓	
People treat me like a child	✓	✓	✓
I worry about the way people act towards me	✓	✓	✓
The way people talk to me makes me angry	✓	✓	✓
People make me feel embarrassed	✓	✓	✓
I keep away from other people because they are not nice to me	✓	✓	
People think I am not as good as them	✓		
People make fun of my family	✓		
People make fun of me about going to special school/day centre	✓		✓
People on the street look at me in a funny ways		✓	✓
People laugh at me because of the way I talk		✓	✓
I think I am the same as other people			✓
People on the street have hurt me			✓

I = Indonesia, UK = United Kingdom, SA = South Africa

The item structure of the Indonesian version resembles that of the UK version more than the structure the SA version, as eight items are common between the Indonesian and UK versions as opposed to only six common items between the Indonesian and SA versions. The differences in items were possibly caused by the differences in the cultural context of the countries or the characteristics of the participants recruited in the studies. For instance, in a collective society such as Indonesia, it is common for people to associate a person with their family. Therefore, stigma is also overtly directed towards family (affiliate stigma), which is manifested through people stigmatising a person with

ID by making fun of the family, especially parents. This was represented in the item 'people make fun of my family'. This finding confirms that stigma is also directed at the people who have relationship or affiliation with the stigmatised person. This has been defined as affiliation stigma, and it was summarised in a recent systematic review (Mitter et al., 2019).

Another example of cultural influence could be seen in the item 'people make fun of me about going to the special school', which was adapted from the original UK version item 'people make fun of me about going to the day centre'. In the UK version, this item was removed as the examination of the response distribution found that only 14.5% responded with 'yes' (A. Ali et al., 2008), suggesting that in the UK context, a person with ID is less likely to be stigmatised due to receiving specialised services. On the other hand, in the Indonesian and SA contexts, people with ID seem to be stigmatised based on attending a segregated ('special') school and, therefore, the item was retained in both the versions (Kock et al., 2012).

It is important to note that the eleven items retained in the SRSQ-I are items that indicate the presence of experienced stigma. Agreement with the items indicate that the participants experienced higher levels of stigma, compared to those who disagreed with the item. The original twenty-one items included four ‘positive’ items, in which agreement with the items indicates that the participant experienced lower levels of stigma, compared to those who disagreed with the item, i.e. *‘people like to talk to me’*, ‘*I feel welcomed in shops or restaurants*’, ‘*people are nice to me*’, and ‘*I think I am the same of other people*’. However, these positive items were removed during the item analysis process. The first three items (*‘people like to talk to me’*, ‘*I feel welcomed in shops or restaurants*’, and ‘*people are nice to me*’) were removed because more than eighty percent of the participants responded ‘yes’ to the items, which means that the items are less useful in identifying people with different levels of stigma and may reflect a response set bias (A.

Ali et al., 2008). While the fourth item (‘*I think I am the same of other people*’) was removed in the multiple correspondence analysis stage, which indicated that the item did not measure the same construct as, and therefore was incompatible with, the rest of the items in the questionnaire. Interestingly, this result mirrors the findings of the original study (A. Ali et al., 2008) as the four items were removed for exactly the same reasons; which further validates the reasons for excluding these items. Item composition in the SRSQ-I which only consists of ‘negative’ items and removal of ‘positive’ items, raises questions about the questionnaire, such that it would not capture respondents’ positive experiences in society. However, in the context of questionnaire development and item analysis, removal of the items is of necessity; as retaining the item would lower the strength of the questionnaire which aims to differentiate those experiencing higher levels of stigma from those experiencing lower levels of stigma.

The MCA results suggest a one-factor solution for the SRSQ-I, which differed from the previous versions (UK and SA) that retained two factors. The first and second factors in the UK and SA versions were labelled as 'felt stigma' and 'reaction to felt stigma', respectively (A. Ali et al., 2008; Kock et al., 2012). On the other hand, the Indonesian version labelled only one factor, which was 'experience of stigma'. A potential reason for the difference in the number of factors retained in the Indonesian version could be issues with the cross-cultural adaptation process, resulting in the instrument failing to measure the same concepts as the original instrument (Gjersing, Caplehorn, & Clausen, 2010). These include the unstandardized prompts used in this study that may cause participants to interpret the items differently from the way in which they were intended to be interpreted. In such cases, it is suggested that the items be rephrased (Gjersing et al., 2010) instead of being paraphrased or prompted. Despite the difference in the number of factors retained in the final version, a single factor solution achieved in this study is arguably a preferred outcome in the context of scale development, as a scale should ideally represent only one dimension (Acock, 2008). In terms of internal reliability coefficient, the SRSQ-I retained similar results as the UK and SA versions with .73, while the UK version has .72 and .69 of Cronbach alpha as its two factors respectively, and the SA version reported a Cronbach Alpha of .73 for its full questionnaire.

It is important to mention that the translation of idioms was a major challenge in this study. Items containing idioms such as 'people talk down to me' was translated into '*orang berbicara kepada saya seolah saya sulit mengerti maksud mereka*', which literally translates to 'people talk to me as if I don't understand their thoughts'. The Indonesian language does not have an idiom equivalent to 'talk down'. Therefore, the student translated the idiom connotation in order to retain the item's meaning. Such attempts resulted in a wordy item, which may reduce the simplicity and readability of the items, both of which are essential aspects of questionnaires aimed at the ID population. The author compensated for such problems by prompting the participants to provide examples of their experiences.

This study highlighted the relationship between stigma and socio-demographic characteristics such as age, employment status, living area, ethnicity and religious background. The relationship between age and stigma has been highlighted in previous studies that suggested contradictory findings, where the younger (A. Ali et al., 2015) and older groups of people with ID (A. Ali, King, Strydom, & Hassiotis, 2016) were more likely to experience stigma. However, some studies found no relationship between stigma and age (Cooney, Jahoda, Gumley, & Knott, 2006; Paterson, McKenzie, & Lindsay, 2012; Szivos-Bach, 1993).

Differences in reported stigma between ethnic groups was also observed in the SA study mentioned previously. Although the difference was not statistically significant, the study found a trend between ethnicity (Caucasian, Black African, and mixed ethnicity) and participants from the Black African background, who were more likely to experience stigma (A. Ali et al., 2015).

Additionally, this study hinted at a relationship between employment status and living areas. The findings suggested that being employed and living in a rural setting functioned as protective factors against stigma. However, further explanation could not be derived from this quantitative study. Therefore, this finding will be elaborated in Chapter 7, together with the findings from the qualitative studies. This study did not find any significant relationship between the experience of stigma and severity level (mild versus moderate) or sex (male versus female). In a sense, this finding suggests that experience of stigma is equal across participants with these socio-demographic characteristics. This finding is consistent with previous studies, none of which have found a significant relationship between sex and ID severity level, and reported stigma (A. Ali et al., 2015; Paterson et al., 2012).

5.4.3 Strengths and limitations

The key strength of this study is that the items of the SRSQ-I were adapted in consultation with people with ID by taking their input and involving them in the piloting phase. This study recruited 100 adults with ID, a relatively large number for a population considered invisible in Indonesia's public sphere (Komardjaja, 2005). The participants were broadly representative of people with mild to moderate ID across a number of socio-demographic characteristics. Furthermore, the retest of the questionnaire was achieved by 74% of the participants, which increased the credibility of the reliability index.

This study also has limitations. All the participants recruited in this study were recipient of specialist services (a special school, an NGO, and a rehabilitation centre), which may have affected the participants' responses to the items in the questionnaire and influenced the item structure. For instance, responses to the item 'people make fun of me about going to the special school' could reflect the participants' background in special education. However, it is common for people with ID to not have access to specialist services such as a special school, as it is a scarce resource in many parts of Indonesia, especially in rural areas. Under such circumstances, the item mentioning the special school would not be appropriate. Therefore, future work using the SRSQ-I should determine whether or not to use the item based on the characteristics of the target population sample.

Despite this limitation, the item mentioning special school was deemed important, as the findings suggest that people with ID are stigmatised due to their affiliation with specialist services in general. Future use of the SRSQ-I should use percentages to determine the total stigma score to mitigate the limitation that may occur due to the inclusion or exclusion of the item mentioning special school and to allow comparison of stigma scores across studies. The conversion of the raw score to percentages in order to account for the unused/unanswered item was also utilised in another questionnaire used to screen people with ID (McKenzie & Paxton, 2006). Another limitation may have been that the 11 items retained in the final version of the SRSQ-I used positive wording, which makes it vulnerable to acquiescent bias (respondents agree to all the items).

The participants' diagnosis of ID and the level of severity were determined administratively. As mentioned earlier, one of the challenges of the diagnosis of ID in Indonesia is the absence of a gold standard tool to determine such a diagnosis. Furthermore, according to the referring organisations, participant severity levels were primarily determined by IQ scores, since no standardised measure of adaptive function was conducted during the assessment. Despite two psychologists confirming the ID diagnosis and severity level, the assessment performed in this study, which utilised a questionnaire developed on the basis of DSM-5 criteria for mild and moderate ID, could only be considered as a screening assessment. Under such circumstances, the possibility of including individuals who are ineligible for this study (for instance, people with borderline intellectual functioning) was not completely eliminated.

Finally, despite following the stages of translation and adaptation carried out in the previous study (Kock et al., 2012), this study used comparatively simplified stages due to the limited resources available in this study – it involved fewer professionals, participants, and translators. Such a limitation may influence the quality of items produced in the final version of the SRSQ-I. However, since the finding suggests that the SRSQ-I has sound psychometric properties, this limitation does not affect the quality of these properties.

5.5 Critical reflexivity

The development of the SRSQ-I includes qualitative processes which merit critical reflexivity. the student believes that his academic background may affect the development of the adaptation of questionnaire's items. Two professionals (a psychologist and a social worker) were invited to provide comments on the interview schedule. However, the student felt that both professionals may have refrained themselves from making, what could appear as critical comments, to avoid embarrassment. Further, those who pursue a doctoral degree abroad are regarded as more knowledgeable than their peers remaining at home in the Indonesian professional community and this could have compounded the sense of acquiescence.

5.6 Conclusion

This study adapted the self-report experience stigma questionnaire to the Indonesian context. The findings of this study suggest that the SRSQ-I is a sound instrument that can be used to measure self-reported stigma in adults with ID in Indonesia. The instrument may prove useful in clinical as well as research contexts due to the short duration of administration required and its sound psychometric properties.

5.7 Acknowledgement

I thank Dr Christiani Suwartono for reviewing and providing valuable feedback regarding the analysis methods used in this chapter.

Chapter 6 Qualitative exploration of stigma experience and inclusion of adults with mild to moderate in Indonesian context.

6.1 Introduction

This chapter presents the qualitative part of the multimethod study that focuses on exploring the experience of stigma among adults with ID and the extent of their inclusion in the Indonesian society.

Aims

The following questions were addressed in this study:

- Do adults with mild to moderate ID living in the Indonesian society experience stigma? If yes, what is the nature of their experience?
- To what extent are adults with mild to moderate ID included in the Indonesian society?

6.2 Method

6.2.1 Ethics statement

Please see section 5.2.1 of chapter 5 for discussions of ethical-related issues (personal data collection and storage, and participants consent) during participant recruitment process. In this qualitative part of the study, audio data were collected during the interviews with the participants using a digital voice recorder. In line with the recommendation of the UCL Research Ethics Committee, the audio data are stored in UCL Data Save Haven (secured data storage). During the transcription process identifier data such as name and institution name was deleted. The audio data were then deleted after the transcription completed. Removal of identifier information was conducted within the UCL Data Save Haven environment. Furthermore, all study materials were kept in password protected computers in accordance with UCL data protection policies.

During the interview a member of staff—from which the participants received services—was present within the premises where the interview took place. Presence of a staff was endorsed by the UCL Research Ethic Committee to provide help when needed, for instance when the participants feel distressed during the interview.

6.2.2 Participants

Fifteen participants were purposively selected from the 100 participants involved in the quantitative part of the study (chapter 5). The sample size of 15 participants was determined as an initial sample size and was considered to be the appropriate sample size after the coding saturation of interview transcripts was examined. The coding saturation was determined following the coding of three consecutive transcripts that did not generate new codes (Francis et al., 2010), and was reached on the 13th interview transcript.

The participants were purposively selected based on the results of the preliminary 21 items of the self-report stigma scale Indonesia version (SRSQ-I) they completed. Participants were purposively selected among those who had a high score of experience stigma (minimum 10 out of 21 maximum score). The participants' stigma score was used as the primary selection criteria, while also considering their demographic characteristics (e.g. sex, living arrangement, the severity of ID, occupation) to cover participants from a diverse background. Although all participants had given their consent at the initial phase of the study to undergo a recorded interview as part of their participation in the study, the participants were reminded of this consent prior to the interview.

6.2.3 Instruments

A semi-structured interview schedule was developed and used in this study to further explore the experience of stigma, the possibility of internalisation of stigma and the extent of their inclusion in society. The semi-structured interview schedule consisted of 11 questions with prompts exploring the participants' experience of stigma and the extent of their inclusion in society. An example of a question exploring the experience of stigma is '*please tell me about your school experience*', which was developed based on literature suggesting that people with ID experience discrimination in a school setting (Christensen, Fraynt, Neece, & Baker, 2012; Norwich & Kelly, 2004). Questions regarding inclusion started with broad questions such as 'Could you tell me about your daily activities?' which aimed to explore their inclusion in the society's activities. An English version of the interview questions and prompts are presented in table 14 below. The Indonesian version of the interview schedule used in the study are available in appendix 14.

Table 14. Interview schedule, questions and prompts

Introduction

- I would like to know more about you, can you tell me about yourself?
- Who lives in the same house with you?

Beliefs about self/internalisation of stigma

- How would you describe yourself?
  - Things you like and don't like about yourself.
  - People said that you have intellectual disability, what do you know about this?
- What does your family say about you?
  - What do they say about the cause of disability? Do you agree with them?

Experience of stigma/inclusion

- Could you tell me about your daily activities?
  - Have you ever been employed?
- Can you tell me about your school experience?
  - How did/do you get along with your classmates/teachers?
  - What did/do your classmates/teachers say about you?
  - What did/do you find challenging at school?
- Can you tell me about your experience spending time outside your house?
  - Does someone go with you?
  - Do you enjoy going outside the house?

Table 14. Interview schedule, questions and prompts

When was the last time you visited a doctor?
Did someone come with you on that visit?
Do you feel comfortable when you’re at the clinic/hospital?
Have you participated in activities in your neighbourhood?
Festivities.
Religious congregation.
Election.
Future aspiration
What is your plan for your future?
Where do you want to live? With whom?
Have you ever thought about marriage / having a child?

6.2.4 Data collection process

The interviews were carried out based on the availability and convenience of the participants. Therefore, the interviews were conducted within the premises of the special institutions and within the time allocated by their special institution (i.e. during a school/work time for participants from the special school/sheltered workshop, during leisure time for participants from the rehabilitation centre and after weekly meetings for participants from the NGO. During the interview, a member of staff was present within the premises of the facility to provide support when needed, while at the same time maintaining the privacy of the participants. For example, participants from the non-governmental organisation (NGO) collaborating in this study were interviewed in a canteen of a sports venue, while the staff were sitting at a different table from the one where the interview was taking place. The interview was audio recorded, subject to participant consent. The interview duration ranged between 21 to 48 minutes, approximately 31 minutes on average for all interviews.

6.2.5 Data analysis

The interview transcripts were translated into English by the student prior to the analysis. Thematic analysis was utilised to analyse the data collected from the semi-structured interview. The step-by-step guide provided by Braun and Clarke (2006) (i.e. data familiarisation, generating initial codes, searching for themes, reviewing themes, defining and naming of themes, and producing reports) was exercised to analyse the data. The author transcribes the interview recording that helps familiarisation with the data, as well as reading and re-reading the 15 interview transcripts. The coding process was carried out by following a strict line to line coding of the 15 interview transcripts. Two interview transcripts were independently coded by the student and two supervisors (AA & AH) to ensure the quality and credibility of the coding process. The differences in coding of the two interviews were settled through discussion. The initial codes established from the two transcripts were further reviewed by a third supervisor (KS) and another researcher (RS). Feedbacks were acquired from the two reviewers and were used to refine the initial codes. The author carried out the coding process for the rest of the transcripts and established an initial coding structure by collating codes representing a similar notion. The collated codes were then examined to identify patterns (themes) across the data set. The initial coding structure was then reviewed and discussed in a meeting with the three supervisors. The final coding structure was established in the meeting, including defining and naming of themes. The student then used the coding structure to develop a thematic map by identifying the relationship between themes.

6.3 Results

6.3.1 Participants’ demographic

Fifteen adults with mild (n = 12) and moderate (n = 3) ID were recruited in this study. The majority of the participants were female (53%) and the rest were male (47%). The participants’ age ranged from 17 to 43 years (mean = 25.5 years). Most of the participants were in the 17–25 years age group (60%), followed by participants in the 26–35 years old group (27%) and then those who were 36–45 years old (13%). No participant had Down syndrome. Most participants lived in urban areas (60%) while the rest of the participants lived in rural areas (40%). The participants' living areas were determined by the location of their home, and not by the place where the participants were living at the time of the interview. Most of the participants were trainees who enrolled in an occupational course in the rehabilitation centre (53%), followed by students enrolled in a special school (33%) and employees in a sheltered workshop (13%). Most participants adhered to Islamic faith (67%), while 20% adhered to Protestants Christianity and 13% to Catholic Christianity. The majority of participants were Javanese (53%), followed by Chinese (33%), Padangnese (7%) and Talaki (7%). Table 15 describes the participants' demographic characteristics.

Table 15. Participants' demographic background (n=15)

Characteristic	N (%)	Characteristic	N (%)
Gender		Living area	
Female	8 (53)	Urban	9 (60)
Male	7 (47)	Rural	6 (40)
Age		Occupation	
17–25	9 (60)	Trainee	8 (53)
26–35	4 (27)	Student	5 (33)
36–45	2 (13)	Sheltered employment	2 (13)
ID level		Religion	
Mild	11 (73)	Islam	10 (67)
Moderate	4 (27)	Catholicism	2 (13)
Down syndrome		Protestantism	3 (20)
With	0 (0)	Ethnicity	
Without	15 (100)	Javanese	8 (53)
Living arrangement		Chinese	5 (33)
Special institution	9 (60)	Padang	1 (7)
Family house	6 (40)	Talaki	1 (7)

6.3.2 Themes

This section presents the themes established from the coding process of the interview transcripts. Four themes were identified in the analysis i.e. 'discrimination and poor treatment', 'limited social life and activities', 'reaction to and impact of stigma' and 'wish of a normal life'. Figure 6-1 is the theme map that explains the relationship between themes.

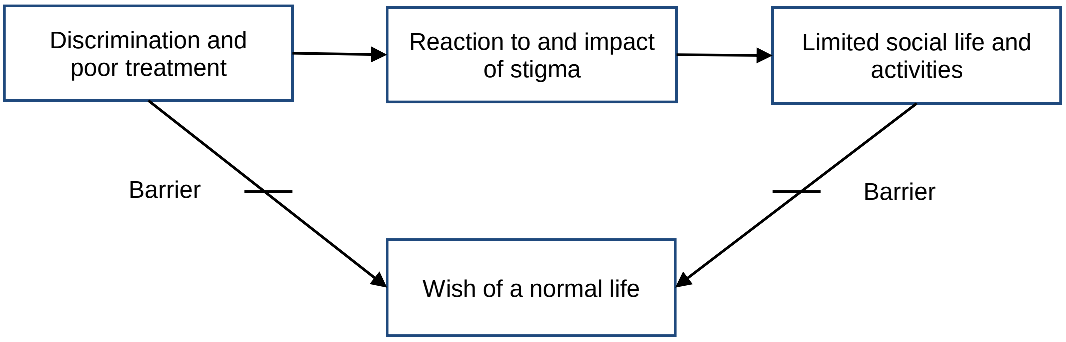

Figure 6-1 Themes map

6.3.2.1 *Discrimination and poor treatment*

This theme compiles the participants' experience of being discriminated against or poorly treated in multiple settings. Among those settings, the majority of participants (n=12) shared their experience of struggling with academic expectations in the mainstream elementary school. As a consequence, some of the participants had to repeat a year or two (grade retention) in elementary school before they were referred to a special school. Having to repeat years was frequently mentioned as the reason for mockery from their peers.

> My normal friend made fun of me Q: What did they say? A: (They said) You have to repeat a year, while I don't have to. (P02/male/moderate ID)

> Q: Did someone mock you? A: Yes, at the primary school Q: Could you tell me more about it? A: (they said) 'You are too big for the third year'. (At that time) My (former) classmates were already in the fourth or fifth year. (P03/female/mild ID)

Name calling, and rejection due to the disability was reported by the majority of participants (n=12), confirming that stigmatising behaviours are present among the younger population.

> A: In the past, when I was in elementary school I was often mocked, people called me autistic. I don't want that, so it's better for me to be here (special school) Q: So, people made fun of you in your previous schools? A: Yes, they were my former classmates (P10/female/moderate ID)

> Q: You said that there was a bad classmate as well, what did they do to you? A: (They were) sarcastic, I felt that way Q: What did they say? A: It was, it was just, (they said) 'she is not the same as us'… it feels uncomfortable, and they avoid me (P06/female/mild ID)

Some participants reported that they were discriminated by neighbours, including their peers in the neighbourhood. Name calling and insults were the most reported discriminative behaviours the participants received from their neighbours, followed by rejection, gossip and extortion. The nature of the disability and attending special school was found to be attributed to insults and gossip.

> They (the neighbours) talked from a distance (behind my back). They don't talk to me directly. Q: What do they say? A: I don't know, but sometimes I hear them talk, but let them be. Q: When you did hear them talk, what did they say about you? A: He (the participant) can't do this and that, but just let them (the neighbours) be (P05/male/mild ID)

> People were mocking me, you're a special school student (*anak SLB*), and I hate it if they mock me for being a special school student. (P03/female/mild ID)

> Q: Do you have friends in your neighbourhood? A: I do, one or two Q: what about your other peer? A: …How should I say it…? I don't know… Q: Do they avoid you? A: No, it's not them, it's me who avoids them…because they are delinquent… they took my phone. (P07/Male/Mild ID)

Three participants received poor treatments from their parents. A participant shared his experience of being neglected by his family. The participant's parents drove him in a car and left him alone on the street. He was then found and sheltered by a social service agency where he lived for a period of time before being sent back to his family.

> Q: Who told you to live in Jakarta? A: My mom. Q: What did your mom say when she told you to live in Jakarta? Q: She didn't (tell me to live in Jakarta). I was left on the street, and my mom left me there. Q: I see, so you were left

> on the street, then you were accommodated by the social service? A: Yes, '*sos*' (referring to social service). Q: Do you stay in touch with your mom? A: I do. Q: But you said that she left you on the street? A: She was searched (for). Q: Did they find her? A: Yes. (P04/male/moderate ID)

A participant shared her experience of being physically abused by her father, which was attributed to her difficulties in school.

> Q: You said that you were beaten by your dad, do you mind telling me more? A: (From) when I was 10 years until I was 15 years, my dad (used to) beat me. Q: Why? A: …I was struggling to learn math; it is difficult… I was working on my homework; it was very difficult, but my parents refused to teach me. I was crying, (and) then I was strangled. After that, my hair was pulled, (and) I was kicked from feet to head… I was bleeding, maybe because of the cup that was thrown at me. (P03/female/mild ID)

A participant was living in a special institution managed by the same organisation running the special school, despite having a family living in the same city. She returns to her family once a year for a period of time, where she spends time with her sister's family. The participant shares her conversation with her sister indicating her challenging behaviour as the reason for the institutionalisation.

> A: …my behaviour was bad; I cried a lot, throwing a tantrum, screaming like a child, like a twisted person (*orang enggak bener*). Since I am here (nursing house), I (Thaver & Lim) changed a lot; I am more independent. (After) I returned home last time, my sister has been fond of me. Q: What did your sister say about you? A: (She said) 'You have changed a lot, if you have changed, I can take you home. If you are still like that (past behaviour), I don't want to take you back to the family'. (P08/female/mild ID)

Another participant had a similar experience when her parents asked her to live in a special institution. Fortunately, at that time the special institution did not have a vacant place.

> I was about to be sent to the care house unit but there was no available room. So, I was sent to the special school unit instead, (and) I go home every day. Q: Why do they want to send you to the nursing house unit? A: I don't know. Q: Did your parent talk to you about it? A: No, they only gave me a paper (brochure) and said, 'it's better if you go here'. (P01/female/mild ID)

6.3.2.2 Reaction to and impact of stigma

The participants experienced stigma in multiple settings such as in schools and neighbourhoods. The participants said that they feel uncomfortable, sad and angry upon experiencing stigma. Some participants preferred to be quiet about their negative emotions, while others shared their feelings with parents or teachers. However, the responses were not always helpful because participants were either asked to be patient or to ignore the people stigmatising them.

> A: (The teacher said), ‘you don’t need to listen to them, act like they do not exist if someone called you stupid (*bodoh*) don’t get mad, (even if you are) called lice or black aunty. (P12/female/moderate ID)

> Q: You said that people make fun of you because you go to a special school? A: It was my neighbour … Q: what did you do afterwards? A: I stayed silent. (P07/male/mild ID)

A participant showed an interesting reaction towards the discrimination he received from his parents. He said that he could not hold negative feelings towards his mother who had neglected him on the street because she is his parent. As it may be simplistic, this perspective should still be considered as a way of a person with ID perceiving such an experience. Such a reaction allowed him to reconcile and maintain a relationship with his parents.

> Q: How do you feel when you meet your mother again? A: err… happy. Q: Did you get mad at your mom because she left you alone? A: Of course, not. Q: Why? A: Because (she is my) parent. (P04/male/moderate ID)

There was evidence that some participants had internalised the stigma and were aware of the negative label directed towards them. A participant was affirming the repeated notion from her parents that she is useless and laughed while she shared this during the interview.

> Q: What do you think about yourself? A: I think I am useless (laughing). Q: What do you mean? Why do you feel like that? A: Because I can't do anything (laughing). Q: Who told you that? A: My mom. Q: Why did she say that? A: Like when I am doing the hair dressing courses, after a few months, after four months, I could not understand anything (the lesson). (P01/female/mild ID)

The same participant admitted to hiding her disabilities when participating in church activities. She was concerned that if people in the church learned about her disability, it will result in rejection.

> Q: Do you go to church? A: I often do, every Saturday. Q: Do you have peers to talk to at the church? A: I do, a lot of them… but because I don't have a mobile phone, it is hard to stay in touch. Q: Do they know that you go to a special school? A: They don't, no one knows about it. Q: You don't tell them? A: No. Q: Why? A: I am ashamed, I am afraid they will avoid me. (P01/female/mild ID)

A similar reaction was reported by another participant who preferred to lock herself in her room—in a family house which she shares with her in-laws—after finishing her work at a sheltered workshop. She avoids talking to her in-laws and neighbours out of fear of being misunderstood, which could result in conflicts.

> A: No, after I finish work, I never talk to the neighbours. I am afraid of being out alone. I am afraid if I misspoke, and I am afraid of being mocked, that is why I go straight to home after work…they (people from old neighbourhood) mocked me for being a special school student…. In my current neighbourhood, no one knows that I worked here (sheltered workshop). I am afraid the information might spread… (That's why) I never go outside after work (P03/female/mild ID).

6.3.2.3 Limited social life and activities

This theme comprises of two sub-theme codes namely 'life within the family and special organisation' and 'a safe haven', which describes the facets of the participants' social life and activities.

6.3.2.3.1 Life within the family and special organisation

Participants live their life within the family and special organisation. Participants who live in the family house said that they mostly spend their time at home where they do house chores such as sweeping and mopping the floor and terrace, or leisure activities such as watching television or playing with electronic devices (i.e. mobile phone, tablet, desktop).

> **Q:** What do you do after school? **A:** Go home; I eat at home, then sleep, wake up late afternoon, because, after school, I get tired. I study, read the bible, read books, usually that. (P10/female/moderate ID)

> **Q:** Can you tell me about your daily activities? A: I usually stay at home. I help my dad after work. Q: What do you help with? A: It's just cleaning the house, my dad told me to. Q: What do you usually do when cleaning the house? A: Make up the bed, sweep (the floor). (P05/male/mild ID)

A participant expressed her feeling of being restricted because her parents make her stay at home most of the time.

> **Q:** Other than school, do you go out of the house? **A:** Never… I am very poor, right? For never leaving the house. Others can go out of their house, while I spend all my time inside. **Q:** Why do you always stay in your house**?** **A:** Because my parents told me to. (P01/female/mild ID)

On the other hand, the participants' living in the rehabilitation centre report more scheduled activities that they must follow as part of their daily life. A participant said that he prefers the scheduled activities at the rehabilitation centre over not having any activities at home.

