

## CURRENT CONVERSATIONS ON PHYSICAL AND MENTAL DISABILITY ISSUES

Cleoputri Yusainya , Anif Fatma Chawab, Siti Kholifahb, & Ziadatul Hikmiaha<sup>1</sup>

### ABSTRACT

Stigma towards persons with disability has been highlighted as one predicting factors for overdiagnosis and more negative prognoses. The extent to which disability equality policies and practices are adopted in any given Southeast Asia societies is dependent upon the ability to capture in a real-time the extremely rapid and massive context of current societal dynamics. The mode of communication, with the support of increasingly affordable digital devices, brings communities into a new form of interaction in social media. As a source of data, the patterns derived from these social media are extremely valuable, especially to support decision-making processes. Data-driven policies are capable of suppressing errors because the target is a measurable goal. Characteristics of specific digital data requires a special approach given the huge volume of data (big data). Related to this research, the applied platform is social listening. Big data processing is conducted through the (1) data mining stage (Twitter API) using six technical terms i.e., "disabilitas" (disability), "difabel" (different ability), "cacat fisik" (physical disability), "cacat genetik" (genetic disability), "gangguan mental" (mental disorder), "gangguan jiwa" (soul illness), "penyandang cacat" (persons with disability), "retardasi mental" (mental retardation), and "skizofrenia" (schizophrenia), (2) data processing, (3) pattern evaluation, and (4) data visualization (Tableau and Gephi software). Findings from this study is expected to overcome the limitations of the tradition of stigma measurement with surveys and interviews that are vulnerable to the tendency of the subject to respond normatively.

**Keywords:** physical disability; mental disability; stigma; big data; social listening.

### 1. INTRODUCTION

The long history of evolution allows humans to interact efficiently and effectively. The complexity of social dynamics creates a form of strategy so that information rush can be simplified into a particular pattern. The ability to summarise this complexity leads not only to the positive, but also negative consequences in terms of the emergence of stigma. This study focuses on the public-stigma towards physically and mentally disabled persons. In Indonesia, the prevalence of physical disability is 11%, emotional mental

<sup>1</sup> **Psychology Dept., Faculty of Social and Political Sciences**, Jl. Veteran, Malang 65145, Indonesia

**Sociology Dept., Faculty of Social and Political Sciences**, Jl. Veteran, Malang 65145, Indonesia

Corresponding author. Tel.: +62-341-575755; fax: +62-341-570038 E-mail address:cleo.yusainya@ub.ac.id





## "International Conference ASEAN Golden Anniversary: Embracing ASEAN Community, Harmonizing Diversity"

disorder of 6%, and severe mental disorder is 1.7 per 1000 population (Health Research and Development Agency of the Ministry of Health of the Republic of Indonesia, 2013).

The World Health Organization and World Bank (2011) notes that regardless of the form of disability, the presence of stigma can affect the overall participation of persons with disabilities, particularly in crucial domains of education, employment, health care, and social engagement. This is due to the fact that public-stigma tends to be internalized by the target as self-stigma, resulting in the reluctance of stigma targets to access the required services (label avoidance) and compounded by structural-stigma in the forms of institutional policies or organizational procedures which isolates the stigma target (see Corrigan and Bink, 2016). As a consequence, public-stigma reduction is the entrance to change, which in the macro perspective of community development is part of social capital for the future of Indonesia.

Speaking of social interaction, traditional stigma measurements through self-reported surveys and interviews tend to produce limited data at the explicit level where the stigma-givers are fully aware of and willing to acknowledge their behavior, unable to represent the true complexity of stigma (Stier and Hinshaw 2007; Yusainy, Herani, Dharmawan, and Semedhi Feb 12 2016). On the other hand, the increasingly advanced technological developments have transformed social structures and processes on a massive scale. This happens because of the availability of social media where people could express and spontaneously communicate everything they experience. Social media users in Indonesia accounted for 40.46% of the total population, with the distribution of active users of YouTube 49%, Facebook 48%, Instagram 39%, and Twitter 38% (We Are Social January, 2017).

