A qualitative exploration of stigma experience and inclusion among adults with mild to moderate intellectual disability in an Indonesian context

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Ethics Statement
This study has been approved by UCL Research Ethics Committee; registration number 8849/001.

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Abstract

Background: People with intellectual disability are among the most stigmatised groups in society. There is a paucity of studies reporting on how stigma is experienced in low- and middle-income countries. This study aims to explore the experience of stigma among adults with mild/moderate intellectual disability and the extent of their inclusion in Indonesian society. **Method:** Fifteen adults with mild/moderate intellectual disability were purposively recruited from three service providers and were interviewed using a semi-structured topic guide. The data were analysed using thematic analysis. **Results:** The findings suggest that adults with intellectual disability experience stigma in multiple settings, have limited access to social activities, and internalised the experienced stigma. Challenging behaviours were identified as a reason for discrimination and poor treatment. **Conclusion:** This study adds to international understanding of stigma experienced by adults with mild/moderate intellectual disability in daily life and their inclusion in society in a middle-income country.

Keywords: Discrimination, Inclusion, Intellectual disability, Stigma, low- and middle-income country

Introduction

The fifth version of Diagnostic and Statistical Manual of Mental Disorders (DSM-5) classifies intellectual disability as a neurodevelopmental disorder characterised by impairment of general mental abilities in three areas of adaptive functioning, namely the conceptual domain (such as language, reading, writing skills), the social domains (such as empathy, social judgement, and interpersonal skills) and the practical domain (mainly in self-management skills, such as personal care, job responsibilities, and money management); which begins during the developmental period (American Psychiatric Association, 2013). Intellectual disability is estimated to affect around 1% of the population, with a higher prevalence in developing countries (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011).

Studies have identified that people with intellectual disability are vulnerable and subjected to stigma (Scior et al., 2015), which makes this population one of the most excluded and marginalised groups in society (Ditchman et al., 2013). People with intellectual disability face stigma in their day-to-day life, including from family (Ngo, Shin, Nhan, & Yang, 2012), at school (Christensen, Fraynt, Neece, & Baker, 2012; Norwich & Kelly, 2004), and in the wider society (Cooney, Jahoda, Gumley, & Knott, 2006; Jahoda & Markova, 2004).

Goffman (1968) describes stigma as a discrediting attribute that spoiled the value of the person being discredited. Link and Phelan (2001) suggest that stigma takes place when elements of stigma, namely labelling, stereotyping, separating, status loss, and discrimination co-occur in a power situation that allows the process to happen; and that stigma could negatively affect the life of the stigmatised person, such as impacting on their psychological well-being, employment opportunities, and housing options.

Studies carried out in middle-income countries suggest that people with intellectual disability are prone to stigmatisation due to various factors such as poverty, limited access to services, and traditional beliefs which endorse negative attitudes towards people with intellectual disability (Carter, 2009; Moreira, 2011). The same drivers also lead families to seek traditional healing as a method of treatment for family members with intellectual disability (Brolan et al., 2014). Furthermore, studies involving families from poor households in rural settings also noted parental concerns regarding sexual abuse of the person with intellectual disability (Carter, 2009; Moreira, 2011; Nguyen, Mitchell, de Lange, & Fritsch, 2015; Terol, 2009). Stigma forces families to withdraw from their local communities which further restricts their family member with intellectual disability from more inclusive opportunities (Komardjaja, 2005; Ngo et al., 2012).

This study focuses on the position of people with intellectual disability in an Indonesian context, living in urban and rural areas. Indonesia is a lower-middle income country in the Southeast Asia with a population of around 255 million people (Indonesia Statistics, 2016; World Bank, 2018). There is limited information regarding the status of people with disability in Indonesia (Australia Indonesia Partnership for Economic Governance, 2017; Irwanto, 2010), including people with intellectual disability. A study exploring the placement of people with intellectual disability conducted in a city in Indonesia, more than a decade ago, provides a limited account of stigma prevailing towards people with intellectual disability in Indonesian society leading to their exclusion (Komardjaja, 2005). Furthermore, it has been reported that students with intellectual disability are more likely to be rejected from Indonesian inclusive education systems due to the negative perception of their educational capabilities (Hadis, 2005). However, a recent study suggests that professionals (i.e. psychologists, medical doctors, teachers, and religious leaders) working with people with intellectual disability hold positive attitudes towards this population group (Handoyo, Ali, Scior, & Hassiotis, in press)

This study aims to explore the experience of stigma of adults with mild to moderate intellectual disability in the Indonesian cultural context. The following questions were addressed:

- How do adults with intellectual disability experience stigma? How does it affect them?
- To what extent are adults with intellectual disability included in the Indonesian society?

