

School of Media, Creative Arts and Social Inquiry

**Communicating Autism on the Internet
The Emerging of Neurodiversity Movement in Indonesia**

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**This thesis is presented for the degree of
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of
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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

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Date: 4 October 2020

Abstract

The ways Autistics use the internet for self-expression and social inclusion has received significant academic attention in recent years. Brownlow and O'Dell (2006) for example, explore how people on the spectrum use online discussion groups to construct their voice while Davidson (2008) investigates the impacts of the internet for virtual communication and cultural expression among Autistics. Judy Singer coined the term “neurodiversity” for recognising Autism as a “variety of human wiring” – this later became closely associated with the Autistic self-advocacy movement (Davidson & Orsini, 2013). This neurodiversity movement influences the way Autism is perceived. Autism is not only a medical label that marks a person’s biological psychiatric condition, but it also becomes a socially, culturally, and historically constructed category of disability.

To date, investigations of the use of the internet and Autistics’ presence has not been covered before in Indonesian studies about Autism. This doctoral thesis aims to provide a study of Autism and advocacy movement on the internet from Indonesian cultural context, particularly to fill the growing need of broader cross-cultural literature in these areas of study.

This thesis applies a critical disability studies approach to examine the rise of an Autistic-focussed online presence in Indonesia – particularly by looking at the idea of Autism as being socially constructed. The voices of various stakeholders are included in the discussion of this thesis, from the public voice on Twitter represented largely by the news media and Autism organisations, to the voices of Autistics and parents. By using textual analysis of Twitter messages and in-depth interviews with Autistics and non-Autistics, this thesis has found that the way Autism is interpreted in Indonesia is still largely related to traditional or medical approaches. It found that in Indonesia, Autism has been represented mostly by non-Autistic people, including parents who have the first-hand experience in engaging with Autistic individuals.

Beyond the medical approach to understand Autism, this thesis also found that online platforms have opened the way for some Autistics in Indonesia to understand their Autism as part of their valuable, politicized identities. What is significant is that the internet plays a critical role in providing the platform for Autistics to share their self-

narratives. Those self-narratives are likely to contribute in the informative stage, although not yet contribute to the transformative interpretations of Autism in Indonesia. The thesis concludes that Autism culture on the internet, in the form of the neurodiversity movement, provides a form of self-awareness among some Autistics in this study – to view themselves beyond the medical definition of Autism that perceives them as ‘disabled’ by a mainstream or neurotypical culture.

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Abbreviations

AAC	Augmented and Alternative Communication
ABA	Applied Behavior Analysis
ADHD	Attention Deficit/Hyperactivity Disorder
AFF	Aspies For Freedom
ALF	Autistic Liberation Front
ANI	Autism Network International
API	Application Programming Interface
AS	Asperger Syndrome
ASD	Autism Spectrum Disorder
ASAN	Autistic Self-Advocacy Network
ASEAN	Association of South East Asian Nation
AUTOCOM	Autism National Committee
BPS	Badan Pusat Statistik (Statistics Indonesia)
CAS	Critical Autism Studies
CDS	Critical Disability Studies
CIPG	Centre for Innovation Policy and Governance
CMC	Computer-mediated Communication
DSM	Diagnostic and Statistical Manual of Mental Disorders
HF	High-Functioning
IEP	Individualized Education Program
KBR	Kantor Berita Radio
LF	Low-Functioning
LIUB	Light It up Blue

MMR	Measles Mumps Rubella
MONE	Ministry of National Education
MPATI	Masyarakat Peduli Autisme (The Autism Society of Indonesia)
NGO	Non-Governmental Organization
PAI	Pemuda Autisme Indonesia (Indonesian Autism Youth)
PDD-NOS	Pervasive Developmental Disorder-Not Otherwise Specified
PWD	Person with Disability
PSG	Parents Support Group
Riskesdas	National Report on Basic Health
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
SLB	Sekolah Luar Biasa (Special Needs' School)
SNS	Social Networking Sites
TEACHH	Treatment and Education of Autistic and related Communication Handicapped Children
YAI	Yayasan Autisma Indonesia (Indonesian Autism Foundation)

List of Publications

Book chapters

Hersinta. (2019)

“Different, not less: Communicating Autism via the internet in Indonesia.”