Social listening (also known as social media monitoring) as an active process of monitoring social interaction through social media and other online interaction sources is a breakthrough that can be offered in data-based stigma research in big quantities (big data). Social listening generally begins with a pattern of recognition of the discourse anatomy developing in social media. For this research, social listening was done by utilizing social media Twitter. Twitter allows account owners to share tweets (short messages with 140 character limits). With its characteristic of product characters, which are real time, historically stored, enormous quantities, diversity of users with wide geographical distribution, and unlimited themes are big data that have tremendous potential to be utilized in interdisciplinary research. A research conducted by Glummole, Orlando, and Tolomei (2013) found that trending topics, a popular collection of Twitter

"International Conference ASEAN Golden Anniversary: Embracing ASEAN  
Community, Harmonizing Diversity"

topics, can predict hot queries, popular search results on Google, with explanatory power of 60%. This shows that the flood of information generated through Twitter's social network (social trends) could be used as a guide on what topics that are most likely to be searched by Internet users.

Citing Marx's concept of power relations, Kenny (2006) explained that the marginalization, oppression, and exploitation of a community occurs because of the gap in resources and power. The gap occurs because the groups with more resources and power try to control or dominate the group with fewer resources, e.g. through public stigma attachment. The empowerment activities that become the ultimate goal of this study used macro perspectives, to change the structure or community that often marginalize communities with physical and mental disabilities. Without improvements at the structural level, capacity building efforts that are usually carried out by groups of people with disabilities can not run optimally. Empowered communities are formed based on identity similarities envisioned by their members (imagined community: Anderson 2004; Gruzdz, Wellman, and Takhteyev 2011).

## **2. STIGMA IN THE CONTEXT OF PHYSICAL AND MENTAL DISABILITIES**

According to the International Classification of Functioning, Disability, and Health (WHO 2001), disability refers to the negative aspects of individual (with health conditions) interactions and relevant contextual factors (e.g. public stigma and individual self-esteem). This definition shows that the concept of disability does not merely focus on the basis of individual conditions, but on functions in the social context. Disability involves three interrelated areas: (1) problems in the functioning of the body or body structure (e.g. paralysis, blindness), (2) difficulty in carrying out activities (e.g. walking, eating), and (3) barriers to participating in various aspects of life (e.g. discrimination at work, transportation limitations). The literature on disability usually categorizes disabilities based on their specific causes, such as "mental disability" and "physical disability". Mental disability includes mental disorders of psychiatry and intellectual disability (Werner et al. 2012).

In Indonesia, the highest prevalence of physical disability is in movement and mobility disabilities, followed by speech and hearing disabilities, as well as visual disabilities (WHO Regional Office for South-East Asia, 2013). Thohari (2013) concludes that the Javanese community's assessment of disability is circulated between deliberations of definition between four different concepts. In addition to the traditional



## "International Conference ASEAN Golden Anniversary: Embracing ASEAN Community, Harmonizing Diversity"

Javanese conception (disability as a form of supernatural power), there is also an Islamic conception (disability is the object of good deeds), medical models (disabilities as abnormalities) and social models (disability as a social construction). Contemporary social models continue to initiate changes in the direction of movement from charity model and medical model. The simplest changes, for example, through the promotion of "disabled people" label replacements that were used before the 1990s became "persons with disabilities," and furthermore "difabel: differently abled people." This redefinition arose as a shift from theoretical analysis of disability as a "personal tragedy" due to physical/mental abnormalities to social construction due to the disruptive environment and the stigma of society.

The classic definition of stigma was put forward by Goffman (1963), as an attitude that degrades and marginalizes the target of stigma. Simply put, stigma is a negative attitude aimed at the target of stigma. As an attitude, stigma includes the basic elements of Affect-Behavior-Cognition (ABC). The element of affective reaction is prejudice, the element of behaviour is discrimination, and the element of cognitive evaluation in stigma is stereotype (Stier and Hinshaw, 2007). Stereotypes describe the structure of knowledge about the members of a particular group, which could form impressions and expectations of the members of a group more efficiently. However, rigidly applied stereotypes tend to be generalized to the other aspects of the group's members. Prejudice involves evaluative components and negative affective responses to stereotypical group members. The cognitive and affective elements of prejudice lead to discrimination reactions, in the form of avoidance behaviour, hostility, and refusal to provide assistance.