Method

Participants

This study received approval from the research ethics committee of the authors' university [details retained]. Fifteen participants were purposively selected from those recruited to a larger quantitative study adapting a self-report stigma questionnaire [reference retained]. The participants were recruited from three service provisions for people with intellectual disability, namely a special school that included a sheltered workshop unit and a care home, a non-governmental organisation, and a rehabilitation centre providing work-related skill training (e.g. sewing, crafting, and farming) run by the Indonesian government. The potential participants were referred to the study by their respective service providers; they all provided written consent prior to being interviewed and had the opportunity to ask questions in a face-to-face meeting with the researcher.

Participants were included if they were 17 or over and had mild or moderate intellectual disability based on a clinical assessment using a structured questionnaire, that was carried out independently by a clinical psychologist and the researcher (RH). This approach was used as there are no measures of IQ that have been validated for people with intellectual disability in Indonesia. Disagreements about whether the participants met the inclusion criteria were resolved through discussion. Participants were excluded if they had comorbid mental health conditions or other developmental disorders such as autism in order to ensure that the experiences that they reported were related to their intellectual disability and not to another condition.

The participants had all scored high in the Indonesian version of a self-reported stigma questionnaire (Ali, Strydom, Hassiotis, Williams, & King, 2008), with a minimum score of ten (above 85th percentile), which was calculated from one hundred adults with mild and moderate intellectual disability (M = 6.42; SD = 3.51). Participants from a range of different ethnic groups, living arrangements and socio-economic backgrounds were selected to ensure a wide range of perspectives were included. The sample size of fifteen participants was considered to be sufficient as saturation of codes was achieved following examination of three consecutive interview transcripts that did not generate new codes (Francis et al., 2010).

Instruments

The authors develop—informed by previous literatures—and use a semi-structured interview schedule to explore the experience of stigma, the possibility of internalisation of stigma, the extent of participants' inclusion in society, and future aspirations. The schedule use open ended questions followed with prompts to facilitate wider discussions, for example, '*can you tell me about your school experience?'* followed with *'what did your classmates say about you?';*which was developed based on literature suggesting that people with intellectual disability experience discrimination in a school setting (Christensen et al., 2012; Norwich & Kelly, 2004). Questions regarding inclusion started with broad questions such as '*Can you tell me about your daily activities?*' followed with question regarding employment experience, if any, which aimed to explore their inclusion in the society's activities. An English version of the interview questions and prompts are presented in table 1.

Data collection process

The researcher meets the participants within the premises of the service providers' facilities and conducted the interviews in Indonesian language. The interviews were audio recorded, subject to the participant consent. The interview duration ranged between 21 to 48 minutes, approximately 31 minutes on average for all interviews.

Data analysis

The researcher transcribed the interview and translated them from Indonesian into English prior to the analysis. Thematic analysis was utilised to analyse the data as indicated 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). For example, transcription and translation of the interviews helped with familiarisation with the data, as well as reading and re-reading the fifteen interview transcripts.

The coding process was carried out by following a strict line to line coding of the transcripts. Two interview transcripts were independently coded by the first, second and fourth author to ensure the quality and credibility of the coding process. Any differences in coding were settled through discussion. The initial codes established from the two transcripts were further reviewed by the third author and another researcher independent from the study. Feedback was acquired from the two reviewers and was used to refine the initial codes.

The first 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 attended by all authors. The final coding structure was established in the meeting, including defining and naming of themes.

The first author then used the coding structure to develop a thematic map by identifying the relationship between themes.

Results

Participants' demographic characteristics

Fifteen adults with mild (n = 12) and moderate (n = 3) intellectual disability were recruited in this study. There were slightly more females (53%) compared to males (47%) aged 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%). Information regarding participants' level of intellectual disability, co-occurrence of Down syndrome, living area, occupation, religion and ethnicity (based on Indonesian sub-cultural groups) are provided in table 2.

Themes

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

Discrimination and poor treatment

This theme compiles the participants' experience of being discriminated against or poorly treated in multiple settings, such the family, school and neighbourhood. Discrimination and poor treatment in school settings were reported by eight participants, suggesting that stigmatising behaviours are present among younger people.