In *Interdisciplinary Approaches to Disability: Looking towards the Future* (Vol. 2, pp. 219-229). K. Ellis, R. Garland-Thomson, M. Kent, & R. Robertson (Eds.), New York: Routledge.

Hersinta. (2019)

“Autisme, Teknologi dan Disabilitas: Memahami Keberagaman Autisme dari Perspektif Disabilitas Kritis.”

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Hersinta. (2018).

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In *4th International Conference on Contemporary Social and Political Affairs, Surabaya, Indonesia*. A. Cashin, E. Abalos, A. Ismail, and P. Tunpungkom, Eds., 13 August 2018, vol. 1: SciTePress, 2018, pp. 142-152, doi: 10.5220/0008818101420152. [Online].

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Chapter 1. Introduction

1.1. Background of the study

The primary role of technology is seen as a functional tool to facilitate human capabilities (Roulstone, 2016). Technology, with its benefits and barriers, has been the focus of interest to be applied for people with disabilities, including those with sensory and social learning difficulties – such as Aspergers Syndrome and Autism (Roulstone, 2016). This thesis focuses on how the internet can be used for self-advocacy for Autistic people in Indonesia and as such, open up a new understanding about the diversity of Autistic presence in Indonesia. The development of internet and digital technology in particular has opened up new opportunities and possibilities for all people, including those with diverse needs. For instance, access to social media sites using digital technology can offer opportunities for employment and enjoyment activities for people with disabilities who are often excluded in society (Ellis & Kent, 2017). For example, the internet and social media have the potential to open up possibilities for Autistic people¹ in terms of social interaction and support (Penny & Standen, 2009).

Historically, Autism is identified by Leo Kanner (1943) as a childhood syndrome characterised by “Autistic aloneness” (Jaarsma & Welin, 2012). Autism, which in Kanner’s description was indicated by extreme isolation and rigidity, has come a long way in the 70 years since its early diagnostic conception (Hart, 2014). In the 1990s, Autism was understood as a broad range of spectrum condition, indicated by the lack of three psychological functions: communication, imagination and social interaction (Wing, 1997). The degrees of the condition within the Autism spectrum are varied, with different levels of ability from the mildest – these are further broadly categorised

¹ For this thesis I opt to use identity-first language (‘Autistic’, ‘Autistic people’, or Aspie/Asperger Syndrome) as neurodiversity discourse views humanity as a spectrum of difference” (Parsloe, 2017), while person-first language (‘person with Autism’) suggests the idea that a person is somehow separable from Autism (Jaarsma & Wellin, 2012). This choice also brought up by some of my participants who choose to use identity-first language to advocate on their behalf and viewing their Autism as a valuable and inseparable part of themselves. However, the person-first language also used interchangeably in this thesis (particularly in quotes from interviews and references) as in Indonesian context this term is broadly used.

into ‘high-functioning’², widely known as those with Asperger syndrome, or those with lower support needs which refers to Autistic individuals who have an IQ in the normal range or above and do not show evidence of language delay – to the more severe at the other end of the spectrum (Jaarsma & Welin, 2012). However, this rather rigid distinction is arguable, as some research and literature has found that Autistics who are considered non-verbal or having limited speech – previously categorised as ‘low-functioning’ or those with higher support needs – can achieve a high score on the non-verbal assessment of intelligence and can communicate through digital technologies (Neil, 2008; Pinchevski & Peters, 2015).