> **Q:** Please tell me a bit about your daily activities. **A:** Monday… Monday, tomorrow, I will… after the Morning Prayer… after the Morning Prayer… I sweep (floor), after I sweep I take a bath, after a bath I do my chores to pick up the breakfast, after picking up the breakfast I eat breakfast at seven, after eating breakfast at seven what was it again?... Washing the dishes, after that, I go to the tennis field for the (weekly national flag-raising) ceremony. (P02/male/moderate ID)

> Q: What did you feel when you arrived here (the rehabilitation centre)? A: I enjoyed (living) here, it's better than staying at home doing nothing. (P07/male/mild ID)

Despite not having many opportunities to go outside the house, participants with milder conditions have better opportunities to access independent leisure activities, such as spending time with friends from the special organisation, buying snacks at a convenience store, going to an internet café or eating at a nearby food stall.

> **Q:** Do you go out of the house often? **A:** No, seldom. I mostly at home, watching television, but sometimes I go out, to the internet café or buy snacks at the kiosk. (P09/male/mild ID)

Having a better opportunity to venture around the neighbourhood is also applied to participants who live in the rehabilitation centre, as trainees are allowed to go outside the centre without supervision.

> **Q:** Do you go out during your free time? **A:** Yes, I take trips **Q:** Where to**? A:** To X (a nearby village) **Q:** With whom? **A:** I go with X (a friend name). (P04/male/moderate ID)

Participants report that they spend leisure activities with their family from time to time. Participants living with their family in the urban areas go to malls for shopping and watching movies, while their counterparts living in the rehabilitation centre shared their experience of spending time with families during visiting times and festive days.

> Q: Other than school, where else do you usually go? A: Mall. Q: With whom? A: My mom. Q: What do you do there? A: Dine, watch movies, look at books and magazines. (P12/female/moderate ID)

> Q: What do you do for Eid al-Fitr (celebration after the fasting month of Ramadhan)? A: I go to a relatives' place, travelling with my family. Q: When was the last time your family visited you? A: On the 16th (this month). Q: What did you do when they came to visit? A: We talked; my parents brought me some clothes and food, and we ate together. (P06/female/mild ID)

Provided with support from family and people from the special organisation (e.g. teachers, friends), participants were able to take part in activities such as accessing health services and voting in an election.

> Q: Can you tell me about your last time meeting a doctor. A: I was ill, I went to the hospital with my mom… A: Do you have any difficulties communicating with the doctor? A: No, it was my parent who did the talking. (P13/female/mild ID)

> Q: Do you participate in elections? A: Oh, I do… I was old enough (to vote)… Q: Who do you go with? A: With my parent. Q: How did you choose your candidate? A: I chose a President who is the most honest, and who is not arrogant, and who is not too rich; I want an honest president… Q: So did you decide the candidate yourself? A: No, it was my mom who decided (it for me). (P12/female/moderate ID)

On the other hand, participants with a milder condition were able to participate in more independent activities such as celebrating the New Year and using public transportation.

> Q: What do you usually do for New Year and Christmas? A: I go out with friends (from the special school & sheltered workshop), but I need to ask permission. If I get permission then I go out, if I don't, I stay at home. Q: Do you get permission often? A: Yes, but I am asked where I will be going, and when will I return home. (P05/male/mild ID)

> Q: What do you usually use to travel? A: The public minivan (*angkot*). Q: Do you have difficulties riding one? A: No, but it does get difficult to travel long distance. I have experience riding the bus. (P03/female/mild ID)

6.3.2.3.2 A safe haven

Participants showed their preference towards families and special institutions over more inclusive opportunities that strengthened their already limited social circle. For example, the preference of living in a special institution over a family house or working in a sheltered workshop over regular employment. Lack of support and opportunity to establish relationships were mentioned as the reason for the preference.

> **A:** (Compared to the mainstream school) it is more fun here (special schools). (I have) lots of friends; the teachers order me around more often, but having friends is the most important. (P10/female/moderate ID)

Preference towards specialised environment over an inclusive environment should be considered as a result of stigma prevalent in society, as participants frequently linked such preferences with their experience of stigma.

> A: I prefer to work here (sheltered workshop) because the people here know about my condition. People were talking behind my back at the shop (where I previously worked), here they talk openly. (P03/female/mild ID)

Participants perceived the world outside their family and special organisation as ‘different’ and ‘dangerous’. Such a perspective seems to come from parents who want to convince their child with ID to stay at home.

> A: What did your mom tell you about not going out by yourself? Q: Someone might do something bad to me. Q: What did she mean by something bad? A: Something bad like someone might give me candy and take me away. (P01/male/mild ID)

> Q: Have you thought about the reason why you go to a special school instead of a mainstream one? A: The school is not similar to me. Q: What do you mean? A: There is no one like me (there) in the mainstream school; (people like me) are in special schools. (P07/male/mild ID)

6.3.2.4 Wish of a normal life

Eight participants mentioned comments regarding their wish about the future which includes having a source of income, getting married, having and raising offspring and living independently. Participants mentioned helping with the family business or running their own business such as opening a juice stall or a tailoring service in which the participants have been trained in their special education.

> Q: Are you planning to work after graduating from school? A: Yes, (in a) fruit shop; it’s my dad’s, it’s near to my house, there, I want to work there. (P12/female/moderate ID)

> Q: What is your plan after graduating? A: I want to work, I want to open a tailoring business at home. A: What do you want to make? A: Clothes, I learned (how to do it) here. (P13/female/mild ID)

On the other hand, some participants mentioned about getting employment in low-skill roles such as janitors and factory labourers, or to keep their current position in the sheltered workshop. However, participants also expressed uncertainty on whether they could attain such employment.

> Q: What do you want to do after graduating? A: I want to work in a factory (as a labourer). Q: Are you confident that you will be an employee there? A: I don’t know, I am not sure. (P07/male/mild ID)

> Q: Do you plan to work after graduating from this school? A: Yes, I want to work in the (sheltered) workshop unit here (the special school). Q: Do you have any other plan? A: I don’t know… it is hard because I don’t have a diploma. (P01/female/mild ID)

Employment was frequently discussed together with marriage as it was perceived as a prerequisite of marriage. A participant made a comment about not getting married before securing a job.

> **Q:** Do you think about marriage in the future? **A:** Of course, I do, after I graduate from here. **Q:** What is your plan after graduating? **A:** Working and getting married. Q: Will you marry before getting a job? A: No. Q: Why not? A: (people) need to work to get married. (P04/male/moderate ID)

The participants’ concepts of marriage revolve around having a partner, raising offspring and doing family activities. The participants perceived that marriage and parenthood will make them and their parents happy. However, participants had difficulties in elaborating the reason for aspiring to get married.

> A: Marriage is to (have a) partner, I mean to share a house with your wife, and to work independently. So, marriage is to live alone (not with parents), together with the girl and then have kids; that is the purpose. (P09/male/moderate ID)

> Q: Do you want to get married in the future? A: Of course, I do. Q: Why do you want to marry? A: I just want it. Q: Why do you want it? A: To make my parents happy. Q: Do you also want to have a child? A: I do. Q: Why? A: To make my mom happy. (P13/female/mild ID)

> Q: Do you want to marry? A: I do. Q: Why do you want to marry? A: I don't know yet. Q: Do you know why people get married? A: I am not sure, I don't know. Q: Do you want to have a child? A: I do. Q: Why do you want a child? A: So, (the child) can help. Q: Help who? A: Help me. Q: Help you in what? A: Washing clothes. Q: Other than that? A: Help in everything (daily chores). (P15/male/mild ID)

Marriage and parenthood were seen as an obligation of an adult. Furthermore, having a relationship without aiming for marriage was seen as improper.

> Q: Do you want to have a child? A: Yes, I do, because that is the purpose of (being) an adult. (P09/male/moderate ID)

> Q: Do you want to marry? A: Of course, I do, I am already old. Q: Why do you think people marry? A: So that they are happy; to have a spouse. Q: Do you think you will be happy if you get married? A: Of course, I do, because if I am only dating, then the neighbours will gossip. Only dating is bad, but if you get married then it's not (bad). (P11/male/moderate ID)

Employment, marriage and parenthood were discussed around the issue of being independent. However, it is interesting to note that some participants do not think that living in their own house is essential, including after marriage. A participant clearly refuses to live separately from her parent.

> Q: Where do you want to live after getting married? A: At my parents' house, at my mom's place. Q: Why do you want to stay at your mom's place? A: I don't have the heart to leave her. (F13/female/mild ID)

> Q: Have you thought about living in your own house? A: No, I want to live with my family. I just want to sleep in my own (room). Q: Don't you want to have your own house? A: No, I don't understand about money. It's expensive to buy a house. (P10/female/moderate ID)

In general, the participants' expectations of the future were shaped by their families, who sometimes were not fully open, or aware, about the opportunities that are available for people with ID in the Indonesian society, such as the limited access to education and employment.

> A: My parents said that the most important thing is study, study, study so that I can go to college and in the future, I can work; that's what my mom and dad said. (P10/female/moderate ID)

> Q: Do you know why people called you intellectually disabled? A: I don't. Q: Did your parents say anything about it? A: They said (I am) intellectually disabled (tuna grahita). Q: Did they mention why people are calling you intellectually disabled? A: I don't know, they never said anything about it. (P13/female/mild ID)

6.4 Discussion

6.4.1 Summary of results

This study found that adults with mild to moderate ID experience stigma in their daily life. They experience stigma in various settings such as family, school and neighbourhood. Some of the participants were aware of the negative labels directed to them which leads to internalisation of such labels. Family and special organisations are the main sources of support and close relationship for adults with ID, which they could not attain from wider social networks. Adults with mild to moderate ID have a limited social circle due to the restriction of social activities, stigma, and the nature of their disability. Furthermore, as a result of the stigma experience and restriction from family, adults with mild to moderate ID tend to hold negative perspectives towards the world outside their family and special organisation and consider them 'different' and 'dangerous'. Such perspectives strengthen the barriers hampering the inclusion of adults with mild to moderate ID in society and may make them more vulnerable to loneliness.

6.4.2 Results in context

This study found that people with ID often experience physical abuse and neglect in the Indonesian society, supporting the notions that people with ID are vulnerable and are subject to abuses (Reiter, Bryen, & Shachar, 2007). Furthermore, it confirmed that person with ID receive rejection and institutionalisation from their family, as it was found in a previous study carried out in the Indonesian context (Komardjaja, 2005).

This study identifies the challenging behaviour as a reason for institutionalisation of people with ID. In the wider scope of the Indonesian context of mental illness, challenging behaviour has been associated with '*pasung*', an Indonesian term for shackling a person with mental illness with a wooden log or chain. People with mental illness, especially schizophrenia, are vulnerable to such a practice due to the display of challenging behaviours such as roaming around the neighbourhood, trespassing the neighbours' house and destroying properties (Lestari, 2014; Minas & Diatri, 2008). Some people with ID have difficulty in inhibiting aggressive responses (van Nieuwenhuijzen, Orobio de Castro, van Aken, & Matthys, 2009) and that challenging behaviour has been noted as a significant problem for people with ID across their lifespan and level of functioning (Benson & Brooks, 2008; Totsika & Hastings, 2009). Therefore, people with ID in Indonesia, especially those who live in traditional communities with limited or no access to service, may also be vulnerable to *pasung* or similar practices.

Furthermore, this study found that challenging behaviours are associated with corporal punishment and neglect, as a participant shared his experience of being hit by a hose and broomstick and being left on the street by his parents. Although it was hard to corroborate and explore more about this experience due to his limited verbal capabilities, the participant attributed his parents' action as his punishment for being naughty (i.e. urinating in public and breaking a mirror). In the context of endorsing inclusion of people with ID, challenging behaviour is also an important issue that needs to be addressed, as it has been recognised as one of the common challenges in the ID population (Totsika & Hastings, 2009) and has been noted as a barrier to inclusion (Gilmore & Cuskelly, 2014). In this study, the findings regarding the relationship between challenging behaviour and poor treatment from family were solely explored from the perspective of people with mild to moderate ID. These findings should be investigated further for better understanding the family's motive of such treatment, and the situation of people with more severe ID. Factors such as family shame due to having a member with ID and limited access to services should be explored as there may be potential for supporting resilience as a way of reducing abuse and maltreatment of people with ID.

This study found that people with ID are rejected and mocked by their non-disabled peers in school; it was also noted in other studies that they experience bullying (Christensen et al., 2012). The finding further suggests that students with ID are subject to verbal and relational bullying, including teasing and name calling, and acts to isolate the victim (Gladden, 2014). In light of this finding, the anti-stigma campaigns targeting stigma of ID need to be initiated in school settings as it has been carried out in campaigns addressing the stigma of mental illness (Chan, Mak, & Law, 2009; Rickwood, Cavanagh, Curtis, & Sakrouge, 2004). Participants mentioned that repeating years (grade retention) was the reason for their rejection. These findings support the initiative to abolish the grade retention policy in the early stage of education that has been started in recent years in Indonesia (Bona, 2016). Efforts to further develop the national inclusive education systems should also be made to keep people with ID in mainstream schools. Additionally, a standardised screening procedure to identify students with ID should be developed and implemented at the national level to allow an uneventful transfer from mainstream to specialised education, when inclusive education no longer benefits the students.

Initiatives to endorse the inclusion of adults with mild to moderate ID in the society should fully consider their perspective, as adults with ID were found to perceive the wider society as different and dangerous. This study indicates that such perception stems from stigma and restriction of social life pushed on adults with mild to moderate ID, which leads them to withdraw from more inclusive social interaction in society. Similar findings have been noted in other studies (Bigby & Knox, 2009; Emerson & McVilly, 2004), suggesting that limited social life is a common situation for people with ID across cultural contexts. On the other hand, these findings raise further concerns regarding the well-being of adults with ID as they are prone to loneliness because of having a limited social life (Gilmore & Cuskelly, 2014). Moreover, loneliness and experience of abuse—both of which were reported in this study—have been identified as the risk factors to depression (Lunsky, 2003) and suicidal behaviour among people with ID (Merrick, Merrick, Lunsky, & Kandel, 2006). Further research is needed to investigate the negative effects of a limited social life and experience of stigma among people with ID in Indonesia.

6.4.3 Strength and limitation

The current study offers unique insights regarding the experience of stigma among adults with mild to moderate ID and the extent of their inclusion in an Indonesian context. Understanding the experience of stigma and inclusion of people with ID is a first step in developing interventions for them. By providing adults with mild to moderate ID an opportunity to directly voice their experiences and perspectives, this study has empowered them to inform future research and practice that will hopefully help them improve the quality of their lives. Furthermore, socio-demographic characteristics such as living arrangements and ID severity levels were considered in the sampling and analysis process, allowing inclusion of participants from wider backgrounds, as well as identification of pattern and contrast in the responses among the group of participants.

All the interviews in this study were conducted by a single interviewer (the student), which increased the reliability of the data collection process.

The following limitation should be addressed to put the findings in a proper context. This study used purposive sampling, derived from a convenience sampling of 100 participants, with a relatively small sample size (n=15) which makes the generalisation of findings to a wider population of adults with ID in Indonesia inappropriate. Moreover, all the participants in this study received support and services from their respective special organisation. Therefore, this study did not include the perspective of adults with ID who did not have access to services and were more likely to experience stigma. This study was exploratory and aimed to portray the experience of stigma, therefore, the results could not fully describe how severe is the impact of stigma on the well-being of adults with ID. The participants recruited in this study had mild to moderate ID level, and they were selected among those who scored high on the SRSQ-I. Therefore, the findings of the study could not be generalised to adults with severe and profound ID and may not represent adults with ID with physical disability who could possibly experience higher levels of stigma due to visible disability. However, selecting only participants with high-level of experienced stigma complies with the aim of this study, to further elaborate the experience of stigma among adults with mild and moderate ID. It would be a point of further enquiry to consider ways in which it would be possible to collect information about the perceived stigma by adults with more severe degree of ID. For example, appropriate methods of communication such as talking mats (Murphy & Cameron, 2008) could facilitate such conversations as well as proxy measures by family or paid carers, all of which, contain inherent limitations.

6.4.4 Critical reflexivity

The student is a clinical psychologist who had experience working with people with ID and their family. Furthermore, the student had performed a systematic review which provided a broad insight regarding the situation of people with ID in Southeast Asia, including Indonesia. Prior experience and knowledge may have shaped the student's assumptions regarding questions addressed in this study, and, to some extent, influenced how the information was collected, and interpreted. For example, from his previous experience and knowledge, the student was aware that people with ID have limited opportunities for civic inclusion in Indonesia which may affect prompts used in the interview. The student may have been more dismissive when hearing information that a participant has more inclusive opportunities, such as going to a new year celebration with friends, or independently shopping in a convenience store, resulting in asking further questions to clarify such statements. In contrast, if the participant reported that they had difficulties in using public transportation (for example), the student would accept such statements as a fairly accurate depiction of their reality without further inquiring about the kind of difficulties the participant was facing.

Power imbalance between participants and the students may also influence participants response towards questions addressed in the interview. For example, participants may be warried to disclose some information in case the information may pose consequences for them. For example, participant living in the rehabilitation centre may reluctant to talk about stigma they experienced within the institution because they perceive the student as part of the institution authority.

6.5 Conclusion

This study explores the stigma experienced by adults with mild to moderate ID and the extent of their inclusion in Indonesian society. The findings of this study suggest that adults with mild to moderate ID experience stigma in their day-to-day lives. Some had experienced stigma since their childhood. Adults with mild to moderate ID have a limited scope of social life that is centralised around their family and special institutions. In light of these findings, it is critical to plan and carry out efforts to eradicate the stigma of ID in the Indonesian society and endorse their inclusion in the Indonesian society.

6.6 Acknowledgement

I thank Dr Rory Sheehan for reviewing the initial coding structure of this study.

Chapter 7 The integration of quantitative and qualitative components

7.1 Introduction

This thesis includes three inter-related studies aimed at exploring the stigma towards people with ID in the Indonesian context. In the first study, eighteen professionals from various backgrounds were interviewed to explore their attitudes towards people with ID and the inclusion of the said people in society. In the second study, one hundred adults with mild to moderate ID were involved to adapt and validate a self-report stigma questionnaire (SRSQ-I), measuring the experience of stigma. In doing so, information regarding the experience of stigma among participants was acquired. In the third study, fifteen adults with mild to moderate ID were purposively selected – based on their SRSQ-I scores – from the one hundred participants who took part in the SRSQ-I adaptation study.

The three inter-related studies were aimed at investigating the stigma of people with ID in the Indonesian context, despite using different methodologies and targeting different groups of participants. This chapter presents the integration of quantitative and qualitative components, extracted from the three studies presented in previous chapters of this PhD thesis.

Aims

This chapter aims to integrate and report the quantitative and qualitative findings presented in Chapter 4, 5 and 6. Here, the following research questions were further explored as follows:

- What is the experience of stigma among adults with mild to moderate ID living in an Indonesian society?
- To what extent are they (adults with mild to moderate ID) included in the society?
- What is the relationship between socio-demographic characteristics and the experience of stigma among the participants (adults with mild to moderate ID)?

7.2 Methods

7.2.1 Design

The three empirical studies included in this thesis were carried out in a multimethod study framework. Morse (2010) defines multimethod designs as the conduct of two or more studies utilising different methodological approaches, exploring the same questions or different parts of the same question. Morse (2010) further explains that each of the studies incorporated in a multimethod design can be considered as self-contained, complete and publishable as an independent article.

7.2.2 Data analysis

Integration of findings was conducted in two steps, in which two techniques of data integration were performed, namely ‘following a thread’ and ‘mixed method matrix’ (O’Cathain, Murphy, & Nicholl, 2010).

7.2.2.1 Following a thread

O’Cathain et al. (2010) explains that the techniques started with an initial analysis of the findings from each of the studies to identify the key themes, which were then used as a starting point and followed across components. In this study, the technique was followed by designating the quantitative (findings) component as one of the key themes and a starting point of the thread. Following this, the relevant information was extracted from the two qualitative components (interview transcripts of 18 professionals and 15 adults with mild to moderate ID). This was carried out by examining the coding structures established in the two qualitative studies (see Chapter 4 and 6). The NVivo 11 software was used in the extraction process. The codes deemed relevant to elaborate the quantitative findings (key themes) were then selected and collated together. Inclusion criteria were established for each of the key themes, to guide identification of the relevant codes as well as the credibility of the process. Inclusion criteria established for the key themes are available in appendix 15.

7.2.2.2 Mixed method matrix

The quotes of interview transcripts extracted in the previous stage were presented and collated together with corresponding quantitative data in a mixed method matrix. This procedure allows identification of patterns and contrasts across components (findings) (O'Cathain et al., 2010) of the three studies (see table 16). An elaborated version of the integration matrix is available in appendix 15.

Table 16. Sample of integration matrix

Quantitative	Qualitative	
SRSQ-I	Adults with mild to moderate ID	Professionals
People living in urban areas were more likely to answer yes to the item 'people on the street make fun of me' and 'people treat me like a child.'	Q: Do you visit places around your house? A: I do, but I did it in secret Q: Why don't you tell your parents? Q: They won't allow me…maybe because they think that I am a special school student, they are afraid I might get swindled, or I might get kidnapped... (P01/Female/Mild/Urban)	…if Rudi lives in a village, wherever he goes, people will recognise him and they may say 'Oh, I saw him there'. (P04/Medical doctor)…in the rural area, where the people are less educated. Their perspective (about people with disability) is burdening for people like Rudy and Gilang; they like to talk about others' misfortune (P09/religious leader-muslim)
	Q: Have you participated in an Independence Day celebration in your neighbourhood? A: Yes, I participated in events, the rug run (balap karung) and the 'putting in pencil in a bottle' (event), I have. Q: How did people treat you there? A: They were cheering for me. (P13/Female/Mild/Rural)	

7.3 Results

The integration of findings identified three themes across the data set, namely ‘Stigma and limited social life: A common experience’, ‘Reaction to stigma: shame, anger and fear’, and ‘Stigma and socio-demographic characteristics’.

7.3.1 Stigma and limited social life: A common experience

Data from the three studies presented in the thesis suggest that stigma towards people with ID in Indonesia is common. Analysis of total stigma scores as measured by the SRSQ-I shows that, out of 100 participating adults with mild to moderate ID, 81% had experienced stigma. This finding was strengthened by reported experience of stigma by adults with mild to moderate ID and comments from professionals in the two qualitative studies. Reported experience of stigma, presented in Chapter 6, suggests that adults with mild to moderate ID experience stigma in various forms and settings. Similarly, professionals also mentioned that stigma towards people with ID is present in Indonesian society, creating a barrier for the inclusion of the said people.

> Q: You said that people make fun about the way you talk? A: Yes Q: What did they say to you? A: It was because they don’t understand what I am saying (P07/male/mild ID)

> Q: In your opinion, what are the challenges faced by people with intellectual disabilities in Indonesia? A: Bullying, being underestimated and considered useless… (P13/mainstream education teacher)

Findings from the two qualitative studies suggest that children with ID are vulnerable and subjected to discrimination and bullying in mainstream schools. Participants reported that they had experienced stigma as elementary school students. Some examples are as follows:

> Q: Have you been to a mainstream school? A: I have, during elementary school Q: Could you please tell me a bit about your experience there? A: sure, they are, their IQ are higher, I can't follow their lesson, they also made fun of me, they avoid me, they don't want to be friend with me, so I avoid them A: Who are they? A: My classmates, they mock me Q: What did they say? A: (They said) 'you are ugly, go away, you're not my friend, go away' (P08/female/mild ID)

> A: …At school, he may be mocked and perceived as stupid (P13/mainstream education teacher).

Children are perceived to be more likely to stigmatise (e.g. mock, tease) people with ID, including their peers. Such behaviour was attributed to unawareness, that children tend to mock people with ID as entertainment, and that they do not understand the proper way to treat people with ID.

> A: It is unjust to bully and reject people with such condition (intellectual disabilities). We may find children do such things to them...they don't have an ill intention, they (the children) just want to have fun, to make fun of people with disability (P17/religious leader-Hindu).

Professionals indicate stigma in school settings (e.g. bullying) as a reason for them to recommend specialised education to student with ID.

> A: …if his parents think that it is impossible for the child to go to school because they are worried about bullying. I often heard about children with disabilities being bullied. Then the second option is home-schooling (P11/religious leader-Protestant).

Exploration of stigma in adults with mild to moderate ID who took part in the study suggests that they spend most of their time at home and are restricted in their basic liberties, such as going outside their home without supervision.

> A: I am not allowed to go (out of the house) on my own, but I can go with my granny Q: Who told you not to go out alone? A: My mom Q: Why your mom doesn't allow you? A: It has always been like that, I am not allowed Q: Do you know the reason? A: No neighbours, I am not allowed to play with neighbours (P10/female/moderate ID).

A professional said that such restrictions have taken place for a long time. In the past, parents tend to hide their child with ID at home. However, professionals said that the situation is improving as more and more parents recognise the importance of inclusion for their child.

> A: In the past, many children with similar condition to Rudy and Gilang (intellectual disabilities) were kept at home, hidden. But it has changed quite significantly now (P06/special education teacher).

7.3.2 Reactions to stigma: shame, anger and fear

Out of eleven items on the SRSQ-I, seven items were answered ‘yes’ by forty per cent or more participants. Four of the seven items represent reaction to stigma, namely ‘the way people talk to me makes me angry’ (48%), ‘people make me feel embarrassed’ (44%), ‘I worry about the way people act towards me’ (44%), ‘I keep away from other people because they are not nice to me (40%). This finding was further elaborated by using the qualitative component obtained from adults with mild to moderate ID. The qualitative component highlights that shame and anger are common emotional reactions to stigmatising behaviour in various contexts.

> A: ...I was mocked, I was called the black aunt, lice, when I was at the elementary school…I was mad, I was mad, I was called stupid…I felt ashamed, I felt offended… (P12/female/moderate ID).

> A: (I feel ashamed) if I was told to do things and I did it wrong… Q: If you made a mistake, what do people say? A: My dad usually says ‘[T]his is a simple task, why did you make such a mistake?’ (P05/male/mild ID).

Adults with mild to moderate ID reported that they have concerns regarding how people may act towards them, which was represented in item ‘I worry about the way people act towards me’. This item is arguably broad as it could be applied in many contexts. Concerns about others (e.g. peers, neighbours) knowing about their disabilities is an example of contexts covered in the item. Adults with mild to moderate ID reported that they prefer to be discreet about their disabilities and put an effort to hide their disability. The qualitative data obtained from adults with mild to moderate ID suggests that such reaction stems from fear of rejection, or poor treatment, when non-disabled people/peers learned about their disabilities.

> A: In my current neighbourhood, no one knows that I work here (sheltered workshop). I am afraid the information might spread. I don't like it (if it's happened). I am afraid (if the new neighbours know) (P03/female/mild ID).

> Q: Do they (peers at church) know that you go to a special school? A: They don't, no one knows about it. Q: You don't tell them? A: No Q: Why? A: I am ashamed, I am afraid they will avoid me (P01/female/mild ID).

Concerns regarding how other people may act has also been highlighted in work or school setting, in which adults with mild to moderate ID feels uncomfortable in relationship with non-disabled colleagues or peers.

> A: I prefer to work here (sheltered workshop) because the people here know about my condition. People were talking behind my back at the shop (where I previously worked), here they talk openly (P03/female/mild ID).

> A: …I want to join them (classmates), but they don't want me to join Q: why they don't want you to join? A: I asked them, but they didn't say anything (P06/female/mild ID).

7.3.3 Stigma and socio-demographic characteristics

This theme was derived from the chi-square analysis showing a difference in the distribution of participants' response regarding the experience of particular stigma, among socio-demographic groups, namely: employment status, age, living area (rural-urban) and ethnicity and religious background. The chi-square analysis suggests that participants living in urban areas were more likely to agree on two SRSQ-I items, namely 'people treat me like a child' and 'people on the street make fun of me'. The qualitative data provided by adults with mild to moderate ID offer relevant information, which includes topics related to parental restriction and lack of opportunities available to people with ID living in urban areas. The examples provided by participants are more readily associated with infantilisation of adults with ID (e.g. incapable, could not maintain safety).

> Q: Do you visit places around your house? A: I do, but I do it in secret Q: Why don't you tell your parent? Q: They won't allow me…maybe because they think that I am a special school student, they are afraid I might get swindled, or I might get kidnapped... (P01/female/mild ID/urban).

In contrast, the integration of findings suggests that participants living in rural areas have more inclusive and positive experiences of being a part of their communities, which include opportunities for employment and more active roles in community life. This notion was supported by the suggestion from a professional that people with mild ID could take part in farming activities.

> A: At home, I help a friend to wash clothes, to do laundry Q: Was it a job? A: Yes Q: You worked at a laundry? A: Yes Q: Please tell me more about it A: My job is to hand clean clothes (to the customer) Q: How did you find that job? A: My friend owns the laundry, she asked me to help her (P14/female/mild ID/rural).

> A: If he (adult with mild ID) lives in rural area, where many farmers grow vegetable, he can also do the same work (P04/medical doctor).

A participant explicitly reported that he was treated like a child at home because all of his sibling was married, leaving him as the only one who is still single. This suggests that marriage is perceived as an indicator of adulthood.

> …my siblings are married. I am the only one who is not, because at home I am still treated as a child, sometimes (I) feels lonely, sometimes I feel ashamed, in my neighbourhood all my peers are married… I am ashamed… (P09/male/mild/urban).