Most of the views on stigma and disability focus on individuals with mental psychiatric disorders. In this context, the stigma creates a vicious cycle between social rejection and self-internalization of stigma in targeted individuals (Stier and Hinshaw, 2007). This condition produces three categories of stigma, namely public stigma, self-stigma, and family-stigma (Werner, Corrigan, Ditchman, and Sokol 2012). Public-stigma focuses on the general attitude of the population to the targets of stigma. Self-stigma focuses on the experience of the target of stigma and internalization of the negative outlook of society. Family stigma is experienced by people who have relationships with stigma targets, including family members and professionals.

### 3. METHODS

The pipeline used in this research involved several stages: data mining, data processing, data visualization, and interpretation.

#### 3.1. Data mining

To get the dataset, target population data was the content available on Twitter as well as its interaction (retweet and mention).

Keywords used in the first filtering: "disabilitas" (disability) and "difabel" (different ability)

In the second screening: "disabilitas" (disability), "difabel" (different ability), "cacat fisik" (physical disability), "cacat genetik" (genetic disability), "gangguan mental" (mental disorder), "gangguan jiwa" (soul illness), "penyandang cacat" (persons with disability), "retardasi mental" (mental retardation), and "skizofrenia" (schizophrenia)

Technique of data retrieval: Data retrieval was done via Twitter API.

Duration of data retrieval: May 28, 2017 - June 12, 2017

#### 3.2. Data processing

As this study was conducted in two stages which were analysis of sentiment and pattern recognition of community anatomy in disability, different analysis tools were needed. It is crucial to carefully selecting the appropriate algorithms in a study involving big data. In order to get anatomy from detecting and extracting patterns or structures from the Twitter conversion, the Infomap algorithm was applied in this study. Infomap is a tested algorithm with robust mathematical foundations (Rosvall, Axelsson and Bergstrom, 2009) and has been used in various studies. Studies using Infomap as an algorithm for finding community anatomy have been tested by Rosvall and Bergstrom (2008) who analyzed the information flow map to find community structures in complex webs, and Rosvall and Bergstrom (2010) who mapped changes in broad networks. Furthermore, Infomap has been also applied in other studies (see <http://www.mapequation.org/publications.html#Rosvall-Bergstrom-2008-Maps-of-information-flow>).

#### 3.3. Data visualization

In order for the results to be easily analyzed, the data obtained was processed using Tableau and Gephi applications. The purpose of this stage was to generate results in graphical form.



#### 4. RESULT

The first step was to retrieve all Twitter conversations related to the theme of disability and general disability (*sensu lato*). At the time of the first data mining (late April to early May 2017), the ongoing trending topic was a case involving Jakarta Capital City Governor Basuki Tjahaja Purnama (Ahok). The magnitude of this case was very large, so it interfered with the data retrieval process. The dispute of sentiment, or known as *tweetwar*, has seeped into the theme of disability and *difabel*.

Social media networks follow the Power Law distribution patterns that form abnormal curves. The density of formation depends on a particular user who has many followers, or is significantly responded by other users through retweets and mentions. If two or more hot issues (trending topics) are discussed at the same time, then the "leak" of unrelated themes is possible.

In the picture of 'mention' it could be seen that the theme about Ahok was very strongly discussed both in small groups as well as in large group (Fig 1.a). This situation could be interpreted that users tend to relate any topic of conversation to the case of Ahok, although in reality it was not interconnected. While from the 'retweet' image, it could be interpreted that there were four community groups that were celebrated by followers (Fig 1.b). These four clusters still form dense local networks, thus aggregately became a contributing factor to noise. Retweet in Twitter could be interpreted as approval of the original statement submitted by a user. In addition to mention and retweet, Twitter provides a like/favorite option (marked with a "love" icon) allowing other users to respond to a statement and archive it in a menu.

Nevertheless, there is a difference between retweets and favorites, because a retweeted statement will instantly appear in the timeline of the retweeters, and could be read by all their followers. While favorite are just putting a mark and input it into a menu that could only be opened specifically.