Previous studies discuss the gap between these two groups, which is considered quite broad, with members of the mildest spectrum considered to have the most possibility for having independent lives in the right kind of environment, while those in the more severe spectrum would still need lifetime dependency (Jaarsma & Welin, 2012; Pinchevski & Peters, 2015). It must therefore be argued that people with Autism do not speak with one voice, and the importance of listening to the various voices of Autistics and, importantly, including them in scientific literature has become a critical point in the understanding of Autism (O’Neil, 2008; O’Dell, et al., 2016). This idea of listening in disability could play an important role in understanding the “power relations” between the disabled and non-disabled, and the new modes of listening through convergent media such as blogs and other digital media are considered to have potential in creating such new kinds of public spheres and, ultimately, understanding (Goggin, 2009).

Among those on the mildest spectrum, the use of the internet as a communication medium has become popular globally, with many finding it a more comfortable space in which to communicate as it provides a more controllable situation (Benford & Standen, 2009). Autistics who are on the mildest spectrum – sometimes referred to as ‘Aspies’, a term for a person who identifies with Asperger’s syndrome – might have problems initiating interaction and communication offline but still has the desire for communication intimacy (Burke, Kraut, & Williams, 2010). Alternative

² Most Autistic self-advocates disagree to dichotomise Autistic people as ‘high functioning’ and ‘low functioning’, as this kind of disjunction tends to diminish individual variations in ability. Houting (2019) argues the dichotomy has the potential to “restrict access to support for those deemed ‘high functioning’ and to deny autonomy and agency to those deemed ‘low functioning’” (Den Houting, 2019).

communication platforms such as email, text messaging, online chat and social media (e.g. social networking sites or SNS) could therefore provide “a highly structured environment without extraneous stimuli” – this would be beneficial to this group as they could have greater control over social communication (Benford & Standen, 2009, p. 14). With its visual anonymity, more flexible pace of communication, and prominence of text, the internet can facilitate communication needs and break down some of the social barriers experienced by those at the high-functioning end of the Autistic spectrum (Benford & Standen, 2009).

However, previous studies also show that the internet has the potential to open up possibilities for all Autistics in terms of social interaction and support (Benford & Standen, 2009) – including Autistics who are non-speaking– allowing them to be present online, raise awareness and communicate their existence to a broader audience. Other studies support this, suggesting that Autistics experience the advantages of using computer-mediated communication not only for written communication, which facilitates communication more easily, but also for advocating their own views (Brownlow & O’Dell, 2006; Ward & Meyer, 1999). Indeed, this idea of advocacy is an important one, and the internet and social media play crucial roles in facilitating communities to encourage advocacy and awareness of Autism (Byrne, 2013).

1.1.1. The internet as a new space for advocacy or “neurodiversity”

Since the beginning of the 1980s, some Autistic adults have initiated debate through their own self-discoveries and by doing independent research about Autism (Ward & Meyer, 1999). However, the history of self-advocacy by people with Autism worldwide began at the end of the 1980s after the first diagnostic criteria were published by Gilberg and Gilberg in 1989 – a key example of this is the establishment of national and international organisations founded by Autism advocates in the United States (US) (Hersinta, 2019; Ward & Meyer, 1999). In the 1990s, the development of the internet and social media further spurred the chains of this self-advocacy movement to an online forum, as many Autistic people may be verbally limited but may have proficient skills related to technology and written communication, an ideal format for the internet (Brownlow & O’Dell, 2006; Ward & Meyer, 1999). This is supported by previous research in the US which states that the internet catalysed the

growth of the Autism self-advocacy community by liberating Autistics from the constraints of in-person communication. The technology also enables them to develop their own Autistic-run communities on various online platforms, such as email lists and forums, where they can often express themselves more easily than in person (Robertson & Ne’eman, 2008). These communities have spread through the internet, encouraging Autism-rights movements both in the United States and in a more global context (Ortega & Choudhury, 2011; Davidson & Orsini, 2013). As an example, global activist groups such as the Autistic Self-Advocacy Network (ASAN) and Autism Network International (ANI) have been advocating and promoting representations of Autism as a valuable “way of being” for the last decade (Chamak, 2007; Tucker, 2013b).