Participants who live in urban areas were more likely to agree on the statement 'people on the street make fun of me'. Agreement to this item indicate that participants were more likely to be made fun of by strangers in public spaces. However, in Indonesian contexts, the translation of 'people on the street' (*orang di jalan*) does not always mean strangers. Participants – especially those who live in a more traditional community – may include neighbours, peers, and other people whom they meet at neighbourhood streets as ‘people on the street’. Therefore, the qualitative data used to explain this finding cover situations that refer to the interaction of adults with mild to moderate ID with people other than family members and staff from special institutions. Despite the difference of response distribution for this item among participants living in rural and urban, the qualitative components suggest ambiguous results as participants from both groups report positive and negative experiences.

> Q: How do your peers from the neighbourhood treats you A: They are nice, but some of them like to make fun of me (P11/male/mild ID/urban).

> A: I have a neighbour, next to the fruit shop (owned by her family), she often talks to me…she is pious (*sholehah*), she is nice to us, she (sometimes) gives cakes, sweet cakes (P12/female/moderate ID/urban).

> Q: How do your neighbours treat you? A: They are nice to me Q: Has someone said something bad about you going to a special school? A: No, never. Q: Does your neighbour knows that you were attending special school? A: Yes, they know (P13/female/mild ID/rural).

Discussion regarding preferred living arrangement (urban vs. rural) was enriched by advantages and disadvantages mentioned by professionals. The advantages of living in rural areas were associated with the collectivist values (Hofstede, 2001) that is predominant in rural areas. Collectivist values allow neighbours to become a support system for people with ID and their family. For instance, neighbours may help to look after the person with ID when they are spending time around the neighbourhood.

> A: …if Rudi lives in a village, wherever he goes, people will recognise him and they may say ‘Oh, I saw him there’ (when the family are looking for him (P04/Medical doctor).

On the contrary, another professional offers a different perspective suggesting that living in rural areas would not benefit people with ID. In his suggestion, the professionals highlighted educational characteristics of people living in rural areas – which he perceived as low – as barriers for people in rural communities to have sufficient knowledge and understanding regarding ID. Having this perspective leads the professional to prefer urban communities as a better place for people with ID to live in. In contrast, professionals highlighted that individualistic values – where ties between individuals are loose and people are only expected to care for oneself, and/or their immediate family (Hofstede, 2001) – that are predominant in the urban community will protect people with ID from stigma.

> A: There is a habit in the (Indonesian) community, especially in the rural area, where the people are less educated. Their perspective (about people with disability) is burdening for people like Rudy and Gilang; they like to talk about others' misfortune. But if they live in a community which understands their condition, it would be good; or for them to live in urban areas where people aren't really cared for each other, including to the limitation and condition of others (P09/religious leader-Muslim).

Another concern regarding people with ID living in rural areas comes from the possibility that they may be referred to as traditional healers instead of health professionals and that there may be stigma coming from the traditional beliefs of a supernatural power as the cause of the disability.

> A: If Rudy and Gilang live in a rural area…there is a possibility for them to be brought to traditional healers…instead to health professionals…or they may be suspected of being possessed by an evil spirit (P01/educational psychologist).

Moving to another result of the Chi-Square analysis, participants with no employment status were more likely to agree to the statement 'people make me embarrassed'. The Indonesian version of this item can be interpreted as people do something to make the participant embarrassed, or an internalisation of shame, which represents the feeling of embarrassment to meet or to interact with other people, as the word 'embarrassed', 'shame' and 'shy' are translated to a single Indonesian word 'malu'. Qualitative information obtained from adults with mild to moderate ID describing emotional and behavioural reactions towards perceived stigma, and those depicting general social interactions were extracted to further explore this finding. The extracted qualitative components were further compared between participants who have been and have never been in employment. Among the fifteen participants included in the qualitative interview, two participants were in sheltered employment. Two participants had inclusive employment in a small business before they were due to leave the position for an apprenticeship in the rehabilitation centre. Therefore, the two participants were included in 'participants with employment status' group.

In contrast of the qualitative data extracted from the two groups (employment vs. unemployment), it does not support the quantitative findings as participants from both groups reported their tendencies to avoid inclusive social interaction. A participant in sheltered employment reported her unwillingness to interact with her neighbours due to past experiences of discrimination.

> A: No, after I finish work, I never talk to the neighbours. I am afraid of being out alone. I am afraid if I misspoke, and I am afraid of being mocked, that is why I go straight to home after work…they (people from old neighbourhood) mocked me for being a special school student…. In my current neighbourhood, no one knows that I worked here (sheltered workshop). I am afraid the information might spread… (That's why) I never go outside after work (P03/female/mild/sheltered employment).

While a participant who is a student reported that she feels ashamed if her peers from the church find out that she goes to a special school.

> Q: Do they (peers) know that you go to a special school? A: They don't, no one knows about it. Q: You don't tell them? A: No. Q: Why? A: I am ashamed, I am afraid they will avoid me. (P01/female/mild ID/student)

Quantitative findings suggest that participants of younger age group (17–23 years old) were more likely to agree with two statements 'people make me feel embarrassed' and

‘I worry about the way people act towards me’. The findings are supported by the results of the multiple regression analysis which indicated age as a predictor of stigma experience. The exploration of qualitative data does not provide specific information regarding the two particular kinds of experiences of stigma. However, the qualitative data suggests that younger participants mostly experience stigma whilst enrolling at mainstream school or with their peer neighbours, which cause them to withdraw from inclusive social interaction; this may also be related to emotional reactions of embarrassment and worries towards social interaction as represented in the two items.

> Q: Do you have friends in your neighbourhood? A: I do, one or two Q: what about your other peer? A: …How should I say it…? I don’t know… Q: Do they avoid you? A: No, it’s not them, it’s me who avoids them…because they are delinquent…they took my phone. (P07/male/mild ID/younger age group).

> Q: You said that there was a bad classmate as well, what did they do to you? A: (They were) sarcastic, I felt that way Q: What did they say? A: It was, it was just, (they said) ‘she is not the same as us’… it feels uncomfortable, and they avoid me (P06/female/mild ID/younger age group).

A participant of older age group provide an important hint regarding the relationship of age and stigma, as he reported that he experienced stigma more frequently when he was younger and subsided as he grew older.

> Q: Who made fun of you? A: People near my house, but it was long ago Q: Who are they? A: Neighbours (peers)…who I usually play with Q: How about now? A: Now it’s not so often Q: How old were you when that happened? A: When I was in middle school (P05/male/mild ID/older age group).

The quantitative findings suggest that participants from minority ethnic groups (other than Javanese) were more likely to agree with the item ‘people laugh at me because of the way I look’ and ‘people make fun of my family’. While participants from minority religious groups (other than Islam) were more likely to agree with the item ‘people talk down to me’. However, it was possible to extract only one qualitative information, which was deemed to be relevant to the quantitative finding. The quote indicates that adults with mild to moderate ID could also be a subject of negative stereotypes related to ethnic background.

> Q: Aside from mocking you because you go to a special school, what else did people say to you? A: Many, for example, like for being a padangnese, ‘stingy’. (Padangnese tribe has the stereotype of ‘stingy’ in the Indonesian community). I don’t think so, my mom is not stingy, she gives a lot (to charity), but people still see us as stingy, so I better avoid them (P03/female/mild ID/minority ethnic group).

7.4 Discussion

7.4.1 Summary of results

The integration of the findings emphasises a convergence of information gleaned from quantitative and qualitative components of the three studies. This study highlights three findings: First, it confirms that adults with mild to moderate ID experienced stigma and are socially restricted. Second, it identifies shame, anger and fear as common reactions towards stigma among the participants. Third, it provides further discussion regarding the relationship of stigma and socio-demographic characteristics, particularly age, employment status, living area (rural-urban), and religious-ethnic background.

7.4.2 Results in context

The feeling of embarrassment and concern over how others would act towards the participant with ID were found to be a common reaction to stigma leading to limited social interactions and hindering full inclusion in society e.g. building friendships. A previous study has noted similar findings that people with ID tend to distance themselves from more inclusive relationship with non-disabled people to avoid stigma (C. H. Chen & Shu, 2012). Furthermore, C. H. Chen and Shu (2012) noted that receiving special services could be a source of embarrassment due to labelling, which was also found in this study.

People with ID attending special school are more likely to be recognised as having disability, and negatively labelled as 'special school kids'.

Embarrassment felt by adults with mild to moderate ID could also be linked to internalisation of embarrassment shown by family members. As it was in Chinese culture, having a family member with ID caused the family to 'lose face' (Yang, 2015). A similar term to 'losing face' is also present in the Indonesian culture in the expression of '*kehilangan muka*', which is literally translated as 'losing face'. The Indonesian term refers to a condition where other family member bear embarrassment or loss of pride due to the 'problem' of one family member. Such situation occurs not only when a family member has a disability, but also for displaying other socially unacceptable behaviours. Internalisation of stigma among family members has been linked with restriction of social life (Moreira, 2011), such as people with ID being concealed in house and forcefully withdrawn from society by their families to avoid stigma.

In this study, the relationship between age and stigma found in the quantitative component were further explained as the results of discriminations and poor treatment that participants received whilst at mainstream education (prior transfer to special school) and/or from the interaction with non-disabled people in their neighbourhood. That participants are more likely to experience stigma in their younger age when they have access to mainstream education. Previous study has also noted that people with ID experience 'bullying' (Christensen et al., 2012) – which includes physical, verbal (name-calling), labelling, and teasing – from fellow students in mainstream school and peers in the neighbourhood (Christensen et al., 2012; Norwich & Kelly, 2004). Furthermore, the study noted that bullying victimisation tends to decreased from middle childhood through early adolescence, which supports the explanation that stigma experience tends to subside through the lifespan (Christensen et al., 2012).

Living in rural settings appears to be a more positive situation for than living in urban environments for participants as the latter may be more restrictive due to safety concerns. A previous study noted that people with ID living in rural areas have better opportunities to engage in community activities, including employment as finding a job may be less competitive or the need for skilled labor lower (Nicholson & Cooper, 2013). People living in Indonesian rural areas rely on family-scale agricultural activities in which people with ID could contribute to most tasks (e.g. feeding cattle animal, ploughing soil, harvesting paddy plant). An alternative explanation as to why people with ID in rural areas have better opportunities of inclusion may be related to the expectation of academic achievement – which considered as one of the common reason for attaching a negative label to people with ID (C. H. Chen & Shu, 2012) – in a more traditional community. It is estimated that among persons aged between 15–19 years old in rural areas in Indonesia, only 66 per cent are currently in the educational system, while 33 per cent are no longer there and 1 per cent had never attained education (Statistics Indonesia, 2018). Looking at the statistics of the labour force in Central Java – a major province in Indonesia which mostly consists of rural areas – the majority of the workforce (52%) are elementary school graduates (Wahyu, 2016). People with ID construct their identity comparing themselves with other people in their surroundings (Logeswaran, Hollett, Zala, Richardson, & Scior, 2019). Therefore, living in a community where academic achievement is not seen as a priority and dropping out of education is common, helps people with ID to maintain a positive view of themselves. On the other hand, the low academic expectation at community level could also shape the perspectives of the community at large with the unintended consequence of fostering more tolerant views of less educated people.

Quantitative findings suggest that participants from minority ethnic and religious background were more likely to experience a particular form of stigma. However, the qualitative components were limited to further elaborate the quantitative finding as only one of the comments obtained from an adult with ID was deemed relevant. Despite insufficiently supported, the finding regarding the relationship between minority background and stigma should be explored in future studies, as Logeswaran et al. (2019) highlights that people with ID may also experience stigma for emotional/mental health problems, other disability condition, or due to racism. It is important that further study is called for to specifically explore this issue, as discrimination in the bases of ethnicity and religion is still present in contemporary Indonesia (Bell, 2001).

7.4.3 Strengths and limitations

This section specifically addressed the strength and limitation of the integration of findings presented in this study, as the strength and limitation of the quantitative and qualitative studies have been addressed in their respective chapters (see Chapter 5 and 6). The strength of this study comes from the three components of studies and multiple perspective of respondents included in this study. This study integrates three components of studies, namely a quantitative data obtained from a survey of 100 adults with ID, a qualitative data obtained from interviews of 15 adults with mild and moderate ID, and a qualitative data obtained from the interviews of 18 professionals, who have the authority to recommend treatment for people with ID in Indonesian context. Including adults with mild to moderate ID and professionals allows this study to explore stigma of ID in two different perspectives and to compare them.

The limitation of this study lies, first, in the difference of information; ‘depth’ between the two approaches. The quantitative studies utilised a single measure of stigma, the SRSQ-I, to explore the experience of stigma. The SRSQ-I is a questionnaire aimed at people with ID. Therefore, it was developed and designed to be simple to allow participants to fill the questionnaire with minimum assistance. The simplicity of the questionnaire – for instance, the use of the binary format response – restricts the interpretation of the questionnaire results. Second, the data collection instruments used in both studies (the SRSQ-I and the semi-structured interview questionnaire) were developed separately, each with its own focus. Consequently, there was a gap between topics covered in each of the studies despite both studies exploring the experience of stigma. Future studies should consider merging the SRSQ-I items in the semi-structured interview questions used in the qualitative study or to use items as prompts to relevant interview questions.

7.4.4 Conclusion

This chapter integrates quantitative and qualitative components of this thesis to further explore the experience of stigma in adults with mild to moderate ID in the Indonesian context. This study suggests that adults with mild to moderate ID experience stigma and that such experience is common; but there may be protective factors in age and setting, as it is shown that older age and rural settings tend to normalise social response towards people with ID. Given that younger participants appeared to be more vulnerable to particular experiences of stigma, anti-stigma intervention should be tailored to address this groups. Furthermore, efforts to reduce stigma should also be carried out in school settings to eradicate bullying towards students with ID in mainstream and/or inclusive schools.

Chapter 8 Concluding remarks, implications and future directions

8.1 Summary of results

This PhD thesis comprises of a systematic review investigating the stigma towards people with ID in Southeast Asia and three interrelated empirical studies exploring the experience of stigma in people with ID carried out in a multimethod approach. The systematic review suggests that stigma towards people with ID is present in parts of the Southeast Asian countries, especially in a more traditional communities living in rural areas. Studies suggested that cultural factors including religious beliefs and social expectation plays an essential role in shaping the stigma of people with ID. It is important to note that stigma associated with ID was closely related to poverty and limited access to service and support, especially in rural areas.

The study exploring professionals' attitudes suggests encouraging findings of positive attitudes towards people with ID and their inclusion in society. Professionals express their willingness to provide service for people with ID despite expecting higher efforts that are needed to provide the service. The perceived capabilities of people with ID were found as an important driver of professionals' attitudes, resulting in more positive attitudes towards people with mild ID compared to their counterparts with more severe ID. The availability of good quality services was also found to affect professionals' decision regarding the management of people with ID. Professionals' tend to be more eager to recommend more inclusive options, such as inclusive education, when the school could offer sufficient support to students with ID, or when families have the financial resources to attain an inclusive school with a good reputation.

The adaptation study of the self-report stigma questionnaire has produced an Indonesian version of the questionnaire named the SRSQ-I. The Indonesian version of the questionnaire consists of 11 statements exploring the experience of stigma in people with mild to moderate ID. The SRSQ-I has a good test-retest reliability ranging from .402 to .802 for all of the items, internal reliability of .727 and test-retest relibility of .780. A single underlying common factor, labelled as ‘experienced stigma’ was identified in the questionnaire. The findings suggest that the SRSQ-I has sound psychometric properties and is usable to explore experience of stigma in adults with mild to moderate ID in the Indonesian context. The analysis of quantitative data obtained from the SRSQ-I suggests that the experience of stigma is common among adults with mild/moderate ID. Further exploration of the quantitative data indicated the relationship between stigma and age; that participants of younger age are more vulnerable to stigma. The finding also indicated the relationship between particular forms of stigma with demographic characteristic, such as living area (urban, rural), employment status, and minority backgrounds (ethnicity, religion), which needs to be explored at a greater length in future studies.

Thematic analysis of qualitative data obtained from fifteen semi-structured interview with adults with mild to moderate ID identify four themes, namely: ‘discrimination and poor treatment’, ‘limited social life and activities’, ‘reaction to and impact of stigma’, and ‘wish of a normal life’, which portrays various discrimination adults with ID experience in their daily life, the extents of their inclusion in society, their reaction towards and internalisation of stigma, and how stigma erects barriers towards inclusion and future aspiration of adults with mild to moderate ID. The study confirms that adults with mild to moderate ID participating in this study experience stigma in their daily life. The experience of stigma started at the age of school, often during participants’ time in mainstream education, before they were transferred to special education. The participants experienced stigma in various forms and settings, from mockery and rejection from peers to physical abuse and neglect from parents. The integration of quantitative and qualitative findings was carried out to further explore experience of stigma in people with ID. The integration confirms that stigma towards adults with ID is prevalent. Anger, shame and fear were identified as common reaction to stigma among adults with mild to moderate ID. Further discussion regarding the relationship between stigma and socio-demographic characteristics were provided.

To summarise, this thesis found that stigma towards people with ID is present in parts of Indonesian society in the Java Island where this PhD project was carried out; and that adults with mild to moderate ID are subjected to discrimination and poor treatment in various extent. One hundred adults with mild to moderate ID involved in this study were recruited in two areas, namely the Indonesian capital city Jakarta and Temanggung, West Java; which respectively represent Indonesian urban and rural areas. Despite its relatively small sample size and convenience sampling methods, the finding of this project indicates that the stigma happens in both the settings. This study is the first to explore stigma towards people with ID in the Indonesian context, which becomes its strength to provide important information regarding the situation.

8.2 Implications

8.2.1 Implications for practice

This study provides information regarding stigma towards people with ID and indications of how it negatively affects people with ID and their inclusion in society. These findings are important for the development of ID-related stigma framework and initiatives to reduce stigma. The Indonesian government, as the sponsor of this project, could benefit from using the findings as initial information to tailor evidence-based policies regarding people with ID in the Indonesian context, as this thesis has indicated that cultural context plays an important role in shaping stigma of ID, and therefore cultural factors should be considered in developing an anti-stigma program. This study indicated that particular groups in the ID population (e.g. younger age) may be more vulnerable to stigma than others, which could help set up priorities in the efforts to reduce stigma. Elaborated in the previous section, this thesis highlights the importance of developing a school-based anti-stigma program given that two qualitative studies encapsulated in this thesis have consistently suggested that discrimination and bullying towards students with ID happens in mainstream school settings; to include professionals, such as medical doctors, psychologists, teachers, and faith leaders as potential allies in initiatives to eradicate stigma and promote inclusion. Finally, the government could use the SRSQ-I, produced in this thesis, in a larger study to better explore the experience of stigma among people with ID to inform public policies related to this population.

8.2.2 Implication for future research

This thesis suggests that stigma associated with ID is present and common in Indonesian society. Future research aiming to develop anti-stigma intervention targeting people with ID could use the information provided in this study as a baseline of their work. Additionally, the SRSQ-I developed in this project provides a sound instrument to measure experience of stigma in adults with mild to moderate ID population, as well as endorsing future research in this area to be carried out in the Indonesian context. As previously noted, the identification of people with ID in this project was a major challenge. This was due to the absence of a standardised procedure in ID diagnosis in Indonesia. Future studies should aim to develop or adapt a standardised diagnostic tool related to ID diagnoses, such as instrument to measure IQ and adaptive skills in people with ID. Lastly, this study explored stigma from professionals’ and adults with ID perspectives. Future research should aim to explore the stigma from other stakeholders’ perspective, such as parents, family members, and the lay members of public to provide a comprehensive view of ID stigma in Indonesia cultural context.

8.3 Future directions

Stigma hampers the inclusion of adults with mild to moderate ID in Indonesian society. Consequently, efforts to eradicate stigma are needed to endorse inclusion of this one of the most underserved and disadvantaged groups. Studies in the field of mental illness have noted initiatives carried out in countries around the world to reduce stigma towards people with mental illness (Dalky, 2012). Anti-stigma programmes addressing mental illness-related stigma mainly revolve around two methods, namely education and contact (Dalky, 2012). Educational methods aim at changing inaccurate stereotypes regarding the stigmatised people with factual information (Corrigan & Gelb, 2006), while contact involves providing opportunities for participants to interact personally with the stigmatised person, and use that experience to reduce the stigma (Corrigan & Gelb, 2006).

Initiatives to reduce stigma towards people with disabilities, including ID, has also been carried out in different parts of the world, although most of the interventions have not been empirically evaluated, and are limited in implementation (Werner & Scior, 2016). Werner and Scior (2016) propose a multilevel model for reducing ID related stigma, which places family as the central force in anti-stigma campaign and activism. The first level is the interpersonal and familial which aims to help people with ID to mitigate the negative impact of stigma. On the next level, the interpersonal-level interventions focus on social interaction between the stigmatised people and other member of the society (outside of family). At this level, the two methods mentioned earlier, i.e. education and contact are mainly used to reduce stigma. The third level is the structural-level interventions which target societies and its institution, utilising public and organisational policies, and media to reach a larger audience. The approaches mentioned above have also been suggested for use in a broader attempt to reduce stigma towards people with disabilities in developing countries (Rohwerder, 2018)

In the Indonesian context, interpersonal-level intervention can be carried out by empowering the community health centres (*puskesmas*), which are established within the Indonesian health system. The *puskesmas* functions as the primary health care service, equivalent to the General Practitioners (GP) surgery in the UK National Health Service. For the past two decades, basic mental health services are provided by general practitioners and nurses trained in assessment of mental health problems in *puskesmas*, prior to referral to secondary mental health services (I.e., mental hospitals, mental health services in general hospitals, and practices of mental health specialists)(Sari, 2016). In recent years, improvement of mental health services in the *puskesmas* has seen the introduction of psychologists to the setting (Sari, 2016; Setiyawati, Blashki, Wraith, Colucci, & Minas, 2014). However, due to the limited number of psychologists available, this development can only be implemented in *puskesmas* based in large cities, such as Jakarta and Yogyakarta.

Empowering *puskesmas* to achieve stigma reduction goals should commence from raising awareness of mental health and disabilities related issues, starting from its cadre (lay member of the community, recruited and trained to assist health promotion to another member). As suggested by Werner and Scior (2016) and supported by findings in this study, efforts to eradicate stigma towards people with ID should actively involve families of people with ID. Family participation is needed to address self-stigma and inclusion of people with ID in the wider society, as parents play an important role in the internalisation of stigma and hold the power to restrict or promote inclusion of people with ID (Ngo et al., 2012), which was also highlighted in this thesis.

In the Indonesian context where culture is diverse, the mental health promotion team is an important resource to deliver a tailored anti-stigma campaign, as the team, consisting of local people, is familiar with cultural factors prevalent in the targeted community. Similar approach—that an anti-stigma campaign should involve people that are familiar with the targeted communities—has also been highlighted as part of strategy to reduce stigma towards people with disabilities (Rohwerder, 2018). Furthermore, being the primary health service in the community, *puskesmas* have direct access to patients including people with ID, and therefore able to provide anti-stigma programs directly to people with ID. Formally assigning anti-stigma program to *puskesmas* is also an important step for local government to join the effort in battling stigma towards people with disabilities, which has been mainly carried out by NGOs (Mahendradhata et al., 2017), and to comply with the new Indonesian disabilities law ratified in 2016.

The student argues that anti-stigma campaign should also be carried out in school settings. This suggestion is relevant with the finding of this study which suggests that people with ID experienced stigma as early as in their elementary school life; and that nurturing positive attitudes towards people with ID should start at a young age (Werner & Scior, 2016). Embedding anti-stigma programmes within the formal education system allows the program to reach a wider and younger audience, as well as to ensure sustainability of the program. The program could start with incorporating anti-stigma content in lessons which aims to shape moral and characters, such as the citizenship education (*pendidikan kewarganegaraan*) and religious education (*pendidikan agama*). Incorporation of anti-stigma intervention within the existing curriculum has been achieved in reducing stigma towards people with a mental health problem (Rickwood et al., 2004; Swartz et al., 2010), and the strategy has been referred as ‘literacy-based education’ (S.-P. Chen, Sargent, & Stuart, 2018).

However, the efficacy of school-based interventions to reduce stigma is still of concern (Mellor, 2014).

In parallel, inclusive education, which has been implemented in recent years in Indonesia, should be further promoted and supported by providing sufficient numbers of teachers trained in special education, the establishment of inclusive education curriculum and investment in infrastructures needed to accommodate students with ID and other disabilities in public schools. However, implementation of inclusive education policy at a national level should be carried out carefully, as studies show risk of bullying towards people with ID in school settings (Christensen et al., 2012; Griffin, Fisher, Lane, & Morin, 2019) as well as concerns from professionals regarding limited resources available in existing inclusive schools (see chapter 3). The awareness of policymakers is called for to tackle this challenge (Scior et al., 2015); investment to ensure schools has sufficient funding and resources to deliver a good quality inclusive education should be made. Improving teacher attitudes has also been noted as a key element to successful inclusion of students with disabilities in education (Avramidis & Norwich, 2002; Thaver & Lim, 2014). This study found that teachers generally hold positive attitudes towards people with ID and their inclusion in society. Therefore, they should be seen as potential allies in order to ensure the delivery of anti-stigma content in school.

This thesis was aimed to provide initial information to the Indonesian government in their efforts to address issues regarding people with ID in Indonesian society. In light of the findings, it is paramount for policy makers to be aware of the stigma attached to people with ID and how it negatively affects so many lives. Policy maker should also be aware of the interwoven issue of poverty and disability in developing countries, as it has been noted in previous studies; that poverty is both cause and consequence of disability (Braithwaite & Mont, 2009; Hoogeveen, 2005; Yeo & Moore, 2003). Another study suggests that the connection between poverty and disability is more complicated than is commonly thought (Groce et al., 2011). Studies investigating the situation of people with disabilities in developing countries linked poverty with limited access to treatment, neglect, burden of care (J. Carter, 2009; Moreira, 2011), and use of traditional treatments (Brolan et al., 2014). It is also noted that these conditions are more likely to happen in rural areas (Rohwerder, 2018). On the contrary, this thesis suggests that traditional community living in rural areas may be more accommodating towards people with ID, compared to those living in urban areas. This may be explained by being a more tolerant society with lower expectation of education achievements (elaborated in chapter 7) and unskilled labour. In light of this, the initiative to eradicate stigma and to improve the life of people with ID in Indonesian rural settings may require a different strategy and approach.

Furthermore, initiatives to promote inclusion must also account for cultural values prevalent in the communities, includes professionals who are working closely with people with ID, and must place the person with ID at the centre of all initiatives. In parallel, efforts to raise awareness regarding the rights of people with disability should also be improved and continued. A participant involved in this project summarised the aim of initiatives to eradicate stigma and endorse inclusion of people with ID in a simple sentence. ‘If they (people with ID) live in a community which understands them, that would be good’.

8.4 Dissemination

Modified versions of the following chapters had been disseminated at the time this thesis was completed:

- An earlier version of the systematic review presented in chapter 3 has been presented in the CIDDR meeting on March 31st, 2017 and the Intellectual Disability Academic Program on April 10th 2017, London, UK.

- A version of the study exploring professionals' attitudes towards adults with mild/moderate ID (chapter 4) has been presented in the IASSID 4th Asia Pacific Congress, Bangkok, Thailand, on November 15th, 2017; and accepted for publication in the Transcultural Psychiatry on July 3rd 2018. Initial findings of the study have also been presented in the National Postgraduate Seminar hosted by Gadjah Mada University, Indonesia, on March 23rd, 2018.
- A version of the systematic review (Chapter 3) and the qualitative empirical study exploring the experience of adults with mild to moderate ID (Chapter 6) have been accepted for oral presentation at the World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID), which will be held in Glasgow on 6 - 9 August 2019.
- The finding of this thesis will further be disseminated in future opportunities, such as conferences and journal publications.