"International Conference ASEAN Golden Anniversary: Embracing ASEAN Community, Harmonizing Diversity"

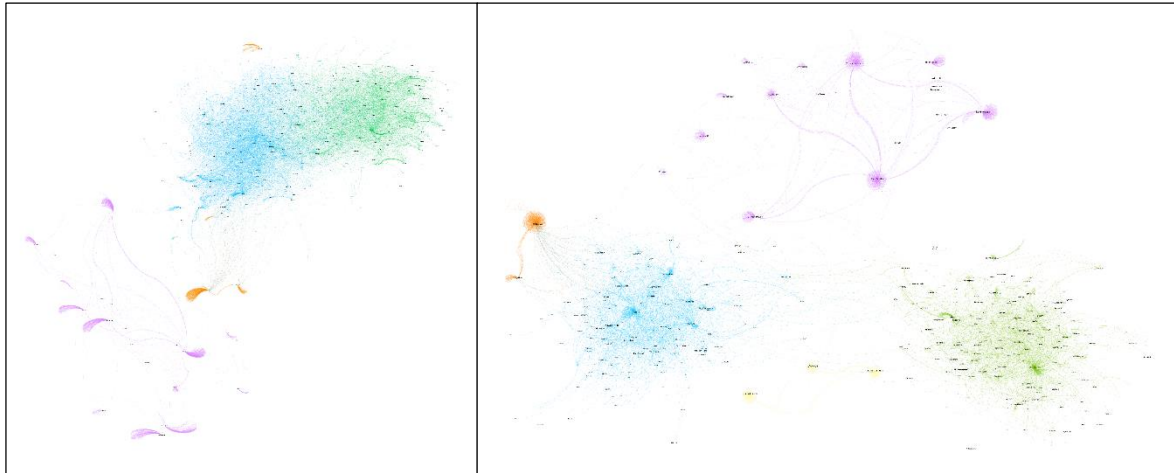


Fig 1. In the first data mining, mentions (a) as well as retweets (b) disability discourse was dominated by the conversations associated with the case of Jakarta Governor Basuki Tjahaja Purnama (Ahok).

Since the data on the first collection contained a large amount of noise, in order to obtain a cleaner data, it was necessary to re-screen using more specific keywords: disability, difabel, physical disability, genetic defects, mental disorders, soul illness, disabled person, mental retardation, and schizophrenia.

The second data filtering process resulted in a better outcome with as much as 7306 total tweet result relevant to the keyword out of a total of 5028 users. In addition, 116 users were detected as the main character that influenced conversations. Furthermore, there were 2357 connections based on retweet and 4164 connections based on mention. In the image generated from the processing of Tableau and Gephi software, a unique pattern was obtained. The flock did not form a complex pattern. Most topologies are one main account as leader followed by other users by responding via retweet or mention.

Filtering with the Infomap algorithm, resulted in a community anatomy that could be clearly defined. There were six main communities successfully detected that are marked with violet, green, blue, orange, dark green, and yellow. The bright and dark gradations of color were used to mark the size of the communities. The darker the color signified a bigger size, while the lighter color indicated the smaller size of the communities.

In the mode of mention (Fig. 2), influential main actors were dominated by media such as Detikcom, Detik Health, Google Facts, Tabloid Bintang. While for the community leaders, the crowd occurred in Hary Tanoesoedibjo, Corbuzier, and Gracyela Veronica.



"International Conference ASEAN Golden Anniversary: Embracing ASEAN Community, Harmonizing Diversity"

Nevertheless, the distribution of small groups that addressed disability issues also occurred. The perspective that could be derived from this mention analysis was the discourse of disability life to be discussed by Twitter users. The pattern that occurred was to cite media coverage and figures to be discussed among users.