Sociologist Judy Singer, who self-identifies with Asperger syndrome, argues that the work of such advocacy online is a demonstration of how the democratisation of information flow on the internet has promoted the emergence of new ways of self-identification for people (Davidson, 2008a; Runswick-Cole, 2014). She calls this “neurodiversity” – a term introduced in her 1999 article ‘Why can’t you be normal for once in your life?’ – arguing that the term ‘neurologically different’ “represents a new addition to the familiar political categories of class/gender/race” (Jaarsma & Welin, 2012; Runswick-Cole, 2014). The goal of the neurodiversity movement, according to Singer, is to “redefine Autism as a human specificity not to be treated but instead to be respected in the same way as other human differences such as gender, race, and sexuality” (Ortega & Choudhury, 2011, p. 330). This neurodiversity movement marked the shifting in viewing ‘Autism-as-disorder’ which rooted more on biogenetic approach and medical model of disability, to ‘Autism-as-difference’ narrative- a neurological difference in human variations rather than a deficit.

Recent studies have highlighted the important role of this new technology not only as a means of personal communication for Autistics but also as a tool to share perceptions from Autistics’ lived experiences (Brownlow & O’Dell, 2006; Neil, 2008), again promoting the idea of advocacy. Historically, people with Autism communicated online using media such as chatrooms, mailing lists and bulletin boards (Davidson, 2008), allowing them to exchange and interact through the medium that eliminates “the ambiguity and sensory overload of the face-to-face” (Pinchevski & Peters, 2015,

p. 11). Later, with the advantages of user-generated content in the form of text and images in blogs, Facebook, YouTube, Twitter and Instagram, people with disabilities and related communities could “take control of the information about disability available to the general public” (Haller, 2010, p. 1). Again, this sense of community has increased the prevalence of advocacy. For example, a SNS such as Facebook hosts many Autistic-run and neurodiversity-oriented groups for Autistics, including Neurodiversity Advocacy, The Autism Acceptance Project, ASAN and Aspie Underground (Facebook Inc., 2008, quoted in Robertson & Ne’eman, 2008). Previous studies also highlight the use of websites and blogs on behalf of Autistics such as Autism Diva – which questions organisations that focus more on cure rather than acceptance – and also Aspies for Freedom and ANI – which highlight the issue of “pride in being oneself” (Neil, 2008). Another example can be seen in the virtual world Second Life, where an online movement called the Autistic Liberation Front (ALF) creates a space for advocacy and activism on behalf of persons with developmental disabilities (Danilovic, 2009).

As an example, Autistics’ utilisation of blogs and video-sharing tools such as YouTube reveals how technology could be used by those previously seen as low-functioning because of their speech impairment to construct alternative views of Autism. There are cases of Autistics who have functional speech difficulties who now can use the internet to communicate and share their experiences as individuals on the spectrum. They write blogs and make videos on YouTube showing how new technology can be used as a tool to communicate, interact and, importantly, advocate for themselves. Two such examples are Americans Ido Kedar (Curwen, 2013) and the late Mel (then Amanda) Baggs. Kedar, now 20 years old, is a non-speaking Autistic person and also an active blogger (<http://idoinAutismland.com>) who communicates by typing on an iPad or letter board. In his 2012 book, titled *Ido in Autism land*, he shares “an Autism diary, telling the story of my symptoms, education, and journey into communication” (Kedar, 2012). Baggs created her 2007 YouTube video titled *In my language* – which in the year 2016 reached over 1.3 million views – to demonstrate how her language is different compared to the normative use of language by showing repetitive behaviours and using text-to-speech software in explaining the way she communicates. In this case, the new technology is giving a ‘voice’ for Autistics who are non-speaking like Baggs. Baggs’ short film gained wide exposure after being covered by CNN, and