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Appendices

Appendix 1: Systematic review keyword list

Intellectual Disability	Stigma	South East Asia
intellectual* disab* OR intellectual* disorder* OR intellectual* impair* OR mental* retard* OR mental* challenge* OR mental* impair* OR mental* deficien* OR mental* handicap* OR learning disab* OR learning disorder* OR learning impair* OR learning difficult* OR delayed learning OR impaired learning OR delay learn* OR development* impair OR development* disorder OR cognitive* delay* OR slow learn* OR slow-learn* OR subaverage intelligence OR sub-average intelligence OR special needs	Stigma* OR public stigma OR self-stigma OR self stigma OR affiliate* stigma OR courtesy stigma OR attitude* or belief* OR perception* OR perceive* OR concept* OR prejudice* OR discrimnat* OR inclu* or social* inclu* OR social* distan* OR accept* OR social* accept* OR community accept* OR social* integrat* OR integrat* OR commun* integrat* OR participat* OR social* participat* OR commun* participat*	Brunei* OR Cambodia* OR East Timor OR Timor-Leste OR Timorese OR Indonesia* OR Lao OR Laos OR Lao PDR OR Lao People Democratic Republic OR Malaysia* OR Myanmar OR Burma OR Burmese OR Philippines OR Filipino OR Singapore* OR Thailand OR Thai OR Vietnam* OR South East Asia* OR Southeast Asia* OR South-East Asia* OR Asia*

Appendix 2: Systematic review, list of 23 selected journal

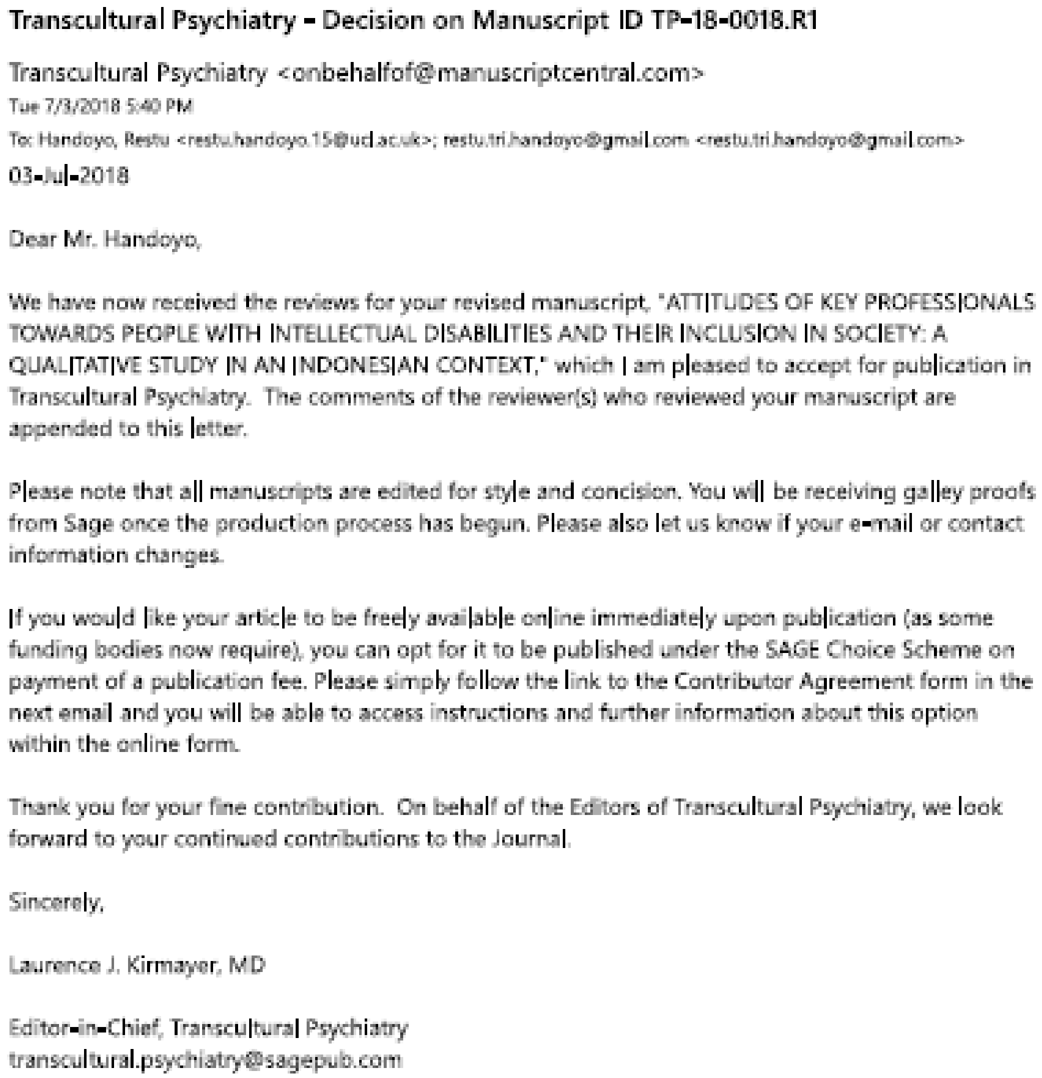
1. Brunei International Medical Journal
2. Acta medica Indonesiana
3. Medical Journal of Indonesia
4. Medical Journal of Malaysia
5. Malaysian Journal of Public Health Medicine
6. Kemanusiaan
7. Kajian Malaysia
8. Asia-Pacific Education Researcher
9. Asian Nursing Research
10. Singapore Medical Journal
11. Southeast Asian Journal of Tropical Medicine and Public Health
12. ScienceAsia
13. Journal of Health Research
14. Journal of intellectual disability research
15. Journal of intellectual and developmental disability
16. Journal of intellectual disability – diagnosis and treatment
17. American journal on intellectual and developmental disabilities
18. Journal of applied research in intellectual disabilities
19. Journal of intellectual disabilities
20. Journal of policy and practice in intellectual disabilities
21. Journal of mental health research in intellectual disabilities
22. Advances in mental health and intellectual disabilities
23. Journal of intellectual disabilities and offending behaviour

Appendix 3: Systematic review quality assessment form

Category of study designs	Methodical quality criteria
Screening questions (for all types)	S1. Are there clear research question?
	S2. Do the collected data allow to address the research questions?
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research questions?
	1.2. Are the qualitative data collection methods adequate to address the research question?
	1.3. Are the findings adequately derived from the data?
	1.4. Is the interpretation of results sufficiently substantiated by data?
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?
	2.2. Are the groups comparable at the baseline?
	2.3. Are there complete outcome data?
	2.4. Are outcome assessors blinded to the intervention provided?
	2.5. Did the participants adhere to the assigned intervention?
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?
	3.2. Are there complete outcome data?
	3.4. Are the confounders accounted for in the design and analysis?
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?
	4.2. Is the sample representative of the target population?
	4.3. Are the measurements appropriate?
	4.4. Is the risk of nonresponse bias low?
	4.5. Is the statistical analysis appropriate to answer the research question?

5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?
	5.2. Are the different components of the study effectively integrated to answer the research question?
	5.3. Are the outputs of the integration of qualitative and quantitative component adequately interpreted?
	5.4. Are the divergences and inconsistencies between quantitative and qualitatve results adequately addressed?
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

Appendix 4: Acceptance notification from Transcultural Psychiatry



Transcultural Psychiatry - Decision on Manuscript ID TP-18-0018.R1

Transcultural Psychiatry <onbehalfof@manuscriptcentral.com>
Tue 7/3/2018 5:40 PM
To: Handoyo, Restu <restu.handoyo.15@ucl.ac.uk>; restu.tri.handoyo@gmail.com <restu.tri.handoyo@gmail.com>
03-Jul-2018

Dear Mr. Handoyo,

We have now received the reviews for your revised manuscript, "ATTITUDES OF KEY PROFESSIONALS TOWARDS PEOPLE WITH INTELLECTUAL DISABILITIES AND THEIR INCLUSION IN SOCIETY: A QUALITATIVE STUDY IN AN INDONESIAN CONTEXT," which I am pleased to accept for publication in Transcultural Psychiatry. The comments of the reviewer(s) who reviewed your manuscript are appended to this letter.

Please note that all manuscripts are edited for style and concision. You will be receiving galley proofs from Sage once the production process has begun. Please also let us know if your e-mail or contact information changes.

If you would like your article to be freely available online immediately upon publication (as some funding bodies now require), you can opt for it to be published under the SAGE Choice Scheme on payment of a publication fee. Please simply follow the link to the Contributor Agreement form in the next email and you will be able to access instructions and further information about this option within the online form.

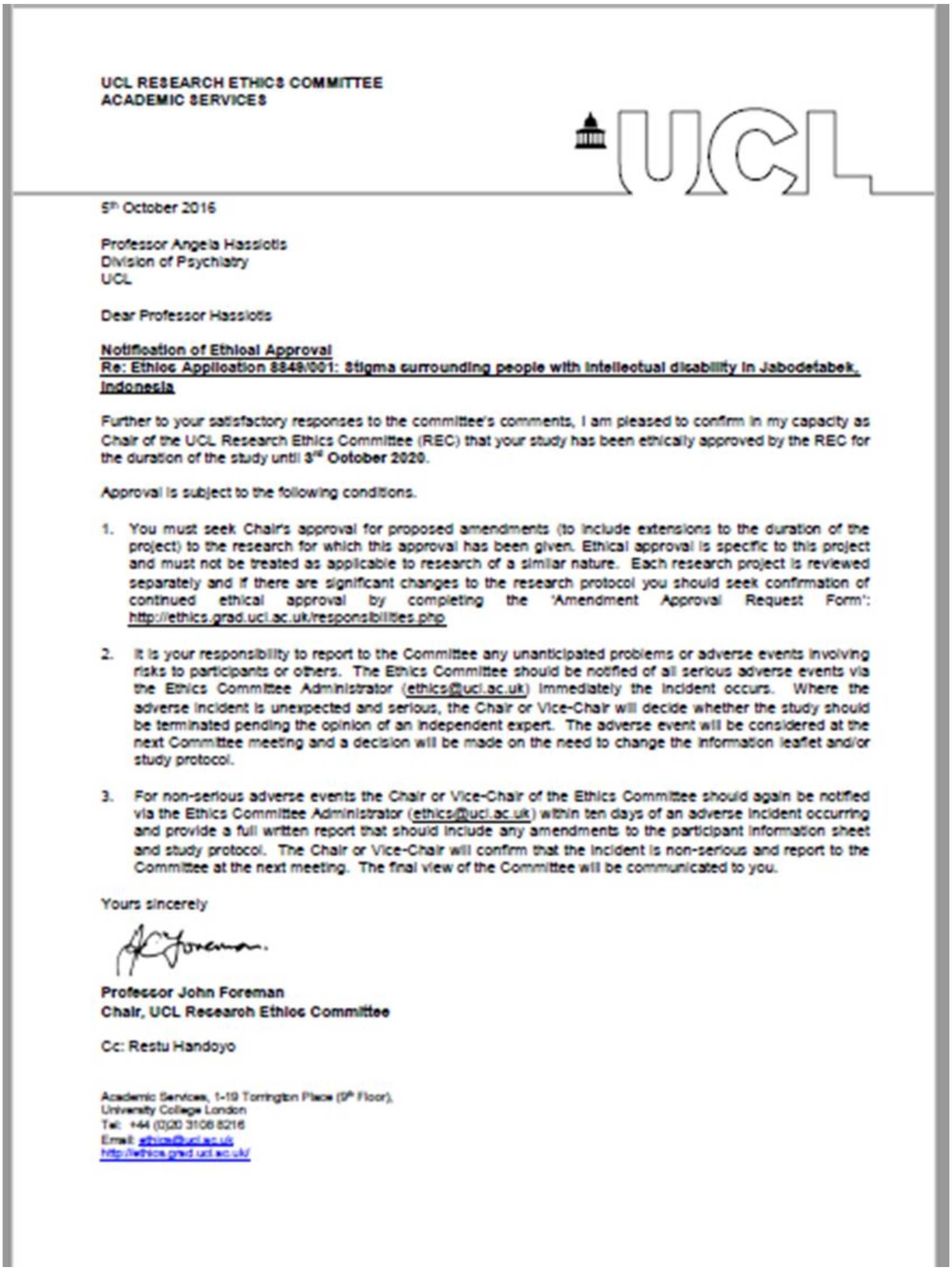
Thank you for your fine contribution. On behalf of the Editors of Transcultural Psychiatry, we look forward to your continued contributions to the Journal.

Sincerely,

Laurence J. Kirmayer, MD

Editor-in-Chief, Transcultural Psychiatry
transcultural.psychiatry@sagepub.com

Appendix 5: Ethical Approval from UCL ethics committee



UCL RESEARCH ETHICS COMMITTEE
ACADEMIC SERVICES

5th October 2016

Professor Angela Hassiotis
Division of Psychiatry
UCL

Dear Professor Hassiotis

Notification of Ethical Approval
Re: Ethics Application 8848/001: Stigma surrounding people with intellectual disability in Jabodetabek, Indonesia

Further to your satisfactory responses to the committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the REC for the duration of the study until **3rd October 2020**.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form': http://ethics.grad.ucl.ac.uk/responsibilities.php

2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

3. For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator (ethics@ucl.ac.uk) within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Yours sincerely

Professor John Foreman
Chair, UCL Research Ethics Committee

Cc: Restu Handoyo

Academic Services, 1-19 Torrington Place (9th Floor),
University College London
Tel: +44 (0)20 3108 8216
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/

Appendix 6: Professional attitude, information sheet & informed consent

Information sheet for participant in research studies: Key professionals main study

You will be given a copy of this information sheet

Title of project: Stigma surrounding people with Intellectual disability in Jabodetabek Indonesia.

This study has been approved by the UCL Research Ethics Committee (project ID number) 8849/001

Nama	Restu Tri Handoyo
Alamat Kerja	UCL Division of Psychiatry, 6th floor Maple House, 149 Tottenham Court Road, London W1T 7NF
Kontak	restu.handoyo.15@ucl.ac.uk

Details of study:

I would like to invite you to participate in the study, which is conducted at UCL and part of my doctoral thesis. Your participation is voluntary and if you decide not to participate in this study, it will not disadvantage you in anyway. It is important to understand the aims of the study before you decide to participate. Please read the following information about the study in this sheet. You can discuss this with other people before making a decision. You can call/email me if something is unclear or you have any other queries.

What is the purpose of this study?

This study aims to gain a better understanding about beliefs and attitudes relating to people with intellectual disabilities (previously referred to mental retardation), and to explore perceptions about social inclusion for people with intellectual disability among key professionals. Key professionals are people who have works in some capacity with people with intellectual disability and include teachers, healthcare workers, social care workers and community/religious leaders. This study involves taking part in a semi structured interview.

Why I have been invited?

You have been identified as a possible ‘key professional’ because you work as a health professionals (psychologist/physician), teacher, or religious leaders, and therefore you may have work with people with intellectual disability or have an opinion on how and whether these individuals should be included in society.

What will happen if I take part?

If you decide to take part, you will be asked to sing a consent form. I will then discuss the interview procedure with you and arrange to interview at your office, at a suitable venue in public site, or via video call (skype) if you prefer. The interview will take approximately 45 minutes to one hour. The interview will be recorded, subject to your permission. The recording will be deleted after it has been transcribed. Even after you have decided to participate, you are free to stop your participation at any time during the process and to have information relating to you withdrawn without the need to give any reason, up to **30 April 2017**

What are the possible benefits and risks of participating?

The information gathered in this study will help to provide a better understanding about beliefs, attitudes, and perceptions of social inclusion relating to people with intellectual disabilities. A better understanding is important to inform the work of stake holders, such as government and non-governmental organisations. You will be sent a summary of the results of the study if you wish. The only disadvantage is that you will need to give up some of your time for a one-off interview. There are no foreseeable risks in participating in this study.

Will my participation be kept confidential?

Information you provide in the interview will be kept confidential and safe. Neither your name nor the organisation where you work will be revealed in the study report. All data will be anonymised and there will be no possibly to link your responses to you. All data collected will be processed and stored in line with the UK Data Protection Act 1998.

How is the study being funded and approved?

This study is funded by the Indonesian Endowment Fund for Education, Ministry of Finance of the Republic of Indonesia. The study has been approved by the University College London, Research Ethic Committee.

What will happen to the data I submitted to the study?

The information collected in the study will be transferred to the UK by uploading the data to the University College London (UCL) server through a secure internet connection. Recorded interview files will be deleted from the recording device after being uploaded to the UCL server. The recorded interview files will then be deleted after it has been transcribed. It will take a maximum of eight-week time after the interview, for all the transcription to be finished. Identifiable data such as name and contacts will be handled and store separately in a secure system called Data Safe Haven, which has been certified to the ISO27001 information security standard. Identifiable data will be deleted after I finished my study, approximately by the end of September 2019. The data will only be stored, handled and analysed for research purposes at University College London.

What will happen to the results of the study?

I will write a summary of the main findings and send it to you, unless you ask me not to. The findings will also be disseminated through publication in academic journals and other outputs and presentation at conferences.

Who should I contact for further information?

If you have any questions about this study, please contact me on the following contact details:
Restu Tri Handoyo
Division of Psychiatry, University College London
Email: restu.handoyo.15@ucl.ac.uk Phone: +44 7476 195 587

What if I wish to make a complaint?

If you wish to make a complaint you should contact the principal researcher:
Professor Angela Hassiotis
Division of Psychiatry, University College London
Email: a.hassiotis@ucl.ac.uk Phone: +44 2076 799451

However, if you feel that your complaint has not been handled to your satisfaction you can contact the chair of the UCL Research Ethics Committee:
Professor J. Foreman
Email: Ethics@ucl.ac.uk
Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information.

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. Of you decide to take part, you are still free to withdraw at any time and without giving a reason.
All data will be collected and stored in accordance with the Data Protection Act 1998.
Thank you for reading this information sheet and for considering take part in this research.

Lembar Informasi Penelitian – untuk responden penelitian

Lembar Informasi ini diberikan untuk Anda

Title of project: **Professionals' attitude towards people with Intellectual Disability in Indonesia**

Penelitian ini telah disetujui oleh University College London Research Ethics Committee (project ID number) 8849/001

Nama	Restu Tri Handoyo
Alamat Kerja	UCL Division of Psychiatry, 6th floor Maple House, 149 Tottenham Court Road, London W1T 7NF
Kontak	restu.handoyo.15@ucl.ac.uk

Deskripsi Penelitian:

Saya ingin mengundang bapak/ibu untuk berpartisipasi dalam penelitian ini. Penelitian ini merupakan bagian dari Disertasi Doktoral saya, yang akan diajukan ke *University College London*, Inggris. Partisipasi anda dalam penelitian ini bersifat sukarela. Bila anda memutuskan untuk tidak berpartisipasi, tidak akan merugikan anda dalam bentuk apapun. Penting bagi anda untuk memahami tujuan penelitian ini sebelum memutuskan untuk berpartisipasi atau tidak. Mohon untuk terlebih dahulu membaca informasi dalam lembar ini. Anda dapat berdiskusi dengan orang lain sebelum mengambil keputusan. Anda juga dapat menghubungi/mengirimkan email kepada saya bila ada sesuatu yang kurang jelas atau memiliki pertanyaan tentang penelitian ini.

Apa tujuan penelitian ini?

Penelitian ini bertujuan untuk lebih memahami keyakinan dan sikap para profesional terhadap penyandang disabilitas intelektual (sebelumnya dikenal dengan istilah retardasi mental atau umum disebut keterbelakangan mental) dan untuk mengetahui persepsi para profesional mengenai keterlibatan mereka di masyarakat. Istilah 'profesional' pada penelitian ini merujuk pada orang-orang yang bekerja/berperan sebagai dokter, psikolog, guru dan pemuka agama. Pada penelitian ini anda akan diminta terlibat dalam sebuah wawancara yang dilakukan dengan saya sebagai peneliti.

Mengapa saya diundang untuk berpartisipasi?

Bapak/Ibu termasuk dalam kategori ‘profesional’ karena anda bekerja/berperan sebagai dokter, psikolog, guru atau pemuka agama. Pekerjaan/peran tersebut membuat bapak/ibu memiliki peran penting dalam memberikan saran atas perawatan dan kesejahteraan penyandang disabilitas intelektual.

Apa yang terjadi bila saya berpartisipasi?

Bila bapak/ibu bersedia berpartisipasi, saya akan menghubungi anda untuk mengatur waktu dan tempat pelaksanaan wawancara. Bapak/ibu juga dapat memilih untuk diwawancarai lewat telepon. Wawancara akan berlangsung sekitar 30 menit. Proses wawancara tersebut akan direkam secara audio, dengan terlebih dahulu meminta persetujuan bapak/ibu. Bapak/ibu dapat menarik diri dari penelitian ini kapanpun bapak/ibu inginkan, bahkan setelah menyatakan bersedia berpartisipasi. Bapak/ibu juga dapat meminta seluruh informasi yang telah diberikan untuk ditarik kembali tanpa perlu memberikan alasan apapun kepada peneliti, **sampai tanggal 30 April 2018**.

Apa keuntungan dan kerugian bila berpartisipasi?

Informasi yang diperoleh dalam penelitian ini akan membantu untuk memahami pandangan para profesional terhadap penyandang disabilitas intelektual dan keterlibatan mereka di masyarakat. Pemahaman lebih lanjut tentang hal-hal ini menjadi penting sebagai informasi bagi para pemangku kepentingan, seperti pemerintah dan organisasi non-pemerintah yang bergerak dibidang pemberdayaan penyandang disabilitas intelektual. Bila bapak/ibu meminta, saya akan mengirimkan rangkuman hasil penelitian ini. Kerugian yang mungkin anda alami adalah waktu yang harus anda luangkan untuk proses wawancara. Tidak ada resiko negatif lain yang diperkirakan akan muncul bila bapak/ibu berpartisipasi dalam penelitian ini.

Apakah partisipasi saya akan dirahasiakan?

Informasi yang bapak/ibu berikan dalam wawancara akan dirahasiakan dan disimpan dengan aman. Nama atau organisasi tempat anda bekerja tidak akan di ungkap dalam laporan penelitian. Seluruh data akan dibuat anonim sehingga tidak mungkin untuk dihubungkan dengan bapak/ibu sebagai pribadi. Seluruh data yang dikumpulkan dalam penleitian ini akan di proses dan disimpan dengan mengikuti ketentuan yang berlaku menurut undang-undang perlindungan data negara Inggris tahun 1998.

Siapa yang mendanai dan menyetujui penelitian ini?

Penelitian ini didanai oleh Lembaga Pengelola Dana Pendidikan (LPDP), Kementerian Keuangan Republik Indonesia. Penelitian ini telah disetujui oleh Komite Etik Penelitian dari University College London.

Apa yang akan terjadi pada data yang saya berikan dalam penelitian ini?

Informasi yang bapak/ibu berikan dalam penelitian ini akan dipindahkan ke negara Inggris dengan mengunggah data tersebut ke server *University College London* (UCL) melalui jaringan internet yang aman. Rekaman wawancara akan dihapus dari alat perekam setelah proses transkripsi. Proses transkripsi akan memakan waktu sekitar delapan minggu setelah wawancara selesai dilakukan. Data pribadi seperti nama dan kontak akan diproses dan disimpan secara terpisah dalam sebuah sistem yang disebut *Data Safe Haven*. Sistem ini telah memperoleh sertifikasi ISO27001 dalam standar keamanan informasi. Data pribadi akan dihapus setelah masa studi saya berakhir, diperkirakan pada akhir bulan September 2019. Data tersebut hanya akan disimpan, diproses dan dianalisis untuk tujuan penelitian di UCL.

Apa yang akan terjadi pada hasil penelitian?

Bila anda meminta, saya akan mengirimkan rangkuman hasil penelitian ini kepada anda. Hasil penelitian ini juga akan dipublikasikan melalui jurnal ilmiah dan bentuk publikasi lain seperti presentasi ilmiah dalam sebuah konferensi.

Siapa yang harus saya hubungi untuk informasi lebih lanjut?

Bila anda memiliki pertanyaan mengenai penelitian ini, mohon menghubungi saya melalui kontak dibawah ini:

Restu Tri Handoyo
Division of Psychiatry, University College London
Email: restu.handoyo.15@ucl.ac.uk   Phone: +44 7476 195 587 (WhatsApp)

Bagaimana bila saya ingin mengajukan keluhan/protes?

Bila anda ingin mengajukan keluhan/protes terkait penelitian ini, anda dapat menghubungi **Peneliti Utama**:

Professor Angela Hassiotis
Division of Psychiatry, University College London
Email: a.hassiotis@ucl.ac.uk   Phone: +44 2076 799451

Bila keluhan anda tidak ditanggapi dengan baik, anda dapat menghubungi **Ketua Komite Etik Penelitian UCL** untuk menindaklanjuti hal ini:

Professor J. Foreman
Email: ethics@ucl.ac.uk

Anda dipersilahkan untuk mendiskusikan informasi di atas dengan orang lain bila anda merasa perlu, atau bertanya kepada saya bila ada hal yang tidak jelas, atau bila anda memerlukan informasi tambahan.

Pilihan untuk berpartisipasi atau tidak berpartisipasi sepenuhnya ada pada anda. Memilih untuk tidak berpartisipasi tidak akan merugikan anda dalam bentuk apapun. Bila anda memilih untuk berpartisipasi, anda tetap dapat mengundurkan diri kapanpun anda mau, tanpa harus memberikan alasan apapun

Seluruh data yang dikumpulkan akan disimpan sesuai dengan Undang-Undang Perlindungan Data tahun 1998 yang berlaku di negara Inggris.

Terima kasih telah membaca lembar informasi ini, dan telah mempertimbangkan untuk berpartisipasi dalam penelitian ini.

Informed Consent Form for Participant in Research Studies

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: **Stigma Surrounding People with Intellectual Disability in *Jabodetabek* Indonesia**

This study has been approved by the UCL Research Ethics Committee (Project ID Number): **8849/001**

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I (tick if agree)

- ☐ have read the notes written above and the Information Sheet, and understand what the study involves.
- ☐ understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- ☐ consent to the processing of my personal information for the purposes of this research study.
- ☐ understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- ☐ understand that my participation will be audio recorded and I consent to the use of this material as part of the project.
- ☐ understand that the information I have given will be transferred to the United Kingdom, processed and stored for research purposes at the University College London.
- ☐ understand that the information I have submitted will be published as a report and I will be sent a copy. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.
- ☐ agree that my data, after it has been fully anonymised, can be shared with other researchers
- ☐ agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Signed:

Date:

lpdp
lembaga pengelola dana pendidikan

UCL

LEMBAR PERSETUJUAN PARTISIPASI

Mohon untuk mengisi formulir ini setelah anda membaca lembar informasi penelitian dan/atau mendengar penjelasan mengenai penelitian yang dimaksud

Judul penelitian: **Professionals attitude towards people with intellectual disabilities and their inclusion**

Penelitian ini telah disetujui oleh komite etik penelitian di University College London (UCL), dengan nomor registrasi: **8849/001**

Terima kasih atas ketertarikan anda untuk berpartisipasi dalam penelitian ini. sebelum anda memutuskan untuk berpartisipasi, peneliti harus terlebih dahulu menjelaskan maksud, tujuan, dan proses penelitian ini kepada anda.

Bila ada pertanyaan yang muncul setelah anda membaca lembar informasi penelitian atau setelah anda mendengar penjelasan mengenai penelitian ini, mohon untuk terlebih dahulu menanyakan pertanyaan tersebut sebelum memutuskan untuk berpartisipasi. Anda akan diberikan salinan lembar persetujuan ini untuk disimpan dan menjadi rujukan.

Participant’s statement

Saya (centang bila setuju)

- ☐ Telah membaca tulisan di atas dan lembar informasi penelitian, serta mememahami apa yang tercakup dalam penelitian ini.
- ☐ Memahami bahwa bila saya memutuskan untuk berhenti terlibat dalam penelitian ini, saya dapat menghubungi peneliti kapanpun dan mengundurkan diri dengan segera.
- ☐ Memberikan persetujuan kepada peneliti untuk memproses data pribadi saya untuk keperluan penelitian ini
- ☐ Memahami bahwa data pribadi yang saya berikan akan diperlakukan dengan sangat rahasia dan ditangani sesuai degan ketentuan dalam Undang-Undang Perlindungan Data Tahun 1998 yang berlaku di negara Inggris.
- ☐ Memahami bahwa partisipasi saya akan direkam secara audio dan saya memberikan persetujuan kepada peneliti untuk menggunakan rekaman tersebut untuk keperluan penelitian ini

☐ Memahami bahwa informasi yang saya berikan akan dipindahkan ke negara inggris, serta diproses dan disimpan dengan tujuan penelitian di University College London

☐ Memahami bahwa informasi yang saya berikan akan dipublikasikan sebagai sebuah laporan, dan saya akan diberikan salinan dari hasil penelitian ini. kerahasiaan dan anonimitas dari informasi tersebut akan selalu dijaga, sehingga dari informasi yang dipublikasikan tersebut tidak dimungkinkan untuk mengidentifikasi saya sebagai pribadi.

☐ Menyetujui bahwa data yang saya berikan, setelah dibuat anonym, dapat dibagi dengan penelitian lain

☐ Menyetujui bahwa penelitian yang disebutkan di atas sudah dijelaskan kepada saya dan saya setuju untuk terlibat dalam penelitian ini.

Tandatangan:

Tanggal:

Appendix 7: Professional attitude, semi structured interview & vignette

English

Introduction

1) Overview of role and profession: Ask the respondent to explain a bit about his/her self, their profession and their role.
2) Prior contact: Have you met people with a condition similar condition to that of Rudy/Gilang? on what occasion?
3) Knowledge about conditions and terms: What do you think happen to Rudy/Gilang?
   Prompts:
   - Do you know any terms that are used to describe people like Rudy/Gilang?
   - Are you familiar with the terms intellectual disability? mental retardation? (one at a time)

Attitudes towards people with ID

4) Causal beliefs*:* What do you think caused Rudy’s/Gilang’s condition*?*
5) Future life: What kind of future will Rudy/Gilang have?
6) Attitude as professional: How do you feel having people like Rudy/Gilang as your patient/ student/ congregation member? What would you do for them?