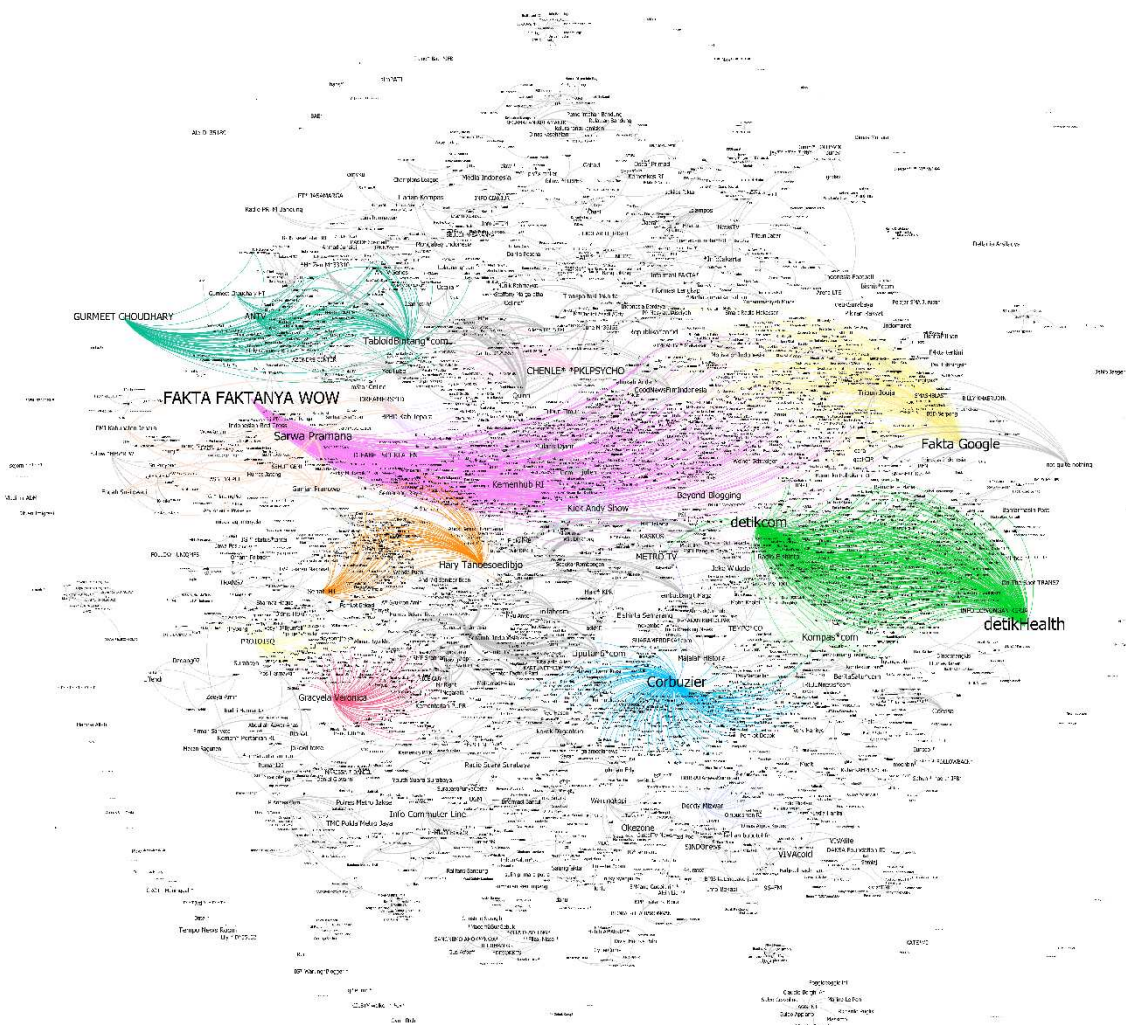
Judging from the retweets that reflected the approval (endorsement), it appeared that news about disabilities released by the media was responded and retweeted widely, either by the media itself, the public figures, or the general public (Fig. 3). The involvement of print, electronic, and online media in disability discourse was good.

Some of the electronic media that was tracked namely ANTV, Metro TV, Trans 7, Kompas TV. Radio included Radio Suara Surabaya, Radio Elshinta, Radio PRFM Bandung. The printed media included Harian Kompas, Media Indonesia, Suara Merdeka, Pikiran Rakyat. Online media encompassed Kompas.com, Detik.com, Liputan6.com, TabloidBintang.com, Tribun News. While the public figures involved Hary Tanoesudibjo, Deddy Mizwar, Lukman Edy, Sarwa Pramana. Several ministries were also participated in disability discourse, such as Kominfo (Ministry of Communication and Information), Ministry of PUPR (Public Works and Public Housings) and Ministry of Agriculture.