opened people's minds about normalcy by providing an example of people who think and communicate in non-traditional ways (Genzlinger, 2020). Baggs' story created various responses from the public – some believed the video was a fake story and created a discussion thread on Wrong Planet, an online community forum for Autistics, and those with Asperger syndrome (wrongplanet, 2008). Others claimed that by showcasing the video of herself, Baggs would give the wrong impression to public that all Autistics were like her (Gupta, 2007). However, despite such controversies, it can be seen that the internet acts as “media in an expanded sense” for someone who is non-speaking and considered as ‘low-functioning’ (Pinchevski & Peters, 2015). This case, as Pinchevski and Peters states (2015), “has shown how the limitations disability imposes on people who are consequently excluded from the norm might prove productive in encouraging various work-arounds and substitutions” (p. 15). Indeed, these kinds of reactions incite further exploration of how the use of the internet could provide different ways of understanding Autism, of seeing Autistics as a diverse culture (Grandin, quoted in Davidson, 2008). This will be one of the main points in this study.

Globally, the appearance of Autistic autobiographies in the late 1980s and early 1990s initiated a more social understanding of Autism; prior to this it was understood purely from a medical perspective, reliant on diagnosis and treatment (Krcek, 2013) (Masschelein & Goidsenhoven, 2016). In research by Davidson (2008), over 40 Autistic biographies were analysed to explore a particular Autistic style of communication (Hersinta, 2019). They were found to be precisely straightforward as the written word is the preferred mode of communication for the Autism community (Davidson, 2008). While autobiographies provide a form of self-expression and self-narrative for Autistics as they challenge the mainstream views of Autism, it is undeniable that the internet is a much more accessible medium (Masschelein & Goidsenhoven, 2016). Online personal narratives in the form of blogs accommodate Autistic individuals to voice out their identities and increase awareness about neurodiversity discourse. In Haller (2010), William Peace – a disability activist and scholar who actively blogs as Bad Cripple (badcripple.blogspot.com.au) – explains that his decision to blog on disability issues is to act as an advocate and “antithesis to what the mainstream media is presenting” as the media often portrays disabled people either as the “supercrip (the hero)” or the “lazy crip (the lowlife)” (Haller, 2010, p. 3).

In a study of a popular Flemish blog from Autistic man Tistje, the blog turns out to have functions as “an extension that marks the writer’s identity” and indicates individual ethics and activism (Masschelein & Goidsenhoven, 2015, p. 269).

1.1.2. Autism and the online movement in Indonesia

Following this global pattern, the internet and social media have also therefore become a convivial tool for many civil society groups, activists, organisations and communities for social activism in many forms in Indonesia (Nugroho, 2011). For example, an Indonesian community called Kartunet – an acronym from the Indonesian words for ‘the work of the blind’ – has, since 2006, used the internet to build a website-based community network for blind people and to publish their writings. They aim to empower, and open up possibilities and accessibilities for the blind (Kartunet, n.d.), as well as to educate the public about inclusiveness, where disability is part of plurality in society. The internet becomes a key tool in their activism as they build online information and networks focusing on disability issues, and use social media to publish disability awareness campaigns (Kartunet, n.d.). Compared to other disability movements – for example, the Blind and Deaf movements – in Indonesia, the Autism movement is still in its infancy, initiated by individuals who are using social media to build an awareness campaign and communicate their identities to the public. The challenges also lie in the broad spectrum of Autism itself; as previously mentioned, there is a recognised gap between Autistics with higher versus lower support needs. In Indonesia, the gap is even wider due to the vast disparities in socio-economic and cultural backgrounds (Tucker, 2013b). Further, there is still no exact data on the rate of Autism prevalence in Indonesia; however, in 2009 the Ministry of Health stated that one in every 150 children in Indonesia is born with Autism, and the number of children diagnosed with the disorder is continuing to increase (Mardiyati, 2011). This condition is similar with the rising prevalence of children with Autism in both western and eastern countries, such as in the United States (one in 68 children, or 1.5%) and Korea (2.6%) (Riany, et al., 2016).