Attitudes towards inclusion of people with ID

7) Education: What kind of education is suitable for people like Rudy/Gilang?
   Prompts:
   - Options: mainstream school, special school, inclusive school, home-school?
8) Living arrangements: What kind of living arrangements are suitable for people like Rudy/Gilang?
   Prompts:
   - Options: own house, family house, boarding special institution
9) Employment: Do you think Rudy is able to be employed?
   Prompt:
   - What kind of job is suitable for Rudy?
10) Marriage and parenthood: Do you think Rudy is able to marry? Do you think he should have his own child? Why?
11) Participation in community activities: Do you think Rudy/Gilang should be involved in community activities?
   Prompts:
   - Public festivities, weekly prayers, elections

Indonesian

Pembuka

1) Latar belakang peran dan profesi: Tanyakan kepada responden untuk menjelaskan sedikit mengenai dirinya, serta profesi dan perannya.
2) Kontak sebelumnya: Apakah anda pernah bertemu dengan orang yang memiliki kondisi seperti Rudy/gilang? Dalam situasi apa?
3) Pengetahuan mengenai kondisi dan istilah: Menurut anda apa yang terjadi pada Rudy/Gilang?
   - Istilah apa yang biasa digunakan untuk merujuk orang-orang seperti Rudy/gilang?
   - Apakah anda familiar dengan istilah disabilitas intelektual? Retardasi mental? (satu per satu)

Sikap terhadap orang dengan DI

4) Penyebab: Menurut anda apa yang menyebabkan Rudi/Gilang mengalami kondisi tersebut?
5) Masa depan: Masa depan seperti apa yang akan dimiliki oleh Gilang/Rudi?
6) Sikap sebagai professional: Apa yang anda rasakan saat mendapatkan pasien/murid/jamaat seperti Rudy dan Gilang? Apa yang akan anda lakukan untuk mereka?

Sikap terhadap inklusi pada DI

7) Pendidikan: Pendidikan seperti apa yang tepat untuk orang seperti Rudy/Gilang?

Prompt:

- Pilihan: Sekolah regular, sekolah luar biasa, sekolah inklusi, home-schooling

8) Tempat tinggal: Tempat tinggal seperti apa yang tepat untuk orang seperti Rudy/Gilang?

Prompt:

- Pilihan: Rumah sendiri, rumah keluarga, institusi khusus dengan bentuk asrama

9) Pekerjaan: Apakah Rudy dapat memiliki pekerjaan?

Prompt:

- Pekerjaan seperti apa yang tepat untuk Rudy?

10) Pernikahan dan keturunan: Apakah Rudy dapat menikah? Apakah sebaiknya dia memiliki keturunan? Kenapa?
11) Partisipasi dalam kegiatan masyarakat: Apakah Rudy/Gilang sebaiknya terlibat dalam kegiatan masyarakat?

Prompt:

- Perayaan hari besar, ibadah mingguan, pemilu/pilkada

English

Vignette 1 - Mild Intelectual disabilities

Rudy is 22 and lives at home with his family. As a child, he struggled to follow lessons taught at school and dropped out after being held back in the same grade twice. Rudy is capable of taking care his personal daily needs such as maintaining self-hygiene (bathing, changing clothes, toilets) and feeding, but sometimes his parent needs to remind him. Rudy can engage in conversation with other people. However, he has difficulties in understanding abstract concepts. He owns a mobile phone and is able to use it. He can read and write at a basic level but cannot read a newspaper, or use money correctly to pay for things.

Vignette 2 – Severe intelectual disabilities.

Gilang is 19 years old and lives at home with his family. He has difficulty communicating his needs as he can only speak a few words and cannot read or write. His mother supports him in most of his needs, which include bathing him and dressing him. He can feed himself, but he cannot be left on his own, and he cannot go outside and his own as he is unaware of how to keep himself safe.

Indonesian

Studi Kasus 1 – Disabilitas intelektual ringan

Rudy berusia 22 tahun. Saat ini Ia tinggal di rumah bersama keluarganya. Semasa sekolah dasar ia mengalami kesulitan untuk mengikuti pelajaran. Ia pernah tinggal kelas sebanyak dua kali, sebelum akhirnya putus sekolah. Rudy mandiri dalam menjaga kesehatan dan merawat diri (contoh: mandi, berpakaian, makan), walaupun kadang perlu diingatkan. Rudy dapat diajak berbicara, tetapi ia kesulitan untuk membicarakan hal-hal yang bersifat abstrak dan terlalu rumit. Ia tahu bagaimana cara menggunakan telepon. Rudy dapat membaca dan menulis dalam tingkatan sederhana, tetapi ia tidak dapat membaca koran atau menggunakan uang untuk membayar dengan jumlah yang benar.

Studi Kasus 2 – Disabilitas intelektual berat

Gilang berusia 19 tahun, Saat ini Ia tinggal di rumah bersama keluarganya. Gilang sulit untuk memberitahu orang lain tentang keinginannya, karena ia hanya dapat berbicara beberapa patah kata saja. Gilang tidak dapat membaca ataupun menulis. Ibunya harus selalu membantu Gilang untuk memenuhi kebutuhannya sehari-hari, seperti mandi dan berpakaian. Gilang dapat menyuap makanannya sendiri, tetapi ia tidak dapat ditinggal seorang diri. Gilang tidak dapat pergi ke luar rumah sendiri, karena ia tidak tahu bagaimana cara menjaga keamanan dirinya di luar rumah.

Appendix 8: Adults with mild to moderate ID, information sheet & informed consent

Information sheet, Indonesian version

Penelitian tentang pengalaman sehari-hari penyandang Tuna Grahita

	Halo, nama saya Restu
	Saya sedang melakukan penelitian Saya bertanya kepada orang-orang untuk mengetahui jawaban mereka
	Saya menghubungi anda karena saya memerlukan bantuan anda. Untuk membantu memahami lembar informasi ini anda dapat: • Meminta seseorang untuk membacakannya • Bertanya kepada orangtua/pendamping anda
	*Apa yang ingin saya ketahui?* • Saya ingin tahu bagaimana penyandang tuna grahita menjalani kehidupannya • Saya ingin tahu bagaimana penyandang tuna grahita bersosialisasi dengan orang lain. • Saya ingin tahu pandangan orang tentang penyandang tuna grahita

	Mengapa saya meminta bantuan anda? • Karena anda adalah penyandang tuna grahita • Karena anda berusia 17 tahun atau lebih
	*Apa yang akan anda lakukan bila bersedia ikut dalam penelian ini?* • Saya akan minta anda untuk mengisi beberapa formulir • Saya akan memandu anda untuk mengisi formulir tersebut • Anda dapat meminta seseorang yang anda percayai untuk mendampingi anda selama mengisi formulir • Bila anda terpilih, mungkin saya juga akan mengobrol dengan anda, dan merekam obrolan tersebut.
	*Apakah saya harus ikut penelitian ini?* • Anda dapat mengatakan **Ya** bila anda ingin ikut • Anda dapat mengatakan **Tidak** bila anda tidak ingin ikut • Bila anda Tidak ikut, tidak akan mengubah perawatan atau pendidikan yang saat ini anda dapatkan • Jika anda bersedia ikut, saya akan meminta anda untuk menandatangi lembar persetujuan. • Anda dapat berhenti untuk mengikuti penelitian ini kapan saja anda mau.

Apa yang akan terjadi bila anda ikut dalam penelitian ini?

- Informasi yang anda berikan akan dirahasiakan
- Saya tidak akan memberikan informasi anda kepada siapapun tanpa meminta izin anda terlebih dahulu.
- Saya tidak akan mencantumkan nama dan nomor kontak anda dalam informasi yang saya gunakan
- Saya mungkin harus memberitahu seseorang bila saya merasa khawatir dengan kesehatan atau perawatan yang anda terima.

Saya akan mencatat nama dan nomor kontak anda dalam sebuah daftar, sehingga saya dapat menghubungi anda lagi bila diperlukan untuk

- Informasi lebih lanjut
- Penelitian lanjutan

Daftar tersebut akan disimpan dengan aman dan dihapus saat penelitian saya telah selesai, diperkirakan pada bulan September 2019

Apa yang akan terjadi setelah anda bertemu dengan saya?

- Saya akan menyimpan formulir yang anda isi ke dalam komputer di universitas saya di Inggris
- Bila saya bercakap-cakap dengan anda, saya juga akan menyimpan rekaman percakapan tersebut dalam komputer yang sama
- Hanya saya dan dosen pembimbing saya yang dapat melihat informasi anda dalam komputer tersebut.
- Tapi, pembimbing saya tidak akan tahu data tersebut dari anda, saya akan memisahkan nama dan nomor kontak (data pribadi) anda sebelum saya menyimpannya dalam komputer
- Saya akan memberikan hadiah kecil kepada anda sebagai ucapan terima kasih

	*Bagaimana cara menghubungi saya?* Anda dapat menelpon/mengirimkan pesan pada saya di nomor berikut: +44 7476 195 587 atau Anda dapat mengirimkan email pada saya di alamat berikut restu.handoyo.15@ucl.ac.uk - Bila anda ingin ikut penelitian ini, atau - Bila anda punya pertanyaan tentang penelitian ini?
	*Bagaimana bila saya ingin menyampaikan keluhan?* Bila anda ingin menyampaikan keluhan, anda dapat mengubungi peneliti utama: Prof. Angela Hassiotis Email: a.hassiotis@ucl.ac.uk Telepon: +44 2076 799451 Bila keluhan anda tidak ditanggapi dengan baik, anda dapat menyampaikan keluhan kepada <u>ketua komite etik University College London:</u> Prof. J. Foreman Email: ethics@ucl.ac.uk
	Terima kasih sudah membaca lembar informasi ini

Information sheet, English version

A study to understand the experience of people with intellectual disability

	Hello, my name is Restu Tri Handoyo
	I am a researcher I ask people questions to find things out
	I am writing to ask if you would like to help me To help you understand this letter you can • Ask someone to read it for you • Talk to your carer about it
	*What am I trying to find out?* • I want to know how people with Intellectual Disability live their life • I want to know how people with Intellectual Disability interact with other people, and how they are treated by other people • I want to understand how other people think about people with Intellectual Disability
	Why do I want to see you? • Because you have Intellectual Disability • Because you are 18 years old or older

	*What will happen if you take part?* • I will ask you to fill in some forms • I will be there to help you fill the forms • You can ask someone you trust, to be there with you while filling the forms. • In a special occasion, I may ask you some questions and record our conversation • You can ask someone you trust to be there with you during our conversation.
	*Do you have to take part?* • You can tell us **Yes** if you want to take part • You can tell us **No** if you do not want to take part • If you say no it will not change the care or education, you get • If you decide to take part, I will ask you to sign a consent form • You can stop taking part at any time
 	*What will happen after you agree to take part?* • The information you give will be confidential • I will not talk to anyone about you without asking you first • I will not use any information with your name and contact number • I might have to tell someone if I am worried about your health or care I would like to keep your name and contact number on a list This so I can contact you if I need • More information • To do more research The list will be kept securely and will be deleted when the study has finished approximately by the end of September 2019.
	What will happen after you meet me? • I will put the form you fill in a computer at my university in the United Kingdom.

	• In occasion I ask you questions and record it, I will also put the recording in the computer. • Only me and my supervisors can look at the information I put in the computer • However, my supervisors will not know it is you – I will take out your name and address (personal information) before I put it on the computer • I will give you a small gift to say thank you
 	*How to talk to me?* You can phone me on +44 7476 195 587 or You can email me at restu.handoyo.15@ucl.ac.uk • If you would like to take part in the study • If you have any questions about the study
	**What if I wish to make a complaint?** If you wish to make a complaint you should contact the Principal Researcher: Prof. Angela Hassiotis Division of Psychiatry, University College London Email: a.hassiotis@ucl.ac.uk Phone: +44 2076 799451 However, if you feel that your complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee: Prof. J. Foreman Email: ethics@ucl.ac.uk
	**Thank you for looking at this**

Informed consent, Indonesian version

Lembar Persetujuan (Informed Consent Form) untuk Partisipan Penelitian

Mohon untuk mengisi formulir ini setelah anda membaca lembar informasi penelitian dan/atau mendengar penjelasan mengenai penelitian yang dimaksud.

Judul penelitian: **Stigma terhadap Disabilitas Intelektual di Indonesia**

Penelitian ini telah disetujui oleh Komite Etik Penelitian University College London (UCL), dengan nomor penelitian: **8849/001**

Penelitian dilakukan untuk memahami pandangan orang terhadap penyandang disabilitas intelektual di Indonesia

	Terima kasih atas ketertarikan anda untuk berpartisipasi dalam penelitian ini
	Sebelum anda setuju untuk berpartisipasi, peneliti harus terlebih dahulu menjelaskan penelitian ini pada anda.
	Bila anda punya pertanyaan, mohon bertanya kepada peneliti sebelum memutuskan untuk berpartisipasi atau tidak.
	Saya akan memberikan salinan form ini untuk anda simpan dan menjadi panduan

Mohon menjawab dengan melingkari pilihan “YA” atau “Tidak”:

	PERNYATAAN PARTISIPAN	✓	X
	Apakah anda telah membaca atau dibacakan lembar informasi partisipan, dan anda punya waktu untuk berpikir mengenai lembar informasi tersebut?	YA	TIDAK
	Apakah anda memahami maksud, tujuan dan proses penelitian ini?	YA	TIDAK
	Apakah anda memahami hal baik dan hal kurang baik yang mungkin terjadi bila anda berpartisipasi dalam penelitian ini?	YA	TIDAK
	Apakah anda memahami bahwa informasi yang anda berikan akan dipindahkan atau dibawa ke negara Inggris?	YA	TIDAK
	Apakah anda sudah menanyakan semua pertanyaan yang anda miliki tentang penelitian ini?	YA	TIDAK
	Apakah anda memahami bahwa wawancara yang dilakukan akan direkam dan anda boleh berhenti kapanpun anda mau?	YA	TIDAK
	Apakah anda senang untuk berpartisipasi dalam penelitian ini?	YA	TIDAK

Bila anda memilih “tidak”pada salah satu pertanyaan di atas, atau bila anda tidak ingin berpartisipasi dalam penelitian ini, anda tidak perlu memberikan tanda tangan.

Bila anda ingin berpartisipasi dalam penelitian ini, anda dapat memberikan tanda tangan di bawah ini:

Nama :
Tanda Tangan :
Tanggal :

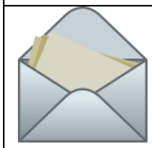
Orang yang menjelaskan penelitian ini kepada anda juga perlu memberikan tandan tangan dibawah ini, untuk menyatakan bahwa mereka memahami maksud, tujuan, dan proses penelitian ini.

Nama :
Tanda Tangan :
Tanggal :

Informed consent, English version

Informed Consent Form for Participant in Research Studies

A study to understand how people think about Intellectual Disability in Indonesia

	Thank you for your interest in taking part
	Before you agree to take part the researcher must explain the project to you
	If you have any questions, please ask the researcher before you decide whether to take part or not.
	You will be given a copy of this form to keep and refer to at any time

Please answer by circling the “YES” or “NO” options:

	PARTICIPANT STATEMENT	👍	👎
	Have you read the information sheet or had it read to you and had a chance to think about it?	YES	NO
	Do you understand what the study about?	YES	NO
	Do you understand the good things and less good things about taking part?	YES	NO
	Do you understand that the information you have submitted will be transferred abroad, to United Kingdom?	YES	NO
	Have you asked all the questions you want and had them answered in a way you understand?	YES	NO
	Do you understand that our interviews will be tape recorded and that it is OK to stop at any time?	YES	NO
	Are you happy to take part?	YES	NO

If you have said “NO” to any of the questions or you don’t want to take part, you don’t have to sign.
If you do want to take part in the study, you can sign below:
Name:
Signature:
Date:
The person who explained the study to you also needs to sign to say they are sure understand.
Name:
Signature:
Date:

Appendix 9: 21 items version of self-report stigma questionnaire

Indonesian version

Lembar pertanyaan tentang sikap terhadap orang dengan disabilitas intelektual

Pertanyaan berikut adalah tentang bagaimana orang lain bersikap kepada anda sebagai orang dengan disabilitas intelektual

Silahkan baca tiap pertanyaan dan beri tanda silang pada salah satu kotak

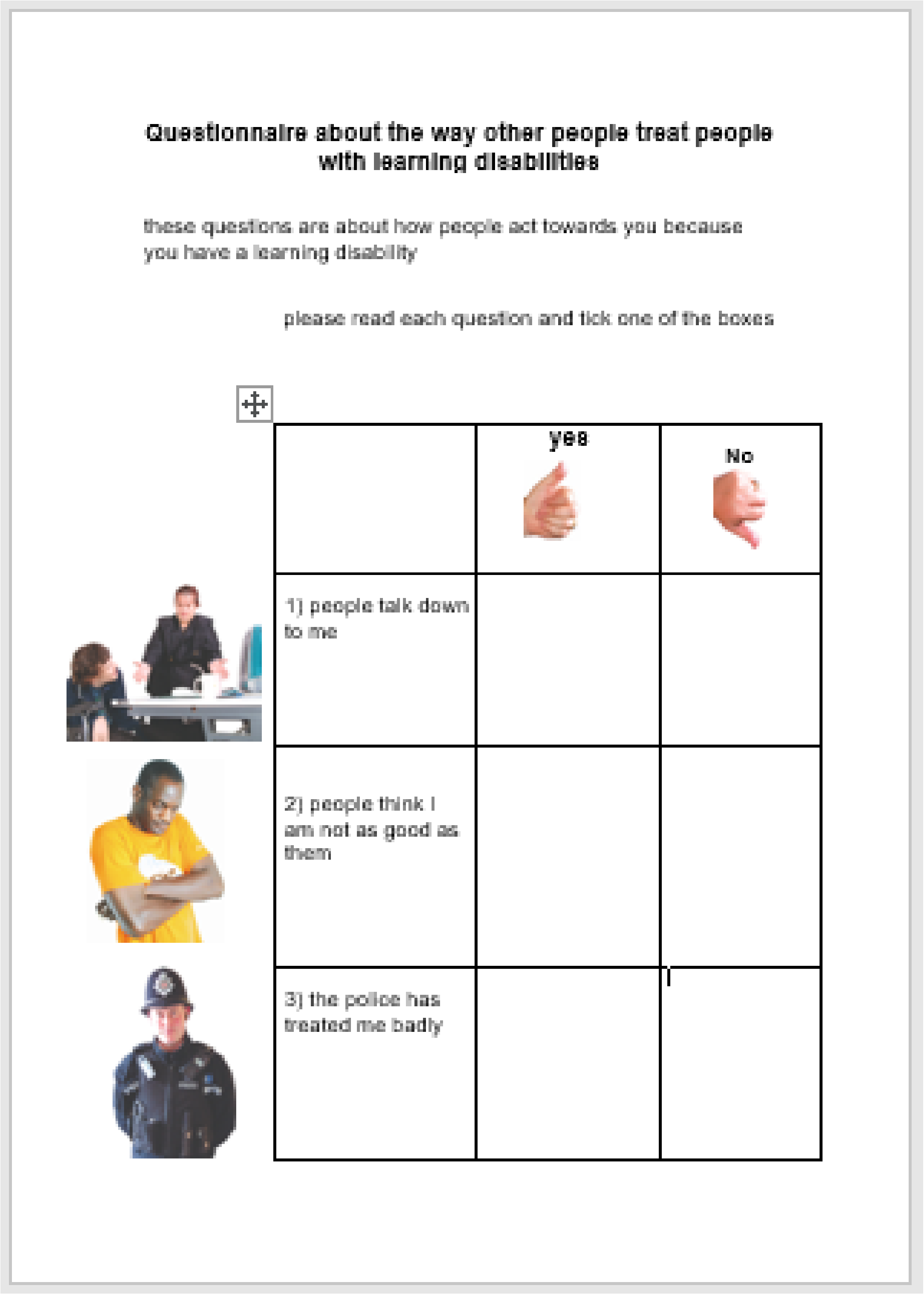
		Ya ✓	**Tidak** X
	1) Orang-orang berbicara kepada saya seolah saya sulit mengerti maksud mereka		
	2) Orang lain menganggap saya tidak memiliki kemampuan sebaik mereka		
	3) Polisi pernah memperlakukan saya dengan buruk		
	4) Saya sama dengan orang lain		
	5) Cara orang-orang berbicara pada saya membuat saya marah		

	6) orang-orang membuat saya merasa malu		
	7) Dokter pernah memperlakukan saya dengan buruk		
	8) Orang-orang di jalan mengejek saya		
	9) Seseorang di jalan pernah memukul saya		
	10) Orang-orang di jalan memandang saya dengan tatapan aneh		
	11) Orang-orang senang berbicara dengan saya		
	12) Orang-orang mengejek keluarga saya		
	13) Seseorang mengganggu saya saat naik mikrolet, bis, kereta atau taksi		
	14) Saya merasa diterima saat berada di toko swalayan, pasar atau restoran		

	15) Orang-orang menertawakan penampilan saya		
	16) Orang-orang memperlakukan saya dengan baik		
	17) Orang-orang memperlakukan saya seperti anak kecil		
	18) Saya menjauhi orang-orang karena mereka memperlakukan saya dengan buruk		
	19) Orang-orang menertawakan cara saya bicara		
	20) Saya khawatir tentang cara orang memperlakukan saya		
	21) Orang-orang mengejek saya karena saya bersekolah di sekolah luar biasa atau sekolah khusus		

Terima kasih telah mengisi lembar pertanyaan ini

English Version

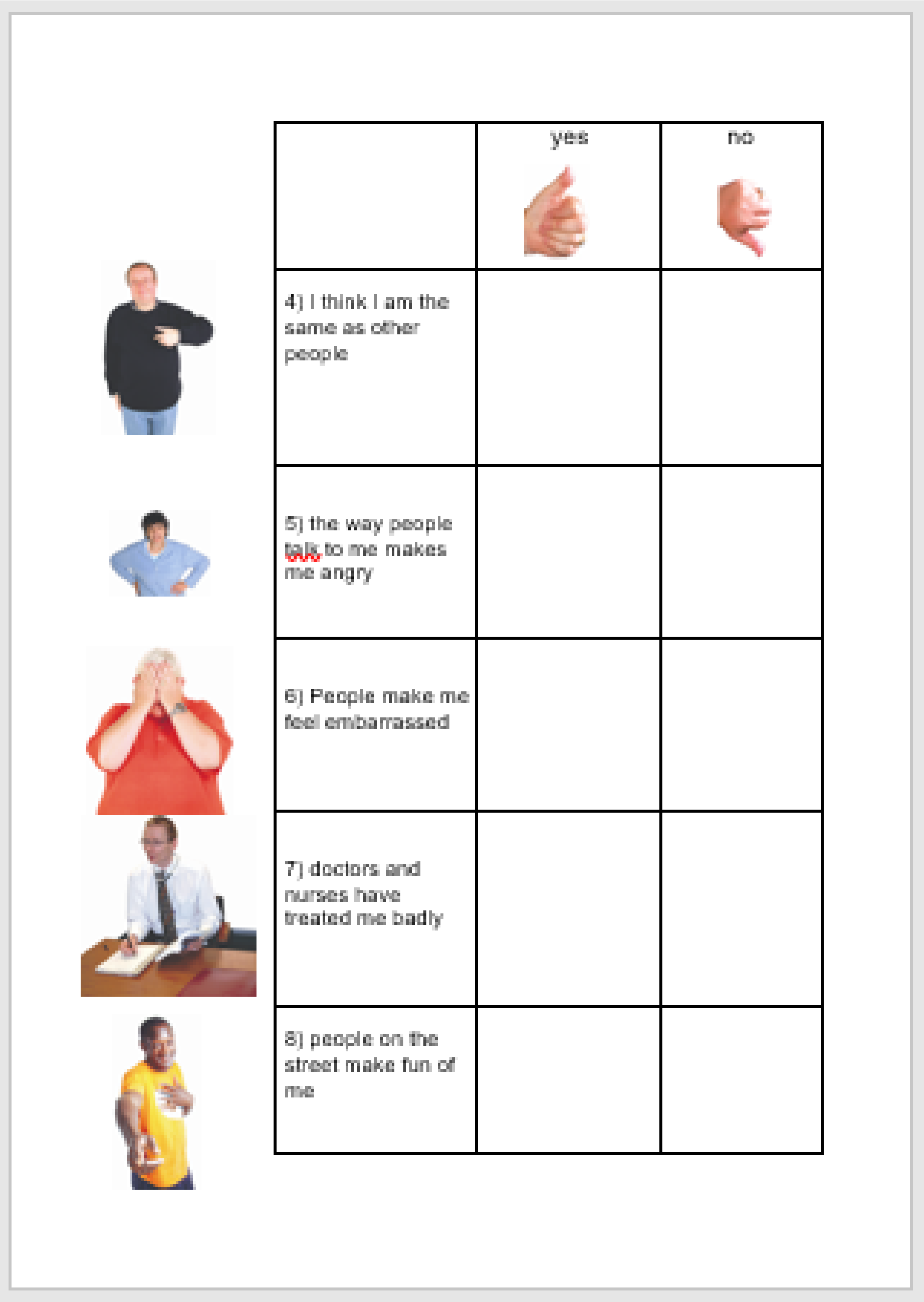


Questionnaire about the way other people treat people with learning disabilities

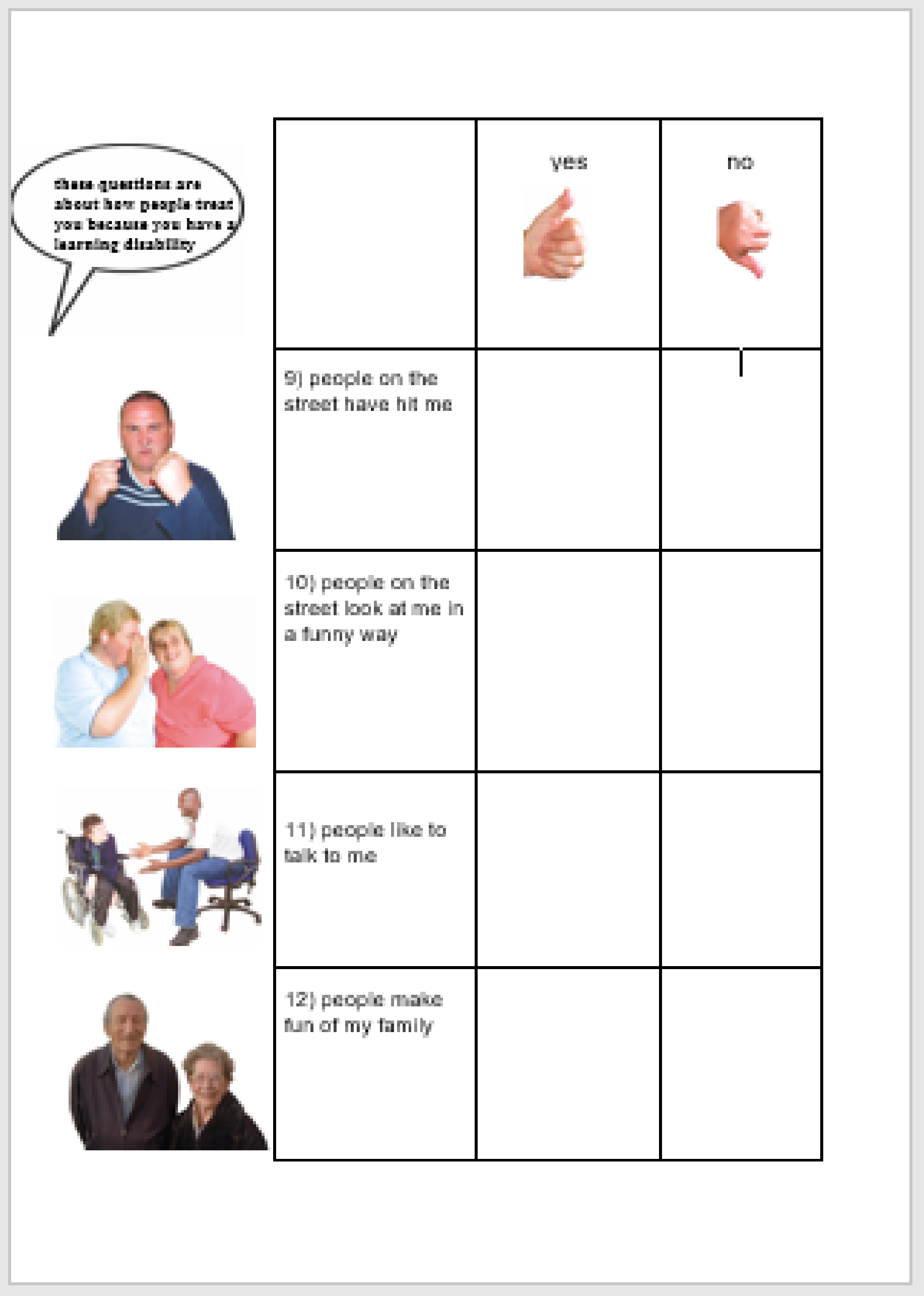
these questions are about how people act towards you because you have a learning disability

please read each question and tick one of the boxes

	yes	No
1) people talk down to me		
2) people think I am not as good as them		
3) the police has treated me badly		

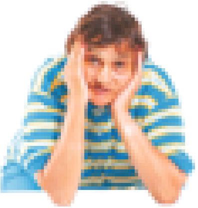


	yes 👍	no 👎
4) I think I am the same as other people		
5) the way people talk to me makes me angry		
6) People make me feel embarrassed		
7) doctors and nurses have treated me badly		
8) people on the street make fun of me		