> In the past, when I was in elementary school, I was often mocked, people [classmates] called me autistic. I don’t want that, so it’s better for me to be here [the special school] (P10/female/moderate)

Repeating grades in mainstream schools seems to be a reason for mockery from their peers.

> My normal friend made fun of me… [they said], you have to repeat a grade, while I don’t have to. (P02/male/moderate).

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

> Yes, people were mocking me, you’re a special school student, and I hate it if they mock me for being a special school student. (P03/female/mild).

> They [the neighbours] talked from a distance [behind my back]. They don’t talk to me directly… sometimes I hear them talk [about me] …He [the participant] can’t do this and that, but just let them be. (P05/male/mild).

Three participants received poor treatment from their parents. One participant shared his experience of rejection and 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 was given shelter by a social service agency where he lived for some time before being sent back to his family.

> I was left on the street. My mom left me there. (P04/male/moderate).

Another participant shared her experience of being physically abused by her father, which was attributed to her educational difficulties at school.

> [From] when I was 10 until I was 15 years old, my dad beat me… I was struggling to learn math; it was very difficult, but my parents refused to teach me. I was crying, then I was strangled. After that, my hair was pulled, I was kicked from feet to head; I was bleeding, maybe because of the cup that was thrown at me. (P03/female/mild).

One participant was living in a care home managed by the same organisation running the special school, despite having family members living in the same city. She returns to her locality 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.

> My behaviour was bad; I cried a lot, throwing tantrums, screaming like a child, like a twisted person. Since I am here [the care home], I changed a lot; I am more independent. After I returned home last time, my sister has been fond of me… [She said] you have changed a lot, if you have changed, I can take you home. If you are still like that [past behaviours], I don't want to take you back to the family'. (P08/female/mild).

Reaction to and impact of stigma

The participants reported that they felt uncomfortable, sad and angry upon experiencing poor treatment from others. 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.

> [The teacher said], you don’t need to listen to them, act like they do not exist if someone called you unintelligent, don’t get mad. (P12/female/moderate).

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

> A: I think I am useless [laughing]**…** 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 was doing a hairdressing course, after a few months, after four months, I could not understand anything. (P01/female/mild).

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

> After finishing work, I never talk to my neighbours. I am afraid of being out alone. I am afraid of misspeaking, 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-laws. I usually only talk to my parents or my husband. I am afraid to offend people, and I am afraid they will misunderstand me. It’s better for me to stay in my room. (P03/female/mild).

Limited social life and activities

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

Life within the family and special institution

The participants lived within their family homes and/or special institutions (rehabilitation centre, care home). Participants who lived in the family house said that they mostly spend their time at home where they do household chores or leisure activities e.g. watching television or playing with electronic devices (e.g., mobile phone, tablet, desktop computers).

> [after school] I 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).

> I usually stay at home. I help my dad after work [at the sheltered workshop]. It's just cleaning the house, my dad told me to… make up the bed, sweep [the floor]. (P05/male/mild).

One participant expressed her feelings of being restricted because her parents made her stay at home most of the time.

> I am very poor, right? for never leaving the house. Others can go out of their house, while I spend all my time inside… because my parents told me to. (P01/female/mild)

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.

> I enjoyed [living] here [the rehabilitation centre], it's better than staying at home doing nothing. (P07/male/mild)

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

> [I went to] shopping mall… with my mom… [I] dine, watch movies, look at books and magazines. (P12/female/moderate).

> [to celebrate Eid] I go to a relatives' place, travelling with my family; We talked; my parents brought me some clothes and food, and we ate together [*Eid al-Fitr*; *celebration after the fasting month of Ramadan*]. (P06/female/mild)

Participants were able to access health services and vote in elections, providing they had support from family and/or staff from the institutions (e.g. teachers, friends),

> I was ill, I went to the hospital with my mom… it was my parent who did the talking. (P13/female/mild).

> Oh, I do; I am old enough [to vote]. 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… it was my mom who decide [the vote]. (P12/female/moderate)

A safe haven

Participants showed their preference towards families and special institutions over more inclusive opportunities that could strengthen their limited social circle. For example, they appeared to prefer special schools over mainstream schools or work in a sheltered workshop over regular employment.

> [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).

> I prefer to work here [the sheltered workshop] because the people here know about my condition. People were talking behind my back at the shop; here they talk openly. (P03/female/mild)

Participants perceived the world outside their family and special institutions as ‘different’ and ‘dangerous’.