It is perhaps important here to consider a brief history of the ‘emergence’ of Autism in Indonesia, both as a new phenomenon and as an online presence. In developing countries like Indonesia, Autism is still considered as a “new phenomenon”, with the

public history of Autism in this country only beginning in the late 1990s (Tucker, 2013b). There is still a limited amount of academic research about Autism in Indonesia and, due to a lack of access to media and health information, a large percentage of Indonesians – mostly those who live in small cities and rural areas – still have little understanding of Autism or, indeed, other disabilities (Riany, et al., 2016).

The Autism movement in Indonesia first started around 1997–1999 – initiated by parents and health experts’ efforts to bring Autism into public awareness in Indonesia, especially in urban areas (Tucker, 2013b). This was – and continues to be – done through inaugurating public discussion and providing group support and information about Autism through online media (Tucker, 2013b). For example, Putrakembara, an online community related to Autism in the form of a parents’ support group, started to emerge in 2000 alongside an increase in diagnoses of Autism in Indonesia. As the first online group discussion forum about Autism in Indonesia, it reached its popularity in 2002, with 3000 members and daily flow of 200–300 emails per day (Yang, 2015). However, currently, mobile messaging apps such as WhatsApp have started to become more popular than mailing list forums, and Putrakembara is no exception; since 2017 some of its members have been migrating to WhatsApp to have more interactive discussions.

This of course goes hand in hand with the increasing numbers of internet users in Indonesia – 64.8% of 264 million people. However, currently, these users are mostly located in cities and are concentrated in West Indonesia, particularly in Java (“Indonesia has 171 million internet users: Study”, 2019). From the same study, it is stated that mobile messaging apps (e.g. WhatsApp and Line) and social media are very popular in Indonesia, ranking first (89.4%) and second (87%) in terms of internet use (Setyowati, 2018). Indonesian social media users have increased rapidly during the period of 2010 to 2016, with Facebook active monthly users reaching 82 million and Twitter users around 50 million (Deliusno, 2015; Yusuf, 2016), while in the last 2 years, the five most popular online platforms among Indonesian users have been YouTube, WhatsApp, Facebook, Instagram and Twitter (Jayani, 2020). In addition, since online media platform started to gain its popularity, there has been a growing presence of Indonesian language web resources such as Facebook groups and parenting blogs (Tucker, 2013b).

However, in contrast to the wider Autistic community, it wasn't until 2005 that Oscar Yura Dompas, a 25-year-old Autistic who was diagnosed at the age of 4, published the first autobiographical book by an Autistic person in Indonesia. Coming from a family with an upper socio-economic background, Oscar managed to get a university degree and experienced living abroad for some years. Oscar, who loves to write, previously blogged on his website www.oscardompas.com. Oscar's blog serves as a narrative media that tells the story about being a teenager on the spectrum. His writing acts as a communication tool to speak out his identity, as he stated that he is proud to be a person on the spectrum, "Say it out loud, I am Autistic and proud of it," (Feinstein, 2005).

In addition, after its emergence in 2005, YouTube also became a popular option for disseminating disability rights messages and also for creating documentaries from disability perspectives (Haller, 2010). In 2013, a famous Indonesian pianist and music composer, Ananda Sukarlan, described himself for the first time as an Aspie and as having Tourette syndrome when he shared his experience on being a "different" person through a video on YouTube (Hersinta, 2019). In the same year, an account on behalf of Pemuda Autisme (Autism Youth) emerged using Twitter and a blog to educate people about Autism, to advocate on behalf of Autistics, and to assist them to build a community. However, the term 'neurodiversity' (translated in Bahasa as *keragaman saraf*) is not a common term in Indonesia and is only used in a few publications³.