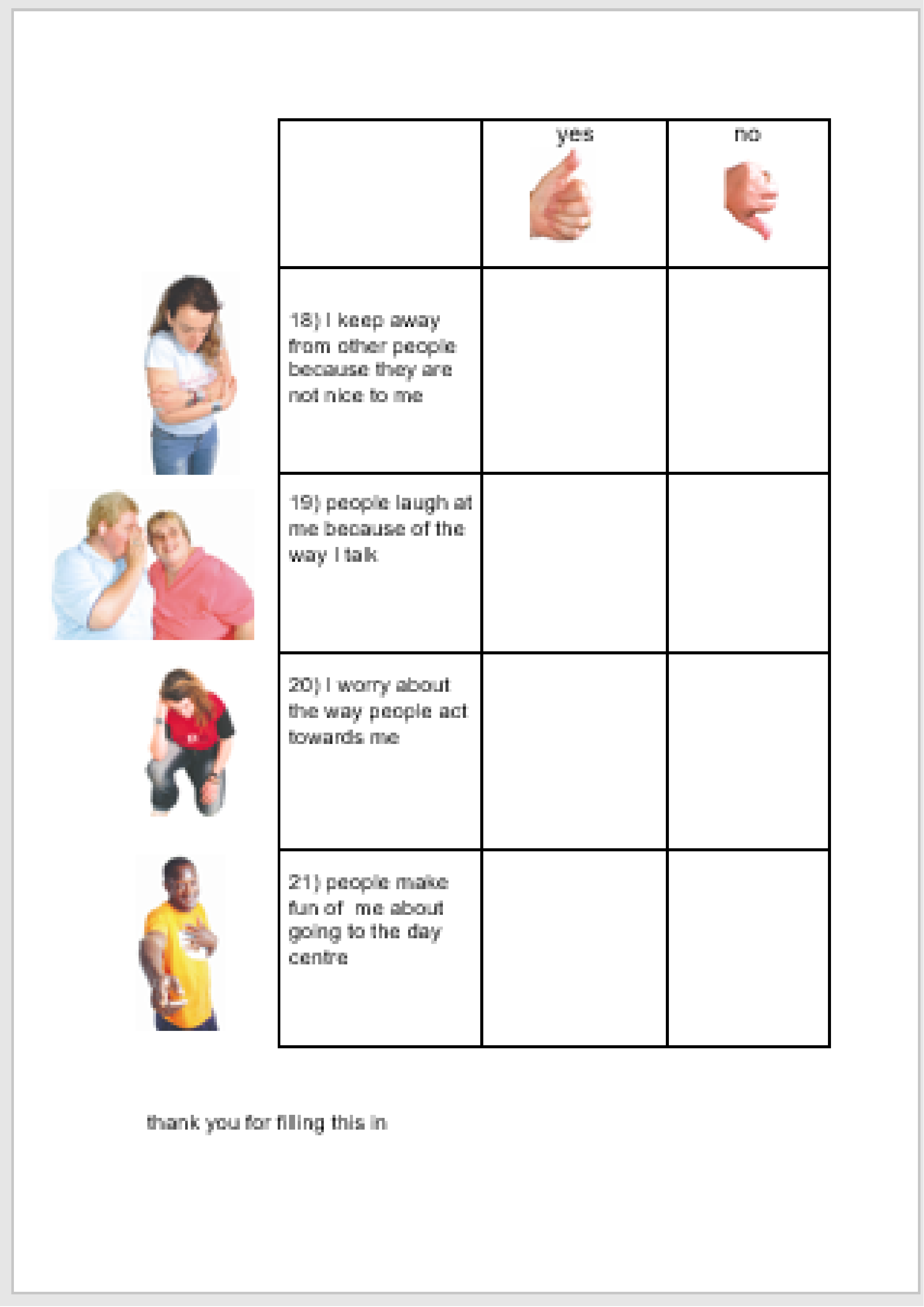


these questions are about how people treat you because you have a learning disability

	yes	no
9) people on the street have hit me		
10) people on the street look at me in a funny way		
11) people like to talk to me		
12) people make fun of my family		



	yes 👍	no 👎
13) no one bothers me when I use buses, trains or taxis		
14) I feel welcome in shops, restaurants or pubs		
15) people laugh at me because of the way I look		
16) people are nice to me		
17) people treat me like a child		



	yes	no
18) I keep away from other people because they are not nice to me		
19) people laugh at me because of the way I talk		
20) I worry about the way people act towards me		
21) people make fun of me about going to the day centre		

thank you for filling this in

Appendix 10: Adults with mild to moderate ID, professionals' feedbacks on the SRSQ-I

No	Items	Feedbacks	Items after refinements
1	People talk down to me Orang-orang bicara kepada saya seolah saya tidak mengerti maksud mereka	Remove negative wording, change 'tidak mengerti' to 'sulit mengerti'	Orang-orang bicara kepada saya seolah saya sulit mengerti maksud mereka
2	People think I am not as good as them Orang-orang menganggap saya tidak memiliki kemampuan sebaik mereka		Orang-orang menganggap saya tidak memiliki kemampuan sebaik mereka
3	The police has treated me badly Polisi pernah memperlakukan saya dengan buruk		Polisi pernah memperlakukan saya dengan buruk
4	I think I am the same as other people Menurut saya, saya sama saja dengan orang lain	Remove 'saja'	Saya sama dengan orang lain
5	The way people talk to me makes me angry Cara orang-orang bicara kepada saya membuat saya marah	Remove multiple use of 'orang'	Cara orang bicara kepada saya membuat saya marah
6	People make me feel embarrassed Orang-orang membuat saya merasa malu		Orang-orang membuat saya merasa malu
7	Doctors and nurses have treated me badly Dokter dan perawat pernah memperlakukan saya dengan buruk		Dokter atau perawat pernah memperlakukan saya dengan buruk
8	People on the street make fun of me Orang-orang dijalan mengejek saya		Orang-orang di jalan mengejek saya
9	People on the street have hit me Orang-orang dijalan pernah memukul saya		Seseorang di jalan pernah memukul saya
10	People on the street look at me in a funny way Orang-orang dijalan melihat saya dengan tatapan aneh		Orang-orang di jalan memandang saya dengan tatapan aneh
11	People like to talk to me		

	Orang-orang senang berbicara dengan saya		Orang-orang senang berbicara dengan saya
12	People make fun of my family Orang-orang mengejek keluarga saya		Orang-orang mengejek keluarga saya
13	No one bothers me when I use buses, trains, or taxis Tidak ada orang yang mengganggu saya saat saya naik bus, kereta atau taksi	Change to positive wordings	Seseorang pernah mengganggu saya saat naik mikrolet, bis, kereta atau taksi.
14	I feel welcome in shops, restaurants or pubs Saya merasa diterima saat datang ke toko dan restoran	Change 'toko' to 'toko swalayan', add pasar	Saya merasa diterima saat berada di toko swalayan, pasar atau restoran
15	People laugh at me because the way I look Orang-orang mentertawakan penampilan saya		Orang-orang menertawakan penampilan saya
16	People are nice to me Orang-orang memperlakukan saya dengan baik		Orang-orang memperlakukan saya dengan baik
17	People treat me like a child Orang-orang memperlakukan saya seperti anak kecil		Orang-orang memperlakukan saya seperti anak kecil
18	I keep away from other people because they are not nice to me Saya menghindari orang lain karena mereka tidak memperlakukan saya dengan baik	Change to a positive sentaces. Change menghindari to 'menjauhi'	Saya menjauhi orang-orang karena mereka memperlakukan saya dengan buruk
19	People laugh at me because of the way I talk Orang-orang mentertawakan saya karena cara saya bicara	Simplified to 'menertawakan cara saya bicara'	Orang-orang menertawakan cara saya bicara
20	I worry about the way people act towards me Saya khawatir mengenai cara orang memperlakukan saya	Change 'mengenai' to 'tentang'	Saya khawatir tentang cara orang memperlakukan saya
21	People make fun of me about going to the day centre	Add 'sekolah khusus' to cover for inclusive schools	Orang-orang mengejek saya karena saya bersekolah di sekolah luar biasa atau sekolah khusus

Appendix 11: Adults with mild to moderate ID, severity screening questionnaire

English

No	Item	Often	Sometimes	Never
1.	Independently maintain self-hygiene (bathing, dressing, toileting)			
2.	Need reminding for self-care activities (bathing, dressing, toileting)			
3.	Cook own food			
4.	Independent use of automatic teller machinei			
5.	Independently shop for own needs (food, clothes) at a market/convinience store.			
6.	Independent use of public transportation			
7.	Attending medical appointment independently			
8.	Independently schedule own daily activities			

Circle one of the following options	Mild	Moderate	Severe	Non-ID

Indonesian

No	Pertanyaan	Selalu	Kadang	Tidak Pernah
1.	Menjaga kebersihan diri (mandi, mengganti pakaian, buang air) secara mandiri			
2.	Diingatkan untuk menjaga kebersihan diri (mandi, mengganti pakaian, buang air)			
3.	Memasak makanan sendiri			
4.	Menggunakan atm sendiri			
5.	Membeli barang kebutuhannya sendiri (makanan, pakaian) di pasar/swalayan			
6.	Menggunakan transportasi umum sendiri			

Lingkari salah satu	Ringan	Sedang	Berat	Non-ID

Appendix 12: Test-retest reliability 21 & 11 items SRSQ-I

21 items SRSQ-I

```
             |    item1    item2    item4    item5    item6    item8   item10
-------------+---------------------------------------------------------------
       item1 |   1.0000
       item2 |   0.5846*  1.0000
       item4 |   0.1271   0.0547   1.0000
       item5 |   0.2016   0.2869   0.0709   1.0000
       item6 |   0.1934   0.4299* -0.0221   0.5653*  1.0000
       item8 |   0.2881   0.2394  -0.1510   0.4861*  0.5506*  1.0000
      item10 |   0.6042*  0.5223* -0.1257   0.4511*  0.6565*  0.4857*  1.0000
      item12 |   0.1972   0.1062   0.0366   0.1516  -0.0129   0.3263   0.0023
      item13 |   0.3632   0.4078  -0.4457* -0.1070   0.0390   0.3812   0.1540
      item15 |   0.2861   0.3306  -0.3458   0.2530   0.3698   0.2327   0.4790*
      item17 |   0.3984   0.2228   0.0332   0.3799   0.5143*  0.4460*  0.7510*
      item18 |   0.4016*  0.4617*  0.0146   0.4416*  0.5303*  0.6078*  0.4457*
      item19 |   0.4016*  0.2953  -0.0751   0.3603   0.3720   0.3454   0.5437*
      item20 |   0.5100*  0.2230   0.1242   0.4552*  0.4423*  0.3083   0.6766*
      item21 |   0.1236   0.1966  -0.1782   0.2679   0.1298   0.2891   0.1841
     reitem1 |   0.4016*  0.5407* -0.1638   0.4416*  0.4531*  0.1510   0.4457*
     reitem2 |   0.5122*  0.7231*  0.0129   0.1692   0.3871*  0.3028   0.2627
     reitem4 |  -0.0448  -0.2936   0.6703* -0.0766  -0.0195  -0.2021  -0.1494
     reitem5 |   0.3160   0.4617*  0.1944   0.6651*  0.2878   0.6851*  0.4457*
     reitem6 |   0.2947   0.1621   0.0710   0.5778*  0.7296*  0.3346   0.3985
     reitem8 |   0.1972   0.2413   0.0366   0.5558*  0.3752   0.7595*  0.4441
    reitem10 |   0.0216   0.2779  -0.0082   0.6073*  0.5080*  0.4004*  0.3506
    reitem12 |   0.3784   0.1584  -0.0416   0.2044   0.3131   0.5139*  0.5197*
    reitem13 |   0.3784   0.6986* -0.0416   0.0781   0.3131   0.1459   0.4005
    reitem15 |   0.0038   0.1907  -0.0191   0.2336   0.3151   0.2421   0.4906*
    reitem17 |   0.2470   0.2876  -0.2254   0.1774   0.5200*  0.5620*  0.6588*
    reitem18 |   0.4316   0.1570  -0.2424   0.6185*  0.2701   0.5962*  0.4450*
    reitem19 |   0.1610   0.3148   0.2312   0.2753   0.3795   0.2671   0.3207
    reitem20 |   0.3259   0.2515   0.4294   0.5292*  0.4218*  0.4231   0.3207
    reitem21 |   0.3699   0.3458  -0.2010   0.3240   0.3235   0.4645*  0.1524

             |   item12   item13   item15   item17   item18   item19   item20
-------------+---------------------------------------------------------------
      item12 |   1.0000
      item13 |   0.4441   1.0000
      item15 |   0.5094*  0.0852   1.0000
      item17 |  -0.0273   0.2482   0.3262   1.0000
      item18 |   0.4736*  0.4457*  0.5620*  0.4902*  1.0000
      item19 |   0.2272   0.2361   0.5620*  0.4902*  0.5707*  1.0000
      item20 |   0.3979  -0.0509   0.6032*  0.5385*  0.4087*  0.3251   1.0000
      item21 |   0.5524*  0.2925   0.4114   0.1322   0.1782   0.0908   0.4246*
     reitem1 |   0.2272   0.3430   0.3458   0.3930   0.4962*  0.4962*  0.3251
     reitem2 |   0.2202   0.1494   0.3583   0.2186   0.4408* -0.0129   0.3318
     reitem4 |  -0.3475  -0.3705  -0.1196   0.0096  -0.0821  -0.0821   0.0448
     reitem5 |  -0.0366   0.1257   0.2309   0.1861   0.5707*  0.2509   0.2386
     reitem6 |  -0.0317   0.1783   0.3847   0.4555*  0.4809*  0.3077   0.4568*
     reitem8 |   0.1368   0.3117   0.0659   0.4132   0.3527   0.4736*  0.1455
    reitem10 |  -0.1352  -0.2790   0.2034   0.3095   0.3009   0.2057   0.4502*
    reitem12 |   0.7548*  0.4005   0.3380   0.3683   0.4069   0.0416   0.0911
    reitem13 |   0.4146   0.8019*  0.1918   0.4885*  0.2893   0.1674   0.4522*
    reitem15 |  -0.0233   0.2093   0.5525*  0.6884*  0.5477*  0.4225   0.4646*
    reitem17 |   0.3889   0.2570   0.4687*  0.5133*  0.6329*  0.2254   0.5392*
    reitem18 |   0.2500   0.3339   0.2940   0.2963   0.5319*  0.2424   0.4912*
    reitem19 |   0.1376  -0.0360   0.2969   0.3846   0.3496   0.2579   0.4097*
    reitem20 |   0.3445   0.1903   0.2632   0.4062   0.6944*  0.5017*  0.6414*
    reitem21 |   0.4945*  0.0390   0.5826*  0.2133   0.4531*  0.5303*  0.0945
```

```
             |   item21  reitem1  reitem2  reitem4  reitem5  reitem6  reitem8
-------------+---------------------------------------------------------------
      item21 |   1.0000
     reitem1 |   0.1782   1.0000
     reitem2 |   0.3804*  0.4408*  1.0000
     reitem4 |  -0.2032  -0.1756  -0.3435   1.0000
     reitem5 |   0.1782   0.3357   0.5220* -0.1756   1.0000
     reitem6 |   0.2461   0.3962*  0.3788   0.2203   0.4809*  1.0000
     reitem8 |   0.3079   0.4736*  0.0856  -0.2202   0.4736*  0.1113   1.0000
    reitem10 |   0.2423   0.3927*  0.2642   0.0464   0.4807*  0.4834*  0.2989
    reitem12 |   0.3620   0.5198*  0.4107  -0.2928   0.4069   0.1947   0.2674
    reitem13 |   0.5910*  0.4069   0.1681  -0.1681   0.1674   0.4359   0.4146
    reitem15 |   0.1125   0.4225   0.2767  -0.4068   0.6692*  0.4304*  0.1757
    reitem17 |   0.6000*  0.2254   0.4722* -0.1963   0.2254   0.4942*  0.3889
    reitem18 |   0.5750*  0.1386   0.1766  -0.0660   0.6190*  0.6774*  0.2500
    reitem19 |   0.2903   0.2579   0.3229  -0.2267   0.4378*  0.3565   0.2721
    reitem20 |   0.3498   0.3977   0.4178*  0.3194   0.5017*  0.4445*  0.4761*
    reitem21 |   0.7428*  0.4531*  0.3871* -0.0195   0.2878   0.2479   0.4945*

             | reitem10 reitem12 reitem13 reitem15 reitem17 reitem18 reitem19
-------------+---------------------------------------------------------------
    reitem10 |   1.0000
    reitem12 |  -0.0235   1.0000
    reitem13 |   0.1175   0.3752   1.0000
    reitem15 |   0.4788*  0.4565*  0.4565*  1.0000
    reitem17 |   0.2706   0.3534   0.6295*  0.2548   1.0000
    reitem18 |   0.4744*  0.3373   0.3373   0.1497   0.3501   1.0000
    reitem19 |   0.3306   0.2218   0.4614*  0.6815*  0.6368*  0.3439   1.0000
    reitem20 |   0.3937   0.3026   0.3026   0.3892   0.2877   0.5855*  0.3649
    reitem21 |   0.1383   0.5406*  0.3131   0.1814   0.3864   0.4654*  0.2886

             | reitem20 reitem21
-------------+------------------
    reitem20 |   1.0000
    reitem21 |   0.3144   1.0000
```

11 items SRSQ-I

```
             |    item1    item2    item5    item6    item8   item12   item15   item17
-------------+------------------------------------------------------------------------
       item1 |   1.0000 
       item2 |   0.5846*  1.0000 
       item5 |   0.2016   0.2869   1.0000 
       item6 |   0.1934   0.4299*  0.5653*  1.0000 
       item8 |   0.2881   0.2394   0.4861*  0.5506*  1.0000 
      item12 |   0.1972   0.1062   0.1516  -0.0129   0.3263   1.0000 
      item15 |   0.2861   0.3306   0.2530   0.3698   0.2327   0.5094*  1.0000 
      item17 |   0.3984   0.2228   0.3799   0.5143*  0.4460* -0.0273   0.3262   1.0000 
      item18 |   0.4016*  0.4617*  0.4416*  0.5303*  0.6078*  0.4736*  0.5620*  0.4902*
      item20 |   0.5100*  0.2230   0.4552*  0.4423*  0.3083   0.3979   0.6032*  0.5385*
      item21 |   0.1236   0.1966   0.2679   0.1298   0.2891   0.5524*  0.4114   0.1322 
     reitem1 |   0.4016*  0.5407*  0.4416*  0.4531*  0.1510   0.2272   0.3458   0.3930 
     reitem2 |   0.5122*  0.7231*  0.1692   0.3871*  0.3028   0.2202   0.3583   0.2186 
     reitem5 |   0.3160   0.4617*  0.6651*  0.2878   0.6851* -0.0366   0.2309   0.1861 
     reitem6 |   0.2947   0.1621   0.5778*  0.7296*  0.3346  -0.0317   0.3847   0.4555*
     reitem8 |   0.1972   0.2413   0.5558*  0.3752   0.7595*  0.1368   0.0659   0.4132 
    reitem12 |   0.3784   0.1584   0.2044   0.3131   0.5139*  0.7548*  0.3380   0.3683 
    reitem15 |   0.0038   0.1907   0.2336   0.3151   0.2421  -0.0233   0.5525*  0.6884*
    reitem17 |   0.2470   0.2876   0.1774   0.5200*  0.5620*  0.3889   0.4687*  0.5133*
    reitem18 |   0.4316   0.1570   0.6185*  0.2701   0.5962*  0.2500   0.2940   0.2963 
    reitem20 |   0.3259   0.2515   0.5292*  0.4218*  0.4231   0.3445   0.2632   0.4062 
    reitem21 |   0.3699   0.3458   0.3240   0.3235   0.4645*  0.4945*  0.5826*  0.2133 

             |   item18   item20   item21  reitem1  reitem2  reitem5  reitem6  reitem8
-------------+------------------------------------------------------------------------
      item18 |   1.0000 
      item20 |   0.4087*  1.0000 
      item21 |   0.1782   0.4246*  1.0000 
     reitem1 |   0.4962*  0.3251   0.1782   1.0000 
     reitem2 |   0.4408*  0.3318   0.3804*  0.4408*  1.0000 
     reitem5 |   0.5707*  0.2386   0.1782   0.3357   0.5220*  1.0000 
     reitem6 |   0.4809*  0.4568*  0.2461   0.3962*  0.3788   0.4809*  1.0000 
     reitem8 |   0.3527   0.1455   0.3079   0.4736*  0.0856   0.4736*  0.1113   1.0000 
    reitem12 |   0.4069   0.0911   0.3620   0.5198*  0.4107   0.4069   0.1947   0.2674 
    reitem15 |   0.5477*  0.4646*  0.1125   0.4225   0.2767   0.6692*  0.4304*  0.1757 
    reitem17 |   0.6329*  0.5392*  0.6000*  0.2254   0.4722*  0.2254   0.4942*  0.3889 
    reitem18 |   0.5319*  0.4912*  0.5750*  0.1386   0.1766   0.6190*  0.6774*  0.2500 
    reitem20 |   0.6944*  0.6414*  0.3498   0.3977   0.4178*  0.5017*  0.4445*  0.4761*
    reitem21 |   0.4531*  0.0945   0.7428*  0.4531*  0.3871*  0.2878   0.2479   0.4945*

             | reitem12 reitem15 reitem17 reitem18 reitem20 reitem21
-------------+------------------------------------------------------
    reitem12 |   1.0000 
    reitem15 |   0.4565*  1.0000 
    reitem17 |   0.3534   0.2548   1.0000 
    reitem18 |   0.3373   0.1497   0.3501   1.0000 
    reitem20 |   0.3026   0.3892   0.2877   0.5855*  1.0000 
    reitem21 |   0.5406*  0.1814   0.3864   0.4654*  0.3144   1.0000 
```

Appendix 13: Chi-Square test of 11 items SRSQ-I and socio-demographic characteristics

Chi-Square test item response*gender

```
           |         item1
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        28         37 |        65 
           |      28.6       36.4 |      65.0 
           |     43.08      56.92 |    100.00 
-----------+----------------------+----------
    female |        16         19 |        35 
           |      15.4       19.6 |      35.0 
           |     45.71      54.29 |    100.00 
-----------+----------------------+----------
     Total |        44         56 |       100 
           |      44.0       56.0 |     100.0 
           |     44.00      56.00 |    100.00 

          Pearson chi2(1) =   0.0642   Pr = 0.800
```

```
           |         item2
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        32         33 |        65 
           |      31.2       33.8 |      65.0 
           |     49.23      50.77 |    100.00 
-----------+----------------------+----------
    female |        16         19 |        35 
           |      16.8       18.2 |      35.0 
           |     45.71      54.29 |    100.00 
-----------+----------------------+----------
     Total |        48         52 |       100 
           |      48.0       52.0 |     100.0 
           |     48.00      52.00 |    100.00 

          Pearson chi2(1) =   0.1127   Pr = 0.737
```

```
           |        item5
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        36         29 |        65
           |      33.8       31.2 |      65.0
           |     55.38      44.62 |    100.00
-----------+----------------------+----------
    female |        16         19 |        35
           |      18.2       16.8 |      35.0
           |     45.71      54.29 |    100.00
-----------+----------------------+----------
     Total |        52         48 |       100
           |      52.0       48.0 |     100.0
           |     52.00      48.00 |    100.00

          Pearson chi2(1) =   0.8524   Pr = 0.356
```

```
           |        item6
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        38         27 |        65
           |      36.4       28.6 |      65.0
           |     58.46      41.54 |    100.00
-----------+----------------------+----------
    female |        18         17 |        35
           |      19.6       15.4 |      35.0
           |     51.43      48.57 |    100.00
-----------+----------------------+----------
     Total |        56         44 |       100
           |      56.0       44.0 |     100.0
           |     56.00      44.00 |    100.00

          Pearson chi2(1) =   0.4567   Pr = 0.499
```

```
           |        item8
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        41         24 |        65
           |      44.2       20.8 |      65.0
           |     63.08      36.92 |    100.00
-----------+----------------------+----------
    female |        27          8 |        35
           |      23.8       11.2 |      35.0
           |     77.14      22.86 |    100.00
-----------+----------------------+----------
     Total |        68         32 |       100
           |      68.0       32.0 |     100.0
           |     68.00      32.00 |    100.00

          Pearson chi2(1) =   2.0685   Pr = 0.150
```

```
           |        item12
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        49         16 |        65
           |      51.4       13.7 |      65.0
           |     75.38      24.62 |    100.00
-----------+----------------------+----------
    female |        30          5 |        35
           |      27.6        7.3 |      35.0
           |     85.71      14.29 |    100.00
-----------+----------------------+----------
     Total |        79         21 |       100
           |      79.0       21.0 |     100.0
           |     79.00      21.00 |    100.00

          Pearson chi2(1) =   1.4632   Pr = 0.226
```

```
           |        item15
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        48         17 |        65
           |      50.7       14.3 |      65.0
           |     73.85      26.15 |    100.00
-----------+----------------------+----------
    female |        30          5 |        35
           |      27.3        7.7 |      35.0
           |     85.71      14.29 |    100.00
-----------+----------------------+----------
     Total |        78         22 |       100
           |      78.0       22.0 |     100.0
           |     78.00      22.00 |    100.00

          Pearson chi2(1) =   1.8674   Pr = 0.172
```

```
           |        item17
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        49         16 |        65
           |      48.1       16.9 |      65.0
           |     75.38      24.62 |    100.00
-----------+----------------------+----------
    female |        25         10 |        35
           |      25.9        9.1 |      35.0
           |     71.43      28.57 |    100.00
-----------+----------------------+----------
     Total |        74         26 |       100
           |      74.0       26.0 |     100.0
           |     74.00      26.00 |    100.00

          Pearson chi2(1) =   0.1851   Pr = 0.667
```

```
           |        item18
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        41         24 |        65 
           |      39.0       26.0 |      65.0 
           |     63.08      36.92 |    100.00 
-----------+----------------------+----------
    female |        19         16 |        35 
           |      21.0       14.0 |      35.0 
           |     54.29      45.71 |    100.00 
-----------+----------------------+----------
     Total |        60         40 |       100 
           |      60.0       40.0 |     100.0 
           |     60.00      40.00 |    100.00 

          Pearson chi2(1) =   0.7326   Pr = 0.392
```

```
           |        item20
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        38         27 |        65 
           |      36.4       28.6 |      65.0 
           |     58.46      41.54 |    100.00 
-----------+----------------------+----------
    female |        18         17 |        35 
           |      19.6       15.4 |      35.0 
           |     51.43      48.57 |    100.00 
-----------+----------------------+----------
     Total |        56         44 |       100 
           |      56.0       44.0 |     100.0 
           |     56.00      44.00 |    100.00 

          Pearson chi2(1) =   0.4567   Pr = 0.499
```

```
           |        item21
    gender |         0          1 |     Total
-----------+----------------------+----------
      male |        31         34 |        65 
           |      34.5       30.6 |      65.0 
           |     47.69      52.31 |    100.00 
-----------+----------------------+----------
    female |        22         13 |        35 
           |      18.6       16.4 |      35.0 
           |     62.86      37.14 |    100.00 
-----------+----------------------+----------
     Total |        53         47 |       100 
           |      53.0       47.0 |     100.0 
           |     53.00      47.00 |    100.00 

          Pearson chi2(1) =   2.1003   Pr = 0.147
```