> The school is not similar to me. There is no one like me in the mainstream school; [people like me] are in special schools. (P07/male/mild)

> Someone might do something bad to me… something bad like someone might give me candy and take me away [abduct]. (P01/male/mild)

Wish of a normal life

Eight participants mentioned their wishes about the future which included 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.

> Yes, [plan to work in a] fruit shop; it’s my dad’s, it’s near to my house, there, I want to work there. (P12/female/moderate)

> I want to work; I want to open a tailoring business at home. [want to make] clothes, I learned [how to do it] here [the rehabilitation centre]. (P13/female/mild)

On the other hand, some participants mentioned obtaining employment in the open market but also expressed uncertainty on whether they could attain such employment.

> I want to work in a factory... [but] I don’t know, I am not sure [that I can work there]. (P07/male/mild)

> Yes, I want to work in the [sheltered] workshop unit here [the special school] … I don’t know, it’s hard [to work elsewhere] because I don’t have a diploma. (P01/female/mild)

Participants expressed their wish to get married, as they perceived that marriage as a rite of passage and that it would make their parents happy.

> The plan is, I mean, how do I say it, first I look for the girl, then I come to her politely, and bring her money, and praying equipment; it’s the common practice, if one wants to marry... Yes, I do [want to have a child], because that is the purpose of [being] an adult. (P09/male/moderate)

> I just want it [to marry]. To make my parents happy… I do [want to have a child]. To make my mom happy. (P13/female/mild)

Employment, marriage and parenthood were discussed around the issue of being independent. However, some participants did not think that living in their own house was essential, including after marriage. One participant clearly stated that she did not wish to live separately from her parent.

> [I want to live] at my parents' house, at my mom's place [after getting married]…
> I don't have the heart to leave her. (F13/female/mild)

Discussion

Overview of findings

This study suggests that adults with mild to moderate intellectual disability in Indonesia experience stigma in their daily life and in many settings including family, school and community. Some of the participants were aware of the negative labels directed at them, and a few internalised these labels. Family members and staff from special institutions are the main sources of social support for adults with intellectual disability. Adults with mild to moderate intellectual disability have a limited social circle due to restrictions in social activities, stigma, and the perception of their disability. Furthermore, as a result of the stigma experienced and restrictions from family, adults with mild to moderate intellectual disability tend to hold negative perspectives towards the world outside their family and special institution and consider it as 'different' and 'dangerous'. Such perspectives reinforce the barriers hampering the social inclusion and integration of adults with mild to moderate intellectual disability in society and may make them more vulnerable to being or remaining isolated.

Findings in context

This study found evidence that people with mild to moderate intellectual disability experience physical abuse, neglect and rejection in the Indonesian society, supporting the notion they are a vulnerable population group (Ditchman et al., 2013; Reiter, Bryen, & Shachar, 2007; Scior et al., 2015); and that discrimination occurs in multiple settings, such as the school and the family.

As noted in other studies, our participants reported that they had experienced bullying and rejection at school (Christensen et al., 2012; Gladden, 2014). Our study suggests that having to repeat year (grade retention) cause students with intellectual disabilities to be rejected by their classmates. In Indonesia, students are to repeat year when they failed to meet the expected minimum mastery in three or more subjects (Ministry of Education and Culture of the Republic of Indonesia, 2015). Although students with disabilities enrolled in special education are exempted from the policy, concerns for those unidentified as having disabilities in their early years in mainstream schools remains. Considering this finding, efforts to increase awareness and knowledge about intellectual disability should be carried out, targeting teachers and parents. Anti-stigma campaigns targeting stigma of intellectual disability should also be initiated in school settings to improve attitudes towards people with intellectual disability among students, as it has been for campaigns addressing the stigma of mental illness (Chan, Mak, & Law, 2009; Rickwood, Cavanagh, Curtis, & Sakrouge, 2004). Efforts to further develop the national inclusive education system should also be made to keep people with intellectual disability in mainstream schools with additional supports. Additionally, a standardised screening procedure to identify students with intellectual disability 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.

Our participants experience verbal and physical abuse, as well as institutionalisation from their family. Family sending their member with intellectual disability to special institution has been noted in a previous study carried out in Indonesia (Komardjaja, 2005). Limited availability of service and support in the community drives family to send their family member with intellectual disability to special institution (Tabatabainia, 2003); which may also relevant in the context of our findings. Our participants mentioned preference to live in the rehabilitation service compared to having no activities at home, which suggests the absence of service and support in their community. Initiatives to include people with mild and moderate intellectual disability should also be accompanied with efforts to establish relevant services and support for the said people in the community.