Related to the theme, disability discourse was linked to some trending topics (Fig. 4) such as persons with disabilities that inspire public, facilities for people with disabilities, the link between mental disorders and creativity, to the notion that marijuana and metal music can cure mental disorders. Reviews of common users involved in the discourse of disability were dominated by urban communities by responding to news broadcast by the media.



# "International Conference ASEAN Golden Anniversary: Embracing ASEAN Community, Harmonizing Diversity"



*Fig 2. Mentions disability issues using keywords: “disabilitas” (disability), “difabel” (different ability), “cacat fisik” (physical disability), “cacat genetik” (genetic disability), “gangguan mental” (mental illness), “gangguan jiwa” (soul illness), “penyandang cacat” (persons with disability), “retardasi mental” (mental retardation), and “skizofrenia” (schizophrenia).*

## "International Conference ASEAN Golden Anniversary: Embracing ASEAN Community, Harmonizing Diversity"

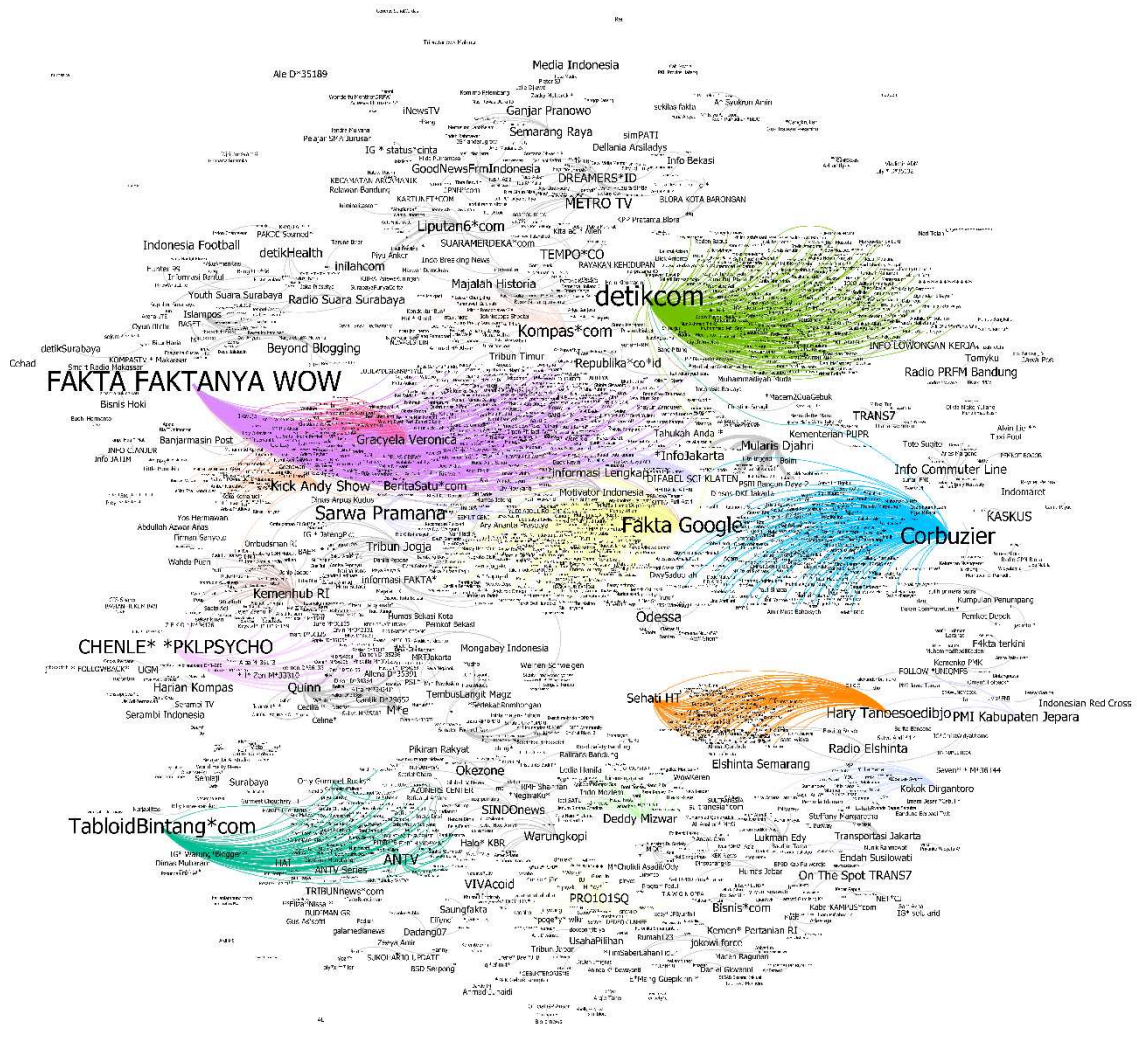


Fig 3. Mentions disability issues using keywords: "disabilitas" (disability), "difabel" (different ability), "cacat fisik" (physical disability), "cacat genetik" (genetic disability), "gangguan mental" (mental illness), "gangguan jiwa" (soul illness), "penyandang cacat" (persons with disability), "retardasi mental" (mental retardation), and "skizofrenia" (schizophrenia).



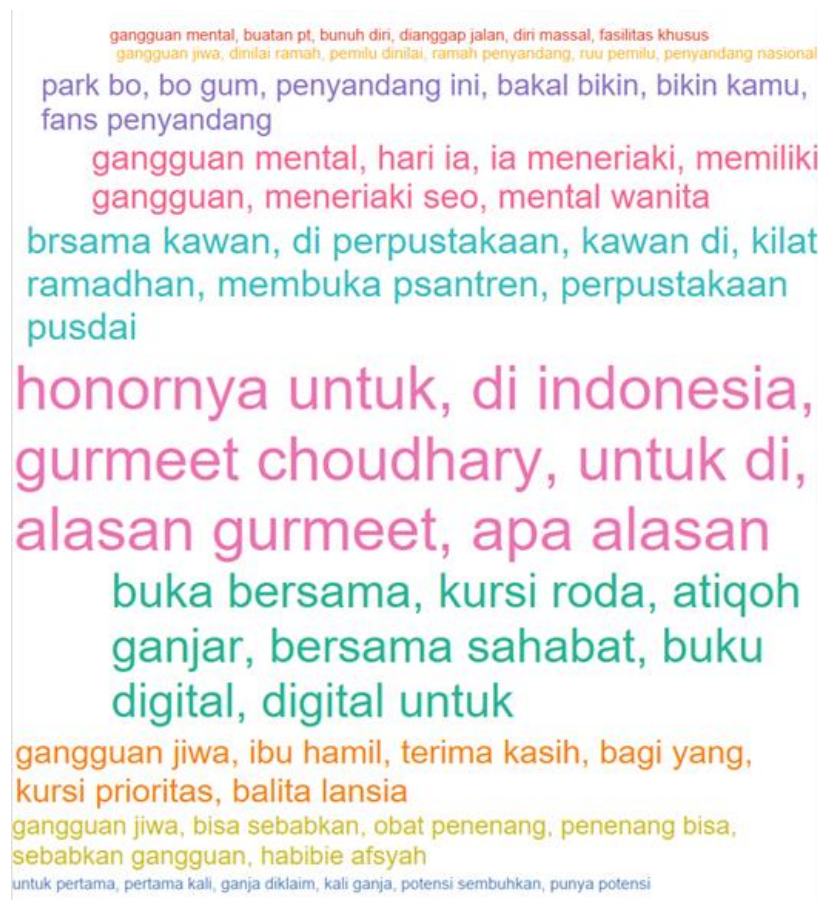


Fig 4. Colour of the fonts indicate trending topics in disability issues, size of the fonts indicates frequency.