Chi-Square test item response*id level

```
           |         item1
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        25         35 |        60 
           |      26.4       33.6 |      60.0 
           |     41.67      58.33 |    100.00 
-----------+----------------------+----------
  moderate |        19         21 |        40 
           |      17.6       22.4 |      40.0 
           |     47.50      52.50 |    100.00 
-----------+----------------------+----------
     Total |        44         56 |       100 
           |      44.0       56.0 |     100.0 
           |     44.00      56.00 |    100.00 

          Pearson chi2(1) =   0.3314   Pr = 0.565
```

```
           |        item2
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        25         35 |        60
           |      28.8       31.2 |      60.0
           |     41.67      58.33 |    100.00
-----------+----------------------+----------
  moderate |        23         17 |        40
           |      19.2       20.8 |      40.0
           |     57.50      42.50 |    100.00
-----------+----------------------+----------
     Total |        48         52 |       100
           |      48.0       52.0 |     100.0
           |     48.00      52.00 |    100.00

          Pearson chi2(1) =   2.4105   Pr = 0.121
```

```
           |        item5
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        27         33 |        60
           |      31.2       28.8 |      60.0
           |     45.00      55.00 |    100.00
-----------+----------------------+----------
  moderate |        25         15 |        40
           |      20.8       19.2 |      40.0
           |     62.50      37.50 |    100.00
-----------+----------------------+----------
     Total |        52         48 |       100
           |      52.0       48.0 |     100.0
           |     52.00      48.00 |    100.00

          Pearson chi2(1) =   2.9447   Pr = 0.086
```

```
           |        item6
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        37         23 |        60
           |      33.6       26.4 |      60.0
           |     61.67      38.33 |    100.00
-----------+----------------------+----------
  moderate |        19         21 |        40
           |      22.4       17.6 |      40.0
           |     47.50      52.50 |    100.00
-----------+----------------------+----------
     Total |        56         44 |       100
           |      56.0       44.0 |     100.0
           |     56.00      44.00 |    100.00

          Pearson chi2(1) =   1.9548   Pr = 0.162
```

```
           |        item8
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        38         22 |        60
           |      40.8       19.2 |      60.0
           |     63.33      36.67 |    100.00
-----------+----------------------+----------
  moderate |        30         10 |        40
           |      27.2       12.8 |      40.0
           |     75.00      25.00 |    100.00
-----------+----------------------+----------
     Total |        68         32 |       100
           |      68.0       32.0 |     100.0
           |     68.00      32.00 |    100.00

          Pearson chi2(1) =   1.5012   Pr = 0.220
```

```
           |        item12
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        46         14 |        60
           |      47.4       12.6 |      60.0
           |     76.67      23.33 |    100.00
-----------+----------------------+----------
  moderate |        33          7 |        40
           |      31.6        8.4 |      40.0
           |     82.50      17.50 |    100.00
-----------+----------------------+----------
     Total |        79         21 |       100
           |      79.0       21.0 |     100.0
           |     79.00      21.00 |    100.00

          Pearson chi2(1) =   0.4923   Pr = 0.483
```

```
           |        item15
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        48         12 |        60
           |      46.8       13.2 |      60.0
           |     80.00      20.00 |    100.00
-----------+----------------------+----------
  moderate |        30         10 |        40
           |      31.2        8.8 |      40.0
           |     75.00      25.00 |    100.00
-----------+----------------------+----------
     Total |        78         22 |       100
           |      78.0       22.0 |     100.0
           |     78.00      22.00 |    100.00

          Pearson chi2(1) =   0.3497   Pr = 0.554
```

```
           |        item17
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        45         15 |        60
           |      44.4       15.6 |      60.0
           |     75.00      25.00 |    100.00
-----------+----------------------+----------
  moderate |        29         11 |        40
           |      29.6       10.4 |      40.0
           |     72.50      27.50 |    100.00
-----------+----------------------+----------
     Total |        74         26 |       100
           |      74.0       26.0 |     100.0
           |     74.00      26.00 |    100.00

          Pearson chi2(1) =   0.0780   Pr = 0.780
```

```
           |        item18
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        36         24 |        60
           |      36.0       24.0 |      60.0
           |     60.00      40.00 |    100.00
-----------+----------------------+----------
  moderate |        24         16 |        40
           |      24.0       16.0 |      40.0
           |     60.00      40.00 |    100.00
-----------+----------------------+----------
     Total |        60         40 |       100
           |      60.0       40.0 |     100.0
           |     60.00      40.00 |    100.00

          Pearson chi2(1) =   0.0000   Pr = 1.000
```

```
           |        item20
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        38         22 |        60
           |      33.6       26.4 |      60.0
           |     63.33      36.67 |    100.00
-----------+----------------------+----------
  moderate |        18         22 |        40
           |      22.4       17.6 |      40.0
           |     45.00      55.00 |    100.00
-----------+----------------------+----------
     Total |        56         44 |       100
           |      56.0       44.0 |     100.0
           |     56.00      44.00 |    100.00

          Pearson chi2(1) =   3.2738   Pr = 0.070
```

```
           |        item21
   idlevel |         0          1 |     Total
-----------+----------------------+----------
      mild |        28         32 |        60 
           |      31.8       28.2 |      60.0 
           |     46.67      53.33 |    100.00 
-----------+----------------------+----------
  moderate |        25         15 |        40 
           |      21.2       18.8 |      40.0 
           |     62.50      37.50 |    100.00 
-----------+----------------------+----------
     Total |        53         47 |       100 
           |      53.0       47.0 |     100.0 
           |     53.00      47.00 |    100.00 

          Pearson chi2(1) =   2.4154   Pr = 0.120

. tabulate downsyndrome item1, chi2 expected row
```

Chi-Square test item response*Down syndrome

```
downsyndro |        item1
        me |         0          1 |     Total
-----------+----------------------+----------
      with |         5          7 |        12 
           |       5.3        6.7 |      12.0 
           |     41.67      58.33 |    100.00 
-----------+----------------------+----------
   without |        39         49 |        88 
           |      38.7       49.3 |      88.0 
           |     44.32      55.68 |    100.00 
-----------+----------------------+----------
     Total |        44         56 |       100 
           |      44.0       56.0 |     100.0 
           |     44.00      56.00 |    100.00 

          Pearson chi2(1) =   0.0301   Pr = 0.862
```

```
downsyndro |        item2
        me |         0          1 |     Total
-----------+----------------------+----------
      with |         7          5 |        12 
           |       5.8        6.2 |      12.0 
           |     58.33      41.67 |    100.00 
-----------+----------------------+----------
   without |        41         47 |        88 
           |      42.2       45.8 |      88.0 
           |     46.59      53.41 |    100.00 
-----------+----------------------+----------
     Total |        48         52 |       100 
           |      48.0       52.0 |     100.0 
           |     48.00      52.00 |    100.00 
```

```
downsyndro |        item5
        me |         0          1 |     Total
-----------+----------------------+----------
      with |         9          3 |        12
           |       6.2        5.8 |      12.0
           |     75.00      25.00 |    100.00
-----------+----------------------+----------
   without |        43         45 |        88
           |      45.8       42.2 |      88.0
           |     48.86      51.14 |    100.00
-----------+----------------------+----------
     Total |        52         48 |       100
           |      52.0       48.0 |     100.0
           |     52.00      48.00 |    100.00

          Pearson chi2(1) =   2.8901   Pr = 0.089
```

```
downsyndro |        item6
        me |         0          1 |     Total
-----------+----------------------+----------
      with |         4          8 |        12
           |       6.7        5.3 |      12.0
           |     33.33      66.67 |    100.00
-----------+----------------------+----------
   without |        52         36 |        88
           |      49.3       38.7 |      88.0
           |     59.09      40.91 |    100.00
-----------+----------------------+----------
     Total |        56         44 |       100
           |      56.0       44.0 |     100.0
           |     56.00      44.00 |    100.00

          Pearson chi2(1) =   2.8434   Pr = 0.092
```

```
downsyndro |        item8
        me |         0          1 |     Total
-----------+----------------------+----------
      with |        11          1 |        12
           |       8.2        3.8 |      12.0
           |     91.67       8.33 |    100.00
-----------+----------------------+----------
   without |        57         31 |        88
           |      59.8       28.2 |      88.0
           |     64.77      35.23 |    100.00
-----------+----------------------+----------
     Total |        68         32 |       100
           |      68.0       32.0 |     100.0
           |     68.00      32.00 |    100.00

          Pearson chi2(1) =   3.5101   Pr = 0.061
```

```
downsyndro |        item12
        me |         0          1 |     Total
-----------+----------------------+----------
      with |         9          3 |        12
           |       9.5        2.5 |      12.0
           |     75.00      25.00 |    100.00
-----------+----------------------+----------
   without |        70         18 |        88
           |      69.5       18.5 |      88.0
           |     79.55      20.45 |    100.00
-----------+----------------------+----------
     Total |        79         21 |       100
           |      79.0       21.0 |     100.0
           |     79.00      21.00 |    100.00

          Pearson chi2(1) =   0.1315   Pr = 0.717
```

```
downsyndro |        item15
        me |         0          1 |     Total
-----------+----------------------+----------
      with |        10          2 |        12
           |       9.4        2.6 |      12.0
           |     83.33      16.67 |    100.00
-----------+----------------------+----------
   without |        68         20 |        88
           |      68.6       19.4 |      88.0
           |     77.27      22.73 |    100.00
-----------+----------------------+----------
     Total |        78         22 |       100
           |      78.0       22.0 |     100.0
           |     78.00      22.00 |    100.00

          Pearson chi2(1) =   0.2260   Pr = 0.634
```

```
downsyndro |        item17
        me |         0          1 |     Total
-----------+----------------------+----------
      with |        10          2 |        12
           |       8.9        3.1 |      12.0
           |     83.33      16.67 |    100.00
-----------+----------------------+----------
   without |        64         24 |        88
           |      65.1       22.9 |      88.0
           |     72.73      27.27 |    100.00
-----------+----------------------+----------
     Total |        74         26 |       100
           |      74.0       26.0 |     100.0
           |     74.00      26.00 |    100.00

          Pearson chi2(1) =   0.6174   Pr = 0.432
```

```
downsyndro |        item18
        me |         0          1 |     Total
-----------+----------------------+----------
      with |        10          2 |        12
           |       7.2        4.8 |      12.0
           |     83.33      16.67 |    100.00
-----------+----------------------+----------
   without |        50         38 |        88
           |      52.8       35.2 |      88.0
           |     56.82      43.18 |    100.00
-----------+----------------------+----------
     Total |        60         40 |       100
           |      60.0       40.0 |     100.0
           |     60.00      40.00 |    100.00

          Pearson chi2(1) =   3.0934   Pr = 0.079


downsyndro |        item20
        me |         0          1 |     Total
-----------+----------------------+----------
      with |         6          6 |        12
           |       6.7        5.3 |      12.0
           |     50.00      50.00 |    100.00
-----------+----------------------+----------
   without |        50         38 |        88
           |      49.3       38.7 |      88.0
           |     56.82      43.18 |    100.00
-----------+----------------------+----------
     Total |        56         44 |       100
           |      56.0       44.0 |     100.0
           |     56.00      44.00 |    100.00

          Pearson chi2(1) =   0.1992   Pr = 0.655
```

```
downsyndro |        item21
        me |         0          1 |     Total
-----------+----------------------+----------
      with |         8          4 |        12
           |       6.4        5.6 |      12.0
           |     66.67      33.33 |    100.00
-----------+----------------------+----------
   without |        45         43 |        88
           |      46.6       41.4 |      88.0
           |     51.14      48.86 |    100.00
-----------+----------------------+----------
     Total |        53         47 |       100
           |      53.0       47.0 |     100.0
           |     53.00      47.00 |    100.00

          Pearson chi2(1) =   1.0225   Pr = 0.312
```

Chi-Square test item response*living area

```
           |         item1
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        20         36 |        56
           |      24.6       31.4 |      56.0
           |     35.71      64.29 |    100.00
-----------+----------------------+----------
     rural |        24         20 |        44
           |      19.4       24.6 |      44.0
           |     54.55      45.45 |    100.00
-----------+----------------------+----------
     Total |        44         56 |       100
           |      44.0       56.0 |     100.0
           |     44.00      56.00 |    100.00

          Pearson chi2(1) =   3.5461   Pr = 0.060
```

```
           |        item2
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        27         29 |        56
           |      26.9       29.1 |      56.0
           |     48.21      51.79 |    100.00
-----------+----------------------+----------
     rural |        21         23 |        44
           |      21.1       22.9 |      44.0
           |     47.73      52.27 |    100.00
-----------+----------------------+----------
     Total |        48         52 |       100
           |      48.0       52.0 |     100.0
           |     48.00      52.00 |    100.00

          Pearson chi2(1) =   0.0023   Pr = 0.961
```

```
           |        item5
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        32         24 |        56
           |      29.1       26.9 |      56.0
           |     57.14      42.86 |    100.00
-----------+----------------------+----------
     rural |        20         24 |        44
           |      22.9       21.1 |      44.0
           |     45.45      54.55 |    100.00
-----------+----------------------+----------
     Total |        52         48 |       100
           |      52.0       48.0 |     100.0
           |     52.00      48.00 |    100.00

          Pearson chi2(1) =   1.3487   Pr = 0.246
```

```
           |        item6
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        35         21 |        56
           |      31.4       24.6 |      56.0
           |     62.50      37.50 |    100.00
-----------+----------------------+----------
     rural |        21         23 |        44
           |      24.6       19.4 |      44.0
           |     47.73      52.27 |    100.00
-----------+----------------------+----------
     Total |        56         44 |       100
           |      56.0       44.0 |     100.0
           |     56.00      44.00 |    100.00

          Pearson chi2(1) =   2.1823   Pr = 0.140
```

```
           |        item8
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        33         23 |        56 
           |      38.1       17.9 |      56.0 
           |     58.93      41.07 |    100.00 
-----------+----------------------+----------
     rural |        35          9 |        44 
           |      29.9       14.1 |      44.0 
           |     79.55      20.45 |    100.00 
-----------+----------------------+----------
     Total |        68         32 |       100 
           |      68.0       32.0 |     100.0 
           |     68.00      32.00 |    100.00 

          Pearson chi2(1) =   4.8131   Pr = 0.028
```

```
           |        item12
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        42         14 |        56 
           |      44.2       11.8 |      56.0 
           |     75.00      25.00 |    100.00 
-----------+----------------------+----------
     rural |        37          7 |        44 
           |      34.8        9.2 |      44.0 
           |     84.09      15.91 |    100.00 
-----------+----------------------+----------
     Total |        79         21 |       100 
           |      79.0       21.0 |     100.0 
           |     79.00      21.00 |    100.00 

          Pearson chi2(1) =   1.2275   Pr = 0.268
```

```
           |        item15
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        41         15 |        56
           |      43.7       12.3 |      56.0
           |     73.21      26.79 |    100.00
-----------+----------------------+----------
     rural |        37          7 |        44
           |      34.3        9.7 |      44.0
           |     84.09      15.91 |    100.00
-----------+----------------------+----------
     Total |        78         22 |       100
           |      78.0       22.0 |     100.0
           |     78.00      22.00 |    100.00

          Pearson chi2(1) =   1.6987   Pr = 0.192
```

```
           |        item17
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        37         19 |        56
           |      41.4       14.6 |      56.0
           |     66.07      33.93 |    100.00
-----------+----------------------+----------
     rural |        37          7 |        44
           |      32.6       11.4 |      44.0
           |     84.09      15.91 |    100.00
-----------+----------------------+----------
     Total |        74         26 |       100
           |      74.0       26.0 |     100.0
           |     74.00      26.00 |    100.00

          Pearson chi2(1) =   4.1583   Pr = 0.041
```

```
           |        item18
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        31         25 |        56
           |      33.6       22.4 |      56.0
           |     55.36      44.64 |    100.00
-----------+----------------------+----------
     rural |        29         15 |        44
           |      26.4       17.6 |      44.0
           |     65.91      34.09 |    100.00
-----------+----------------------+----------
     Total |        60         40 |       100
           |      60.0       40.0 |     100.0
           |     60.00      40.00 |    100.00

          Pearson chi2(1) =   1.1431   Pr = 0.285
```

```
           |        item20
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        33         23 |        56 
           |      31.4       24.6 |      56.0 
           |     58.93      41.07 |    100.00 
-----------+----------------------+----------
     rural |        23         21 |        44 
           |      24.6       19.4 |      44.0 
           |     52.27      47.73 |    100.00 
-----------+----------------------+----------
     Total |        56         44 |       100 
           |      56.0       44.0 |     100.0 
           |     56.00      44.00 |    100.00 

          Pearson chi2(1) =   0.4430   Pr = 0.506
```

```
           |        item21
   livarea |         0          1 |     Total
-----------+----------------------+----------
     urban |        27         29 |        56 
           |      29.7       26.3 |      56.0 
           |     48.21      51.79 |    100.00 
-----------+----------------------+----------
     rural |        26         18 |        44 
           |      23.3       20.7 |      44.0 
           |     59.09      40.91 |    100.00 
-----------+----------------------+----------
     Total |        53         47 |       100 
           |      53.0       47.0 |     100.0 
           |     53.00      47.00 |    100.00 

          Pearson chi2(1) =   1.1702   Pr = 0.279
```

Chi-Square test item response*ethnicity

```
             |        item1
  ethnicity2 |         0          1 |     Total
-------------+----------------------+----------
    javanese |        31         30 |        61 
             |      26.8       34.2 |      61.0 
             |     50.82      49.18 |    100.00 
-------------+----------------------+----------
non-javanese |        13         26 |        39 
             |      17.2       21.8 |      39.0 
             |     33.33      66.67 |    100.00 
-------------+----------------------+----------
       Total |        44         56 |       100 
             |      44.0       56.0 |     100.0 
             |     44.00      56.00 |    100.00 

          Pearson chi2(1) =   2.9522   Pr = 0.086
```

```
             |        item2
  ethnicity2 |         0          1 |     Total
-------------+----------------------+----------
    javanese |        28         33 |        61 
             |      29.3       31.7 |      61.0 
             |     45.90      54.10 |    100.00 
-------------+----------------------+----------
non-javanese |        20         19 |        39 
             |      18.7       20.3 |      39.0 
             |     51.28      48.72 |    100.00 
-------------+----------------------+----------
       Total |        48         52 |       100 
             |      48.0       52.0 |     100.0 
             |     48.00      52.00 |    100.00 

          Pearson chi2(1) =   0.2759   Pr = 0.599
```

```
             |        item5
  ethnicity2 |         0          1 |     Total
-------------+----------------------+----------
    javanese |        29         32 |        61
             |      31.7       29.3 |      61.0
             |     47.54      52.46 |    100.00
-------------+----------------------+----------
non-javanese |        23         16 |        39
             |      20.3       18.7 |      39.0
             |     58.97      41.03 |    100.00
-------------+----------------------+----------
       Total |        52         48 |       100
             |      52.0       48.0 |     100.0
             |     52.00      48.00 |    100.00

          Pearson chi2(1) =   1.2459   Pr = 0.264
```

```
             |        item6
  ethnicity2 |         0          1 |     Total
-------------+----------------------+----------
    javanese |        34         27 |        61
             |      34.2       26.8 |      61.0
             |     55.74      44.26 |    100.00
-------------+----------------------+----------
non-javanese |        22         17 |        39
             |      21.8       17.2 |      39.0
             |     56.41      43.59 |    100.00
-------------+----------------------+----------
       Total |        56         44 |       100
             |      56.0       44.0 |     100.0
             |     56.00      44.00 |    100.00

          Pearson chi2(1) =   0.0044   Pr = 0.947
```

```
             |        item8
  ethnicity2 |         0          1 |     Total
-------------+----------------------+----------
    javanese |        45         16 |        61 
             |      41.5       19.5 |      61.0 
             |     73.77      26.23 |    100.00 
-------------+----------------------+----------
non-javanese |        23         16 |        39 
             |      26.5       12.5 |      39.0 
             |     58.97      41.03 |    100.00 
-------------+----------------------+----------
       Total |        68         32 |       100 
             |      68.0       32.0 |     100.0 
             |     68.00      32.00 |    100.00 

          Pearson chi2(1) =   2.3935   Pr = 0.122

. tabulate ethnicity2 item12, chi2 expected row


             |       item12
  ethnicity2 |         0          1 |     Total
-------------+----------------------+----------
    javanese |        53          8 |        61 
             |      48.2       12.8 |      61.0 
             |     86.89      13.11 |    100.00 
-------------+----------------------+----------
non-javanese |        26         13 |        39 
             |      30.8        8.2 |      39.0 
             |     66.67      33.33 |    100.00 
-------------+----------------------+----------
       Total |        79         21 |       100 
             |      79.0       21.0 |     100.0 
             |     79.00      21.00 |    100.00 

          Pearson chi2(1) =   5.8620   Pr = 0.015



             |       item15
  ethnicity2 |         0          1 |     Total
-------------+----------------------+----------
    javanese |        52          9 |        61 
             |      47.6       13.4 |      61.0 
             |     85.25      14.75 |    100.00 
-------------+----------------------+----------
non-javanese |        26         13 |        39 
             |      30.4        8.6 |      39.0 
             |     66.67      33.33 |    100.00 
-------------+----------------------+----------
       Total |        78         22 |       100 
             |      78.0       22.0 |     100.0 
             |     78.00      22.00 |    100.00 

          Pearson chi2(1) =   4.7856   Pr = 0.029
```

```
             |        item17
  ethnicity2 |         0          1 |     Total
-------------+----------------------+----------
    javanese |        48         13 |        61 
             |      45.1       15.9 |      61.0 
             |     78.69      21.31 |    100.00 
-------------+----------------------+----------
non-javanese |        26         13 |        39 
             |      28.9       10.1 |      39.0 
             |     66.67      33.33 |    100.00 
-------------+----------------------+----------
       Total |        74         26 |       100 
             |      74.0       26.0 |     100.0 
             |     74.00      26.00 |    100.00 

          Pearson chi2(1) =   1.7870   Pr = 0.181


             |        item18
  ethnicity2 |         0          1 |     Total
-------------+----------------------+----------
    javanese |        41         20 |        61 
             |      36.6       24.4 |      61.0 
             |     67.21      32.79 |    100.00 
-------------+----------------------+----------
non-javanese |        19         20 |        39 
             |      23.4       15.6 |      39.0 
             |     48.72      51.28 |    100.00 
-------------+----------------------+----------
       Total |        60         40 |       100 
             |      60.0       40.0 |     100.0 
             |     60.00      40.00 |    100.00 

          Pearson chi2(1) =   3.3908   Pr = 0.066


             |        item20
  ethnicity2 |         0          1 |     Total
-------------+----------------------+----------
    javanese |        33         28 |        61 
             |      34.2       26.8 |      61.0 
             |     54.10      45.90 |    100.00 
-------------+----------------------+----------
non-javanese |        23         16 |        39 
             |      21.8       17.2 |      39.0 
             |     58.97      41.03 |    100.00 
-------------+----------------------+----------
       Total |        56         44 |       100 
             |      56.0       44.0 |     100.0 
             |     56.00      44.00 |    100.00 

          Pearson chi2(1) =   0.2296   Pr = 0.632
```

```
              │       item21
   ethnicity2 │         0          1 │     Total
──────────────┼──────────────────────┼──────────
     javanese │        34         27 │        61
              │      32.3       28.7 │      61.0
              │     55.74      44.26 │    100.00
──────────────┼──────────────────────┼──────────
 non-javanese │        19         20 │        39
              │      20.7       18.3 │      39.0
              │     48.72      51.28 │    100.00
──────────────┼──────────────────────┼──────────
        Total │        53         47 │       100
              │      53.0       47.0 │     100.0
              │     53.00      47.00 │    100.00

          Pearson chi2(1) =   0.4706   Pr = 0.493
```

Chi-Square test item response*religion

```
           │       item1
 religion2 │         0          1 │     Total
───────────┼──────────────────────┼──────────
     Islam │        38         37 │        75
           │      33.0       42.0 │      75.0
           │     50.67      49.33 │    100.00
───────────┼──────────────────────┼──────────
    others │         6         19 │        25
           │      11.0       14.0 │      25.0
           │     24.00      76.00 │    100.00
───────────┼──────────────────────┼──────────
     Total │        44         56 │       100
           │      44.0       56.0 │     100.0
           │     44.00      56.00 │    100.00

          Pearson chi2(1) =   5.4113   Pr = 0.020
```

```
           |        item2
 religion2 |         0          1 |     Total
-----------+----------------------+----------
     Islam |        36         39 |        75 
           |      36.0       39.0 |      75.0 
           |     48.00      52.00 |    100.00 
-----------+----------------------+----------
    others |        12         13 |        25 
           |      12.0       13.0 |      25.0 
           |     48.00      52.00 |    100.00 
-----------+----------------------+----------
     Total |        48         52 |       100 
           |      48.0       52.0 |     100.0 
           |     48.00      52.00 |    100.00 

          Pearson chi2(1) =   0.0000   Pr = 1.000
```

```
           |        item5
 religion2 |         0          1 |     Total
-----------+----------------------+----------
     Islam |        40         35 |        75 
           |      39.0       36.0 |      75.0 
           |     53.33      46.67 |    100.00 
-----------+----------------------+----------
    others |        12         13 |        25 
           |      13.0       12.0 |      25.0 
           |     48.00      52.00 |    100.00 
-----------+----------------------+----------
     Total |        52         48 |       100 
           |      52.0       48.0 |     100.0 
           |     52.00      48.00 |    100.00 

          Pearson chi2(1) =   0.2137   Pr = 0.644
```

```
           |        item6
 religion2 |         0          1 |     Total
-----------+----------------------+----------
     Islam |        41         34 |        75 
           |      42.0       33.0 |      75.0 
           |     54.67      45.33 |    100.00 
-----------+----------------------+----------
    others |        15         10 |        25 
           |      14.0       11.0 |      25.0 
           |     60.00      40.00 |    100.00 
-----------+----------------------+----------
     Total |        56         44 |       100 
           |      56.0       44.0 |     100.0 
           |     56.00      44.00 |    100.00 

          Pearson chi2(1) =   0.2165   Pr = 0.642
```

```
           |        item8
 religion2 |         0          1 |     Total
-----------+----------------------+----------
     Islam |        51         24 |        75 
           |      51.0       24.0 |      75.0 
           |     68.00      32.00 |    100.00 
-----------+----------------------+----------
    others |        17          8 |        25 
           |      17.0        8.0 |      25.0 
           |     68.00      32.00 |    100.00 
-----------+----------------------+----------
     Total |        68         32 |       100 
           |      68.0       32.0 |     100.0 
           |     68.00      32.00 |    100.00 

          Pearson chi2(1) =   0.0000   Pr = 1.000
```

```
           |        item12
 religion2 |         0          1 |     Total
-----------+----------------------+----------
     Islam |        58         17 |        75 
           |      59.3       15.8 |      75.0 
           |     77.33      22.67 |    100.00 
-----------+----------------------+----------
    others |        21          4 |        25 
           |      19.8        5.3 |      25.0 
           |     84.00      16.00 |    100.00 
-----------+----------------------+----------
     Total |        79         21 |       100 
           |      79.0       21.0 |     100.0 
           |     79.00      21.00 |    100.00 

          Pearson chi2(1) =   0.5023   Pr = 0.478
```

```
           |        item15
 religion2 |         0          1 |     Total
-----------+----------------------+----------
     Islam |        60         15 |        75 
           |      58.5       16.5 |      75.0 
           |     80.00      20.00 |    100.00 
-----------+----------------------+----------
    others |        18          7 |        25 
           |      19.5        5.5 |      25.0 
           |     72.00      28.00 |    100.00 
-----------+----------------------+----------
     Total |        78         22 |       100 
           |      78.0       22.0 |     100.0 
           |     78.00      22.00 |    100.00 

          Pearson chi2(1) =   0.6993   Pr = 0.403
```

```
           |        item17
 religion2 |         0          1 |     Total
-----------+----------------------+----------
     Islam |        59         16 |        75 
           |      55.5       19.5 |      75.0 
           |     78.67      21.33 |    100.00 
-----------+----------------------+----------
    others |        15         10 |        25 
           |      18.5        6.5 |      25.0 
           |     60.00      40.00 |    100.00 
-----------+----------------------+----------
     Total |        74         26 |       100 
           |      74.0       26.0 |     100.0 
           |     74.00      26.00 |    100.00 

          Pearson chi2(1) =   3.3957   Pr = 0.065
```

```
           |       item18
 religion2 |         0          1 |     Total
-----------+----------------------+----------
     Islam |        47         28 |        75 
           |      45.0       30.0 |      75.0 
           |     62.67      37.33 |    100.00 
-----------+----------------------+----------
    others |        13         12 |        25 
           |      15.0       10.0 |      25.0 
           |     52.00      48.00 |    100.00 
-----------+----------------------+----------
     Total |        60         40 |       100 
           |      60.0       40.0 |     100.0 
           |     60.00      40.00 |    100.00 

          Pearson chi2(1) =   0.8889   Pr = 0.346
```

```
           |       item20
 religion2 |         0          1 |     Total
-----------+----------------------+----------
     Islam |        43         32 |        75 
           |      42.0       33.0 |      75.0 
           |     57.33      42.67 |    100.00 
-----------+----------------------+----------
    others |        13         12 |        25 
           |      14.0       11.0 |      25.0 
           |     52.00      48.00 |    100.00 
-----------+----------------------+----------
     Total |        56         44 |       100 
           |      56.0       44.0 |     100.0 
           |     56.00      44.00 |    100.00 

          Pearson chi2(1) =   0.2165   Pr = 0.642
```

```
           |        item21
 religion2 |         0          1 |     Total
-----------+----------------------+----------
     Islam |        36         39 |        75
           |      39.8       35.3 |      75.0
           |     48.00      52.00 |    100.00
-----------+----------------------+----------
    others |        17          8 |        25
           |      13.3       11.8 |      25.0
           |     68.00      32.00 |    100.00
-----------+----------------------+----------
     Total |        53         47 |       100
           |      53.0       47.0 |     100.0
           |     53.00      47.00 |    100.00

          Pearson chi2(1) =   3.0108   Pr = 0.083
```