Today, advocating for Autism in Indonesia is done by a variety of stakeholders – communities or groups, individuals, parents of Autistic children and also health practitioners. Some of the pioneering advocacy groups include Yayasan Autisma Indonesia or YAI (translated: the Indonesian Autism Foundation), Masyarakat Peduli Autisme Indonesia or MPATI (translated: the Indonesian Autism Awareness Community) and also the aforementioned online mailing list forum Puterakembara. Since the beginning stage of Indonesian Autism awareness years in the early 2000s, these organisations and online forums have provided information on treatments and recommendations through websites, shared experiences on behalf of the parents and built online networks of parents' support groups, as well as offered offline activities

³ In 2016, *Beritagar*, an Indonesian news site published an article titled "Neurodiversity, Keragaman Saraf dan Autisme" ("Neurodiversity and Autism) to introduce the term to the mainstream readers: <https://beritagar.id/artikel/gaya-hidup/neurodiversity-keragaman-saraf-dan-Autisme>

such as hosting workshops and seminars, and publishing books, memoirs and newsletters (Tucker, 2013b).

Concluding from the aforementioned discussion, this thesis then will focus on two main aspects: how social media is utilised by Autistic people for socialising and communicating their presence, and in the later stage, leads to the self-advocacy and self-determination of their identities as neurodiverse in Indonesia. As discussed by Ward & Meyer (1999) and Brownlow & O'Dell (2006) the global self-advocacy movement was spurred by the development of the internet and social media – as many Autistic people find the internet and social media as a comfortable mediated platform to communicate and interact.

1.2. Significance of the study

Previous research on new media usage by Autistics in Indonesia is still difficult to find, and little has been published, despite the prevalence of persons with Autism increasing up to 15% every year according to the Indonesian Ministry of National Education (Riany et al., 2016). Furthermore, despite the increased diagnoses of the spectrum, assessment and therapy centres only started to be built as recently as 2006, and mainly only in Jakarta (Tucker, 2013b). Indeed, most of the studies to date have been conducted in the clinical area, such as an epidemiological study in 1992 and publications about detection and treatment in Autism (Tucker, 2013b). Other publications were also found in the areas of psychological communication and instructional communication (Hersinta, 2012) as well as proposals for public awareness campaigns (Tucker, 2013b). On the other hand, there is an increasing presence of public awareness on Autism in Indonesia, which is reflected by awareness campaigns and news about Autism in social media and traditional media such as newspapers, magazines and television. There are also book publications in the form of memoirs written by parents of children with Asperger's, and the appearance of Autistic people to speak out and communicate their presence by using social media. Concluding from the previous literatures and the facts of the emerging Autistic presence in social media, this thesis will therefore provide further insights into how online platforms could facilitate social needs for Autistics in the context of Indonesia, such as communicating their presence, making social interactions and promoting self-

advocacy. The research also provide case studies in order to contribute to the knowledge base regarding these common gaps:

1. A lack of understanding of how the internet can contribute to the creation of united Autism advocacy movement in Indonesia similar to the global neurodiversity movement in western countries.
2. A lack of understanding of how Autistic people are using the internet for communicating their presence, having social interactions, expressing their opinions and promoting self-advocacy in a country where public knowledge on Autism is still uneven and socio-economic disparities are vast.

1.3. Research questions and the context of the study

As explained in the earlier part of this chapter, at the beginning of its conception, globally, Autism was largely viewed and classified by medical discourses; this remains a dominant discourse in Indonesia when viewing Autism and other disabilities (Hersinta, 2019). However, globally this is changing – within the neurodiversity movement and generally among Autistic self-advocates, Autism is today conceptualised using the social model of disability (Den Houting, 2019). Molloy and Vasil (2002) argue that in the social model of disability, impairments and illnesses do exist in the world, but the way they are classified, treated and interpreted is socially constructed (Molloy & Vasil, 2002). In a neurodiversity context, which spreads broadly via online communities on the internet, Autism is framed both as “a natural variation and a disability” (Den Houting, 2019). Due to the fact that Autistic personhood has started to emerge on the internet, both globally and particularly in the last 7 years in Indonesia, I argue that the use of the internet and online communication by Autistics can empower Autistic self-advocacy and give understanding about the diversity of Autistic presence in Indonesia. I also propose that parents’ roles as allies and translators are important in this transformation process – from viewing Autism from medical approach to a more progressive one. As such, the research questions were formulated as follows:

- How Autism is represented and understood in Indonesia, particularly through online platforms?