## 5. DISCUSSION

Many things can be utilised from the presence of social media. As a source of data, the patterns obtained from social media have a high use value, especially to support decision-making. Big data processing into relevant information in the context of this research takes the form of social listening issues of physical and mental disability obtained from Twitter. Social listening by utilizing Twitter is expected to overcome the limitations of stigma measurement methods through surveys and interviews because the data obtained is spontaneously generated by stigmatizing subjects without being biased by the social norms that exist in the real world (implicit bias). The short term benefits of implicit bias intervention on ableism have been highlighted elsewhere (see Yusainy, Thohary, and Rachmat 2016).

Through this research, the output of a technical nature of a series of numbers that often make the user uncomfortable are presented in visual form. This will make the





"International Conference ASEAN Golden Anniversary: Embracing ASEAN  
Community, Harmonizing Diversity"

results of data processing more easily digested in a faster time, and allows simpler communication without losing the weight of information to other stakeholders with diverse backgrounds. At the practical level, Indonesian society is one of the active and aggressive population in utilizing social media. The Police of the Republic of Indonesia issued Circular Letter of Chief of Police number SE / 6 / X / 2015 related to the spread of hate speech that may trigger the disintegration of the nation. Changing the structure of society is not easy because of the diversity of existing communities.

The anatomical data of community discourse on the issue of disability can be applied to produce a model of empowerment at the (i) micro level, targeting changes in the way of thinking and awareness of the target group, eg through mindfulness exercises (Yusainy & Lawrence 2014; 2015) with the aim of changing the stigma of the public in the realm of institutions such as educational, business, and other social institutions, and (iii) macro, directed at a potentially stigmatizing public policy change and new policy proposals that encourage the participation of stigma targets in development programs.

## REFERENCES

- Anderson, B. *Imagined communities: Reflections on the origin and spread of nationalism*. London: Verso, 2004.
- Badan Penelitian dan Pengembangan Kesehatan Kementerian Kesehatan Republik Indonesia. *Riset Kesehatan Dasar*. <http://www.depkes.go.id/resources/download/general/Hasil%20Riskesdas%202013.pdf>, 2013.
- Bhattacharyya, J. Theorizing community development. *Journal of the Community Development Society*, 34 (2), (2004): 5-34. <http://dx.doi.org/10.1080/15575330409490110>.
- Corrigan, P. W., & Bink, A. B. The stigma of mental illness. *Encyclopedia of Mental Health*, 4, (2016): 230-234. <http://dx.doi.org/10.1016/B978-0-12-397045-9.00170-1>
- Giummole, F., Orlando, S., & Tolomei, G. Trending topics on Twitter improve the prediction of Google hot queries. In *2013 International Conference on Social Computing*. IEEE, 2013: 39-44. <http://doi.ieeecomputersociety.org/10.1109/SocialCom.2013.12>, 2013.
- Goffman E. *Stigma: Notes on the management of spoiled identity*. Simon and Schuster, New York, 1963.
- Gruzd, A., Wellman, B., & Takhteyev, Y.. Imagining Twitter as an imagined community. *American Behavioral Scientist*, 55(10), (2011): 1294-1318. <http://dx.doi.org/1177/0002764211409378>



"International Conference ASEAN Golden Anniversary: Embracing ASEAN  
Community, Harmonizing Diversity"

- Hagger, M. S., Chatzisarantis, N. L. D., Alberts, H., Anggono, C. O., Birt, A., Brand, R., ... Zweinenberg, M. A multi-lab pre-registered replication of the ego-depletion effect. *Perspectives on Psychological Science*, 11(4), (2016): 546-573. [http://dx.doi.org/ 10.1177/1745691616652873](http://dx.doi.org/10.1177/1745691616652873)
- Kenny, S. *Developing communities: For the future*. Melbourne: Thomson, 2006.
- Liu, B. *Sentiment analysis: Mining opinions, sentiments, and emotions*. New York: Cambridge University Press, 2015.
- Rosvall, M., Axelsson, D., & Bergstrom, C.T. The map equation. *European Physical Journal Special Topics*, 178, (2009): 13-23. <http://dx.doi.org/10.1140/epjst/e2010-01179-1>
- Rosvall, M., & Bergstrom, C.T. Mapping change in large networks. *PLoS ONE* 5(1), (2010): e8694. <https://doi.org/10.1371/journal.pone.0008694>