Chi-Square test item response*living arrangement

```
                   |        item1
          housing2 |         0          1 |     Total
-------------------+----------------------+----------
              home |        20         35 |        55
                   |      24.2       30.8 |      55.0
                   |     36.36      63.64 |    100.00
-------------------+----------------------+----------
special institution |        24         21 |        45
                   |      19.8       25.2 |      45.0
                   |     53.33      46.67 |    100.00
-------------------+----------------------+----------
             Total |        44         56 |       100
                   |      44.0       56.0 |     100.0
                   |     44.00      56.00 |    100.00

          Pearson chi2(1) =   2.8926   Pr = 0.089
```

```
                   |        item2
          housing2 |         0          1 |     Total
-------------------+----------------------+----------
              home |        27         28 |        55
                   |      26.4       28.6 |      55.0
                   |     49.09      50.91 |    100.00
-------------------+----------------------+----------
special institution |        21         24 |        45
                   |      21.6       23.4 |      45.0
                   |     46.67      53.33 |    100.00
-------------------+----------------------+----------
             Total |        48         52 |       100
                   |      48.0       52.0 |     100.0
                   |     48.00      52.00 |    100.00

          Pearson chi2(1) =   0.0583   Pr = 0.809
```

```
                    |        item5
           housing2 |         0          1 |     Total
--------------------+----------------------+----------
               home |        32         23 |        55
                    |      28.6       26.4 |      55.0
                    |     58.18      41.82 |    100.00
--------------------+----------------------+----------
special institution |        20         25 |        45
                    |      23.4       21.6 |      45.0
                    |     44.44      55.56 |    100.00
--------------------+----------------------+----------
              Total |        52         48 |       100
                    |      52.0       48.0 |     100.0
                    |     52.00      48.00 |    100.00

          Pearson chi2(1) =   1.8713   Pr = 0.171
```

```
                    |        item6
           housing2 |         0          1 |     Total
--------------------+----------------------+----------
               home |        35         20 |        55
                    |      30.8       24.2 |      55.0
                    |     63.64      36.36 |    100.00
--------------------+----------------------+----------
special institution |        21         24 |        45
                    |      25.2       19.8 |      45.0
                    |     46.67      53.33 |    100.00
--------------------+----------------------+----------
              Total |        56         44 |       100
                    |      56.0       44.0 |     100.0
                    |     56.00      44.00 |    100.00

          Pearson chi2(1) =   2.8926   Pr = 0.089
```

```
                    |        item8
           housing2 |         0          1 |     Total
--------------------+----------------------+----------
               home |        33         22 |        55
                    |      37.4       17.6 |      55.0
                    |     60.00      40.00 |    100.00
--------------------+----------------------+----------
special institution |        35         10 |        45
                    |      30.6       14.4 |      45.0
                    |     77.78      22.22 |    100.00
--------------------+----------------------+----------
              Total |        68         32 |       100
                    |      68.0       32.0 |     100.0
                    |     68.00      32.00 |    100.00

          Pearson chi2(1) =   3.5948   Pr = 0.058
```

```
                    |        item12
           housing2 |         0          1 |     Total
--------------------+----------------------+----------
               home |        41         14 |        55
                    |      43.5       11.6 |      55.0
                    |     74.55      25.45 |    100.00
--------------------+----------------------+----------
special institution |        38          7 |        45
                    |      35.5        9.4 |      45.0
                    |     84.44      15.56 |    100.00
--------------------+----------------------+----------
              Total |        79         21 |       100
                    |      79.0       21.0 |     100.0
                    |     79.00      21.00 |    100.00

          Pearson chi2(1) =   1.4619   Pr = 0.227
```

```
                    |        item15
           housing2 |         0          1 |     Total
--------------------+----------------------+----------
               home |        40         15 |        55
                    |      42.9       12.1 |      55.0
                    |     72.73      27.27 |    100.00
--------------------+----------------------+----------
special institution |        38          7 |        45
                    |      35.1        9.9 |      45.0
                    |     84.44      15.56 |    100.00
--------------------+----------------------+----------
              Total |        78         22 |       100
                    |      78.0       22.0 |     100.0
                    |     78.00      22.00 |    100.00

          Pearson chi2(1) =   1.9802   Pr = 0.159
```

```
                     |        item17
            housing2 |         0          1 |     Total
---------------------+----------------------+----------
                home |        37         18 |        55 
                     |      40.7       14.3 |      55.0 
                     |     67.27      32.73 |    100.00 
---------------------+----------------------+----------
special institution  |        37          8 |        45 
                     |      33.3       11.7 |      45.0 
                     |     82.22      17.78 |    100.00 
---------------------+----------------------+----------
               Total |        74         26 |       100 
                     |      74.0       26.0 |     100.0 
                     |     74.00      26.00 |    100.00 

          Pearson chi2(1) =   2.8749   Pr = 0.090
```

```
                     |        item18
            housing2 |         0          1 |     Total
---------------------+----------------------+----------
                home |        31         24 |        55 
                     |      33.0       22.0 |      55.0 
                     |     56.36      43.64 |    100.00 
---------------------+----------------------+----------
special institution  |        29         16 |        45 
                     |      27.0       18.0 |      45.0 
                     |     64.44      35.56 |    100.00 
---------------------+----------------------+----------
               Total |        60         40 |       100 
                     |      60.0       40.0 |     100.0 
                     |     60.00      40.00 |    100.00 

          Pearson chi2(1) =   0.6734   Pr = 0.412
```

```
                     |        item20
            housing2 |         0          1 |     Total
---------------------+----------------------+----------
                home |        33         22 |        55 
                     |      30.8       24.2 |      55.0 
                     |     60.00      40.00 |    100.00 
---------------------+----------------------+----------
special institution  |        23         22 |        45 
                     |      25.2       19.8 |      45.0 
                     |     51.11      48.89 |    100.00 
---------------------+----------------------+----------
               Total |        56         44 |       100 
                     |      56.0       44.0 |     100.0 
                     |     56.00      44.00 |    100.00 

          Pearson chi2(1) =   0.7937   Pr = 0.373
```

```
                   |        item21
          housing2 |         0          1 |     Total
-------------------+----------------------+----------
              home |        27         28 |        55
                   |      29.1       25.9 |      55.0
                   |     49.09      50.91 |    100.00
-------------------+----------------------+----------
special institution |        26         19 |        45
                   |      23.9       21.1 |      45.0
                   |     57.78      42.22 |    100.00
-------------------+----------------------+----------
             Total |        53         47 |       100
                   |      53.0       47.0 |     100.0
                   |     53.00      47.00 |    100.00

          Pearson chi2(1) =   0.7498   Pr = 0.387
```

Chi-Square test item response*occupation

```
occupation |        item1
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        38         46 |        84
           |      37.0       47.0 |      84.0
           |     45.24      54.76 |    100.00
-----------+----------------------+----------
  employed |         6         10 |        16
           |       7.0        9.0 |      16.0
           |     37.50      62.50 |    100.00
-----------+----------------------+----------
     Total |        44         56 |       100
           |      44.0       56.0 |     100.0
           |     44.00      56.00 |    100.00

          Pearson chi2(1) =   0.3266   Pr = 0.568
```

```
occupation |         item2
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        40         44 |        84
           |      40.3       43.7 |      84.0
           |     47.62      52.38 |    100.00
-----------+----------------------+----------
  employed |         8          8 |        16
           |       7.7        8.3 |      16.0
           |     50.00      50.00 |    100.00
-----------+----------------------+----------
     Total |        48         52 |       100
           |      48.0       52.0 |     100.0
           |     48.00      52.00 |    100.00

          Pearson chi2(1) =   0.0305   Pr = 0.861
```

```
occupation |         item5
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        43         41 |        84
           |      43.7       40.3 |      84.0
           |     51.19      48.81 |    100.00
-----------+----------------------+----------
  employed |         9          7 |        16
           |       8.3        7.7 |      16.0
           |     56.25      43.75 |    100.00
-----------+----------------------+----------
     Total |        52         48 |       100
           |      52.0       48.0 |     100.0
           |     52.00      48.00 |    100.00

          Pearson chi2(1) =   0.1378   Pr = 0.710
```

```
occupation |         item6
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        43         41 |        84
           |      47.0       37.0 |      84.0
           |     51.19      48.81 |    100.00
-----------+----------------------+----------
  employed |        13          3 |        16
           |       9.0        7.0 |      16.0
           |     81.25      18.75 |    100.00
-----------+----------------------+----------
     Total |        56         44 |       100
           |      56.0       44.0 |     100.0
           |     56.00      44.00 |    100.00

          Pearson chi2(1) =   4.9286   Pr = 0.026
```

```
occupation |        item8
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        54         30 |        84 
           |      57.1       26.9 |      84.0 
           |     64.29      35.71 |    100.00 
-----------+----------------------+----------
  employed |        14          2 |        16 
           |      10.9        5.1 |      16.0 
           |     87.50      12.50 |    100.00 
-----------+----------------------+----------
     Total |        68         32 |       100 
           |      68.0       32.0 |     100.0 
           |     68.00      32.00 |    100.00 

          Pearson chi2(1) =   3.3285   Pr = 0.068
```

```
occupation |        item12
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        68         16 |        84 
           |      66.4       17.6 |      84.0 
           |     80.95      19.05 |    100.00 
-----------+----------------------+----------
  employed |        11          5 |        16 
           |      12.6        3.4 |      16.0 
           |     68.75      31.25 |    100.00 
-----------+----------------------+----------
     Total |        79         21 |       100 
           |      79.0       21.0 |     100.0 
           |     79.00      21.00 |    100.00 

          Pearson chi2(1) =   1.2063   Pr = 0.272
```

```
occupation |        item15
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        67         17 |        84 
           |      65.5       18.5 |      84.0 
           |     79.76      20.24 |    100.00 
-----------+----------------------+----------
  employed |        11          5 |        16 
           |      12.5        3.5 |      16.0 
           |     68.75      31.25 |    100.00 
-----------+----------------------+----------
     Total |        78         22 |       100 
           |      78.0       22.0 |     100.0 
           |     78.00      22.00 |    100.00 

          Pearson chi2(1) =   0.9497   Pr = 0.330
```

```
occupation |        item17
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        61         23 |        84 
           |      62.2       21.8 |      84.0 
           |     72.62      27.38 |    100.00 
-----------+----------------------+----------
  employed |        13          3 |        16 
           |      11.8        4.2 |      16.0 
           |     81.25      18.75 |    100.00 
-----------+----------------------+----------
     Total |        74         26 |       100 
           |      74.0       26.0 |     100.0 
           |     74.00      26.00 |    100.00 

          Pearson chi2(1) =   0.5204   Pr = 0.471
```

```
occupation |        item18
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        49         35 |        84 
           |      50.4       33.6 |      84.0 
           |     58.33      41.67 |    100.00 
-----------+----------------------+----------
  employed |        11          5 |        16 
           |       9.6        6.4 |      16.0 
           |     68.75      31.25 |    100.00 
-----------+----------------------+----------
     Total |        60         40 |       100 
           |      60.0       40.0 |     100.0 
           |     60.00      40.00 |    100.00 

          Pearson chi2(1) =   0.6076   Pr = 0.436
```

```
occupation |        item20
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        47         37 |        84 
           |      47.0       37.0 |      84.0 
           |     55.95      44.05 |    100.00 
-----------+----------------------+----------
  employed |         9          7 |        16 
           |       9.0        7.0 |      16.0 
           |     56.25      43.75 |    100.00 
-----------+----------------------+----------
     Total |        56         44 |       100 
           |      56.0       44.0 |     100.0 
           |     56.00      44.00 |    100.00 

          Pearson chi2(1) =   0.0005   Pr = 0.982
```

```
occupation |        item21
         2 |         0          1 |     Total
-----------+----------------------+----------
unemployed |        45         39 |        84
           |      44.5       39.5 |      84.0
           |     53.57      46.43 |    100.00
-----------+----------------------+----------
  employed |         8          8 |        16
           |       8.5        7.5 |      16.0
           |     50.00      50.00 |    100.00
-----------+----------------------+----------
     Total |        53         47 |       100
           |      53.0       47.0 |     100.0
           |     53.00      47.00 |    100.00

          Pearson chi2(1) =   0.0688   Pr = 0.793
```

Chi-Square test item response*age

```
           |        item1
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        27         28 |        55
           |      24.2       30.8 |      55.0
           |     49.09      50.91 |    100.00
-----------+----------------------+----------
     24-45 |        17         28 |        45
           |      19.8       25.2 |      45.0
           |     37.78      62.22 |    100.00
-----------+----------------------+----------
     Total |        44         56 |       100
           |      44.0       56.0 |     100.0
           |     44.00      56.00 |    100.00

          Pearson chi2(1) =   1.2856   Pr = 0.257
```

```
           |         item2
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        26         29 |        55
           |      26.4       28.6 |      55.0
           |     47.27      52.73 |    100.00
-----------+----------------------+----------
     24-45 |        22         23 |        45
           |      21.6       23.4 |      45.0
           |     48.89      51.11 |    100.00
-----------+----------------------+----------
     Total |        48         52 |       100
           |      48.0       52.0 |     100.0
           |     48.00      52.00 |    100.00

          Pearson chi2(1) =   0.0259   Pr = 0.872
```

```
           |         item5
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        25         30 |        55
           |      28.6       26.4 |      55.0
           |     45.45      54.55 |    100.00
-----------+----------------------+----------
     24-45 |        27         18 |        45
           |      23.4       21.6 |      45.0
           |     60.00      40.00 |    100.00
-----------+----------------------+----------
     Total |        52         48 |       100
           |      52.0       48.0 |     100.0
           |     52.00      48.00 |    100.00

          Pearson chi2(1) =   2.0979   Pr = 0.148
```

```
           |         item6
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        25         30 |        55
           |      30.8       24.2 |      55.0
           |     45.45      54.55 |    100.00
-----------+----------------------+----------
     24-45 |        31         14 |        45
           |      25.2       19.8 |      45.0
           |     68.89      31.11 |    100.00
-----------+----------------------+----------
     Total |        56         44 |       100
           |      56.0       44.0 |     100.0
           |     56.00      44.00 |    100.00

          Pearson chi2(1) =   5.5162   Pr = 0.019
```

```
           |        item8
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        35         20 |        55
           |      37.4       17.6 |      55.0
           |     63.64      36.36 |    100.00
-----------+----------------------+----------
     24-45 |        33         12 |        45
           |      30.6       14.4 |      45.0
           |     73.33      26.67 |    100.00
-----------+----------------------+----------
     Total |        68         32 |       100
           |      68.0       32.0 |     100.0
           |     68.00      32.00 |    100.00

          Pearson chi2(1) =   1.0695   Pr = 0.301
```

```
           |       item12
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        42         13 |        55
           |      43.5       11.6 |      55.0
           |     76.36      23.64 |    100.00
-----------+----------------------+----------
     24-45 |        37          8 |        45
           |      35.5        9.4 |      45.0
           |     82.22      17.78 |    100.00
-----------+----------------------+----------
     Total |        79         21 |       100
           |      79.0       21.0 |     100.0
           |     79.00      21.00 |    100.00

          Pearson chi2(1) =   0.5121   Pr = 0.474
```

```
           |       item15
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        41         14 |        55
           |      42.9       12.1 |      55.0
           |     74.55      25.45 |    100.00
-----------+----------------------+----------
     24-45 |        37          8 |        45
           |      35.1        9.9 |      45.0
           |     82.22      17.78 |    100.00
-----------+----------------------+----------
     Total |        78         22 |       100
           |      78.0       22.0 |     100.0
           |     78.00      22.00 |    100.00

          Pearson chi2(1) =   0.8500   Pr = 0.357
```

```
           |        item17
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        38         17 |        55
           |      40.7       14.3 |      55.0
           |     69.09      30.91 |    100.00
-----------+----------------------+----------
     24-45 |        36          9 |        45
           |      33.3       11.7 |      45.0
           |     80.00      20.00 |    100.00
-----------+----------------------+----------
     Total |        74         26 |       100
           |      74.0       26.0 |     100.0
           |     74.00      26.00 |    100.00

          Pearson chi2(1) =   1.5309   Pr = 0.216
```

```
           |        item18
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        29         26 |        55
           |      33.0       22.0 |      55.0
           |     52.73      47.27 |    100.00
-----------+----------------------+----------
     24-45 |        31         14 |        45
           |      27.0       18.0 |      45.0
           |     68.89      31.11 |    100.00
-----------+----------------------+----------
     Total |        60         40 |       100
           |      60.0       40.0 |     100.0
           |     60.00      40.00 |    100.00

          Pearson chi2(1) =   2.6936   Pr = 0.101
```

```
           |        item20
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        25         30 |        55
           |      30.8       24.2 |      55.0
           |     45.45      54.55 |    100.00
-----------+----------------------+----------
     24-45 |        31         14 |        45
           |      25.2       19.8 |      45.0
           |     68.89      31.11 |    100.00
-----------+----------------------+----------
     Total |        56         44 |       100
           |      56.0       44.0 |     100.0
           |     56.00      44.00 |    100.00

          Pearson chi2(1) =   5.5162   Pr = 0.019
```

```
           |        item21
      age2 |         0          1 |     Total
-----------+----------------------+----------
     17-23 |        30         25 |        55
           |      29.1       25.9 |      55.0
           |     54.55      45.45 |    100.00
-----------+----------------------+----------
     24-45 |        23         22 |        45
           |      23.9       21.1 |      45.0
           |     51.11      48.89 |    100.00
-----------+----------------------+----------
     Total |        53         47 |       100
           |      53.0       47.0 |     100.0
           |     53.00      47.00 |    100.00

          Pearson chi2(1) =   0.1172   Pr = 0.732
```

Appendix 14: Interview schedule for adults with mild to moderate ID

Indonesian

Persiapan

- Ingatkan responden bahwa percakapan akan direkam, sebagaimana telah diberitahukan dalam lembar informasi penelitian
- Berikan gambaran umum mengenai penelitian dan proses wawancara, tanyakan apakah responden memiliki pertanyaan
- Jelaskan bahwa peneliti terterik untuk mengetahui pengalaman dan sudut pandang pribadi, karenanya tidak ada jawaban ‘benar’ atau ‘salah’.
- Minta responden untuk menandatangani lembar persetujuan penelitian, bila belum.

Pengantar

1. Saya ingin tahu lebih banyak tentang kamu, bisakah kamu cerita sedikit tentang dirimu?
2. Siapa saja yang tinggal bersama kamu?

Keyakinan terhadap diri sendiri/Internalisasi stigma

3. Bagaimana kamu menggambarkan dirimu sendiri?
   Prompt:
   - Hal apa yang kamu suka dari dirimu? Hal apa yang kamu tidak sukai dari dirimu?
   - Beberapa orang bilang ke saya bahwa kamu adalah penyandang tuna grahita, apa yang kamu tahu tentang tuna grahita?
4. Apa yang keluarga kamu katakan tentang kamu?
   Prompt:
   - Apa yang mereka bilang soal penyebab kondisimu? Apakah kamu setuju dengan mereka?

Pengalaman stigma/inklusi

5. Apa saja kegiatanmu sehari-hari?
   - Apakah kamu pernah bekerja?
6. Bisakah kamu ceritakan tentang pengalamanmu saat (masih) di sekolah?
   Prompts:

  - Bagaimana kamu berhubungan dengan (teman) (guru) di sekolah?
  - Apa yang (teman) (guru) katakan tentang dirimu?
  - Hal apa yang kamu anggap (menyenangkan) (sulit) di sekolah?
7. Bisakah kamu ceritakan tentang pengalamanmu saat beraktivitas di luar rumah?
   - Dengan siapa kamu pergi
   - Apakah kamu senang berada di luar rumah?
8. Kapan terakhir kali kamu berobat ke dokter?
   - Dengan siapa kamu pergi?
   - Apakah kamu merasa nyaman berada di klinik/rumah sakit?
9. Apakah kamu terlibat dalam kegiatan masyarakat dilingkungan tempat tinggalmu?
   Prompts:

   - Perayaan publik
   - Aktifitas keagamaan
   - Pemilu/Pilkada

<u>Harapan masa depan</u>

10. Apa rencanamu untuk masa depan?
    Prompts:

    - Dimana kamu ingin tinggal? Dengan siapa?
    - Apakah kamu pernah berpikir untuk menikah?/memiliki anak

Appendix 15: Integration matrix (coding structure), integration of quantitative and qualitative study

Quantitative components	Key Theme	Codes	Qualitative components	
SRSQ-I			Adults with mild to moderate ID	Professionals
81% of participants had experience stigma	Stigma and social restriction are common experience Inclusion criteria: Quotes portrayed experience of stigma in various settings and social restriction as its qonsequences, including those reported by professionals	Discrimination: Mockery, bullying, rejection	Q: You said that people make fun about the way you talk? A: Yes Q: What did they say to you? A: It was because they don’t understand what I am saying (P07Male/MildID) Q: Could you please tell me a bit about your experience there? A: sure, they are, their IQ are higher, I can’t follow their lesson, they also made fun of me, they avoid me, they don’t want to be friend with me, and so I avoid them (P08/Female/Mild) Q: how does your friends from the neighbourhood treats you A: They are nice, but some of them like to make fun of me Q: how do they make fun of you A: (they said) ‘you are a special school kid’. (P11/Male/Mild) Q: Did someone make fun of you? A: yes, at the primary school Q: could you tell me more about it? A: (they said) ‘you are too big for a third grade’. My (former) classmates were on the fourth or fifth grade. Q: who told you that? A: it was my classmates (P03/Female/Mild)	Q: In your opinion, what are the challenges faced by people with intellectual disabilities in Indonesia? A: Bullying, being underestimated and considered useless… (P13/mainstream education teacher) …At school, he may be mocked and perceived as stupid (P13/mainstream education teacher). A: There will always be people who perceived individual with disabilities in derogating view and remarks; such as 'give it up, you don't understand, do not even try to get involved' and because he can't use money in a correct amount, there is a chance for him to get swindled. P01/Psychologist Teachers in the mainstream schools will give the label whenever they could not understand a student condition. They would say “this child won’t have a future” P03/Psychologist A: It is unjust to bully and reject people with such condition (intellectual disabilities). We may find children do such things to them...they don’t have an ill intention, they (the children) just want to have fun, to make fun of people with disability (P17/religious leader-Hindu).

		Social restriction	**Q:** Do you spend most of your time inside the house? **A:** Yes, I never go out, if I do I go with my parents. I never go out by myself; I am afraid that someone may kidnap me (P01/Female/MildID) A: I am not allowed to go (out of the house) on my own, but I can go with my granny Q: Who told you not to go out alone? A: My mom Q: Why your mom doesn't allow you? A: It has always been like that, I am not allowed Q: Do you know the reason? A: No neighbours, I am not allowed to play with neighbours (P10/Female/ModerateID). A: …I want to join them (classmates), but they don't want me to join Q: why they don't want you to join? A: I asked them, but they didn't say anything (P06/Female/MildID).	A: …if his parents think that it is impossible for the child to go to school because they are worried about bullying. I often heard about children with disabilities being bullied. Then the second option is home-schooling (P11/religious leader-protestant). People like Rudy and Gilang can be included in the society, but then again, a lot of people may reject them. The rejection may affect Rudy and Gilang. They will feel excluded… (P05/mainstream teacher) A: In the past, many children with similar condition to Rudy and Gilang (intellectual disabilities) were kept at home, hidden. But it has changed quite significantly now (P06/special education teacher). their parents do not allow them to do an activity as they are ashamed of themselves for having children with such a condition, they never bring their children with them to attend a wedding party or to attend religious activities, then it would be harder for such children to socialize, (P06/special education teacher)
Four items of the SRSQ-I representing emotional reactions were answered yes by forty percent or more participants	Reaction to stigma: shame, anger and fear Inclusion criteria: Comments portraying emotional reactions towards stigma		A: ...I was mocked, I was called the black aunt, lice, when I was at the elementary school…I was mad, I was mad, I was called stupid…I felt ashamed, I felt offended… (P12/Female/ModerateID). A: (I feel ashamed) if I was told to do things and I did it wrong… Q: If you made a mistake, what do people say? A: My dad usually says '[T]his is a simple task, why did you make such a mistake?' (P05/Male/MildID). A: In my current neighbourhood, no one knows that I work here (sheltered workshop). I am afraid the information might spread. I don't like it	

			(if it’s happened)…I am afraid (if the new neighbours know) (P03/Female/Mild). Q: Do they (peers at church) know that you go to a special school? A: They don’t, no one knows about it. Q: You don’t tell them? A: No Q: Why? A: I am ashamed, I am afraid they will avoid me (P01/Female/Mild).	
People living in urban areas were more likely to answer yes to the item ‘people on the street make fun of me’ and ‘people treat me like a child.’	Inclusion criteria: Comments portraying participants interactions with people outside family and special institution	Urban	Q: do you know why they make fun of you? A: I don’t know, I just keep quiet about it Q: what are the words they use to make fun of you? A: not responsive (*kagak tanggep*) Q: not responsive for what? A: its… for difficult things Q: who said that? A: people near my house, but it was long ago Q: who are they? (P05/Male/Mild ID/Urban) Q: Do you visit places around your house? A: I do, but I do it in secret Q: Why don’t you tell your parent? Q: They won’t allow me…maybe because they think that I am a special school student, they are afraid I might get swindled, or I might get kidnapped... (P01/Female/Mild ID/Urban).	…if Rudi lives in a village, wherever he goes, people will recognise him and they may say ‘Oh, I saw him there’. (P04/Medical doctor)… if they live in a community which understands their condition, it would be good; or for them to live in urban areas where people aren’t really cared for each other, including to the limitation and condition of others (P09/religious leader-Muslim).
		Rural	A: At home, I help a friend to wash clothes, to do laundry Q: Was it a job? A: Yes Q: You worked at a laundry? A: Yes Q: Please tell me more about it A: My job is to hand clean clothes (to the customer) Q: How did you find that job? A: My friend owns the laundry, she asked me to help her (P14/Female/Mild/Rural). in my neighbourhood, I am known as a joker. I was invited to… it’s not a lecture, how do you say it? **A**: a comedy show? **Q**: yes, a comedy show. **Q:** How did it go? A: you know, I put up jokes, I was making jokes out of some of the audience (P02/Male/Moderate/Rural) Q: what are the activities in your neighbourhood? for example at the mosque? A: sometimes, during the fasting month, there is	I think the suitable living arrangement for them would be a house, not too big, with neighbours who can also look after him (P15/Psychologist) If Rudy and Gilang live in a rural area…there is a possibility for them to be brought to traditional healers…instead to health professionals…or they may be suspected of being possessed by an evil spirit (P01/Educational psychologist). A: If he (adult with mild ID) lives in rural area, where many farmers grow vegetable, he can also do the same work (P04/medical doctor). in the rural area, where the people are less educated. Their perspective (about people

			the Qur'an recital study in the mosque, in the afternoon, usually start at three to five, so before sunset, I already at home. Q: P06/female/Rural	with disability) is burdening for people like Rudy and Gilang; they like to talk about others' misfortune (P09/religious leader-muslim)
Participants with no employment status were more likely to agree to the statement 'people make me embarrassed'.	The Indonesian version of this item can be interpreted as 'people do something to make the participant embarrassed' or 'concerns to interact with other people'	With employment	Q: you said that people makes you ashamed, can you tell me in what kind of situation that you feel ashamed? A: when I am told to do something, and I do it wrong (P05/Male/Mild ID/Sheltered workshop) No, after I finish work, I never talk to the neighbours. I am afraid of being out alone. I am afraid if I misspoke, and I am afraid of being mocked, that is why I go straight to home after work. I never go outside. I don't even talk much with my in-law (P03/Female/Mild ID/Sheltered workshop)	
	Inclusion criteria: Comments portraying emotional and behavioural reactions towards social interactions with people outside family and special institution	No employment	Q: how was that made you feel? Being mocked like that? A: of course, I feel ashamed, I felt offended, I don't like to be called stupid (*bodoh*) P12/Student/Female/Moderate Q: Do your peers at the church know that you go to a special school? A: They don't, no one knows about it. Q: You don't tell them? A: No Q: Why? A: I am ashamed, I afraid they will avoid me (P01/Female/Mild/Student).	
participants of younger age group (17–23 years old) were more likely to agree with two statements 'people make me feel	Inclusion criteria: Comments regarding experience of stigma in younger (early life) and older age (adult life) and explanation	Younger age	Q: Do you have friends in your neighbourhood? A: I do, one or two Q: what about your other peer? A: …How should I say it…? I don't know… Q: Do they avoid you? A: No, it's not them, it's me who avoids them…because they are delinquent…they took my phone. (P07/Male/Mild/Younger age) **Q:** You said that there was a bad classmate as well, what did they do to you? **A:** (They were)	**A:** Within the adult age group, I think there is no problem. From what I have seen on television, it's the children, which is regrettable. Recently there was news about bullying towards a person with autism;

embarrassed' and 'I worry about the way people act towards me'.	why it happened, including reports from professionals		sarcastic, I felt that way **Q:** What did they say? **A:** It was, it was just, (they said) 'she is not the same as us'… it feels uncomfortable, and they avoid me (P06/Female/Mild/Younger age).	
		Older age	Q: Who made fun of you? A: People near my house, but it was long ago Q: Who are they? A: Neighbours (peers)…who I usually play with Q: How about now? A: Now it's not so often Q: How old were you when that happened? A: When I was in middle school (P05/Male/Mild/Older age)	
Participants from minority ethnic groups (other than Javanese) were more likely to agree with the item 'people laugh at me because of the way I look' and 'people make fun of my family'. Participants from minority religious group were more likely to agree with the item 'people talk down to me'	Inclusion criteria: Comments regarding experience of stigma related to the particular items, as well as ethnicity and religious backgrounds	Ethnic minority	Q: Aside from mocking you because you go to a special school, what else did people say to you? A: Many, for example, like for being a padangnese, 'stingy'. (Padangnese tribe has the stereotype of 'stingy' in the Indonesian community). I don't think so, my mom is not stingy, she gives a lot (to charity), but people still see us as stingy, so I better avoid them (P03FMi).	