Initiatives to endorse the inclusion of adults with mild to moderate intellectual disability in the society should also fully consider their perspective, as adults with intellectual disability were found to perceive the wider society as different and dangerous. This study indicates that such perceptions stem from stigma and restriction of social life pushed on adults with mild to moderate intellectual disability by their family, which leads them to withdraw from more inclusive social interaction in society also noted in studies from high income countries (Bigby & Knox, 2009; Emerson & McVilly, 2004). These similarities suggest that limited social life is a common situation for people with intellectual disability across cultural contexts. On the other hand, these findings raise further concerns regarding the well-being of adults with intellectual disability as they are prone to loneliness because of having a limited social life (Gilmore & Cuskelly, 2014).

Strength and limitations

The current study offers insights regarding the experience of stigma and inclusion among adults with mild to moderate intellectual disability; who responded to the adaptation of a self-reported stigma questionnaire and obtained a high score. Understanding the experience of stigma and inclusion of people with intellectual disability is a first step in developing interventions for them. By empowering adults with mild to moderate intellectual disability to directly voice their experiences and perspectives, this study can inform future research and practice that will help to improve the quality of their lives. All the interviews in this study were conducted by a single interviewer, which increased the reliability of the data collection process.

However, the study also has limitations. It used purposive sampling, derived from a convenience sampling of one hundred participants. Moreover, all the participants in this study were recruited from service providers, but the study did not include the perspective of adults with intellectual disability who did not have access to services neither did it include the viewpoint of persons with more severe intellectual disability who are more likely to experience stigma and be less included overall. The views of participants who obtained a low score on the stigma questionnaire was not included and these participants may have had a more positive experience of social inclusion. However, the study is one of the very few available systematic explorations of experience of stigma in a middle-income country with specific cultural aspects and therefore, of value in understanding the context of stigma in more detail.

Conclusion

This study explores the stigma experienced by adults with mild to moderate intellectual disability, and the extent of their inclusion in the Indonesian society. The findings of this study suggest that adults with mild to moderate intellectual disability in Indonesia experience stigma in their day-to-day lives. Some had experienced stigma since their childhood. Adults with mild to moderate intellectual disability have a limited scope of social life that is centralised around their family and service providers. In light of these findings, it is critical to plan and implement strategies to eradicate the stigmatisation of people with intellectual disability and promote their inclusion in the Indonesian society.

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Table 1. 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 *tuna grahita* [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
  - Can you tell me about your daily activities?
    - Have you ever in employment?
  - 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?
  - How often do you usually go outside your house?
    - Does someone go with you?
    - Do you enjoy going outside the house?
  - 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?

Table 2. 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)	Rehabilitation trainee	8 (53)
26–35	4 (27)	Student	5 (33)
36–45	2 (13)	Sheltered employment	2 (13)
Level of disability		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)

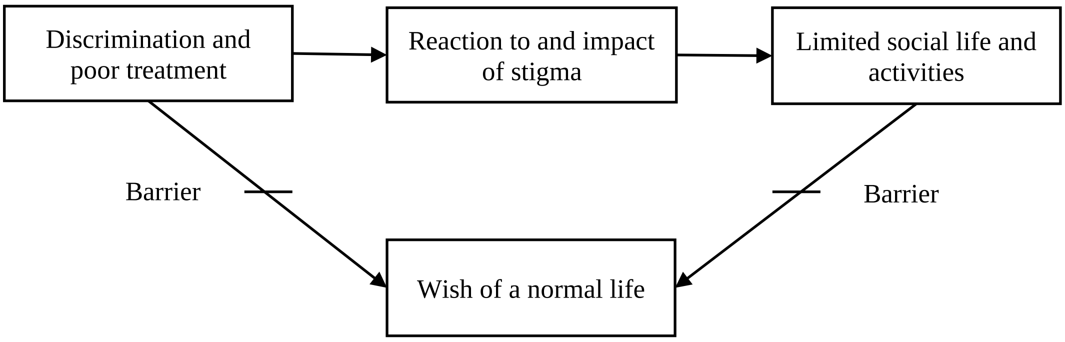

Figure 1 Themes map