- In what ways do parents support and assist their children's and the broader movements' online self-advocacy?
- How social media can offer alternative ways of understanding Autism in Indonesia and become a catalyst for new forms of expression for Autistic adults?

In order to answer the research question, the following objectives are considered in this thesis:

1. Investigate the narrative of Autism being discussed on Indonesian social media, mainly on Twitter, to explore further main issues surrounding the context of Autism and how it is framed in the online platform.
2. Investigate the parents' experiences on Autism advocacy and their perspectives about current and future Autistic self-advocacy in Indonesia – regarding the recent phenomenon of the changing landscape in Autism advocacy, from parents' advocacy to Autistic self-advocacy.
3. Investigate the notion of Autistic personhood in social media, and their practice in using social media – particularly in terms of social use and making online presence such as expressing their opinions, communicating with others, promoting self-advocacy and as a means for self-narrative – and how this distribution of narratives could provide different ways of understanding Autism in Indonesia.

In this thesis I employ a critical approach in studying Autism – based on Orsini and Davidson's work in 2013 on Critical Autism Studies (CAS) – to examine the rise of an Autistic-focussed online presence in Indonesia. This approach intends to explore the power relationships that construct Autism, enabling narratives that challenge the dominant-negative medical Autism discourse, as well as developing theoretical and methodological approaches that are emancipatory and inclusive (O'dell, et al., 2016). To include the voices of various stakeholders in Autism discussion in Indonesia, in this thesis I employ a case study research supported by dual methodologies: (i) content analysis of Twitter messages and (ii) interviews with Autistics and non-Autistics (parents). This enables me to explore the differences evident in how Autism is understood and interpreted in Indonesia. The theories and methodologies applied for this thesis will be discussed further in chapters 2 and 3.

It is important to note that my experience will be inexorable in the research process of this thesis – which acts as one of the analytical factors from a particular perspective. My personal and professional experience – as a mother of an Autistic teen and a lecturer who taught a few students on the spectrum in Indonesia – plays part in the process of writing this thesis. This of course will raise a question about objectivity, but the position of this thesis is not about finding an ‘objective judgement’ as it tries to find a subjective understanding in examining Autism as a social phenomenon in Indonesia.

1.4. Structure of the thesis

Following this introductory chapter, chapters 2 and 3 will explain the main concepts and methods underlying the overall thesis. Chapter 2 consists of literature reviews on the concepts behind and historical definitions of neurodiversity, critical disability studies, critical Autism studies, the social construction of Autism, and the critical role of the internet and social media as a means of communication among Autistics.

Chapter 3 addresses the methodology used in the thesis: the case study, grounded theory approach and content analysis method. This chapter also gives a further description of how the chosen methods will support this study, including the procedures of data collection used.

Chapter 4, Autism awareness and online advocacy, consists of literature reviews on Autism history in the global context, as well as further explanations about the clinical, social and cultural aspects of Autism. The discussion of the emerging Autism movement and advocacy groups in a global context, and the internet as a platform of disability movements and advocacies in Indonesian context will also be presented in this chapter.

Chapter 5, Autism in Indonesia: an overview, addresses the historical aspect and current state of public understanding of Autism, the stigma surrounding Autism, and how Autism is represented in the news and entertainment media, to provide a more thorough picture of how Autism is understood among the mainstream society in Indonesia.

Chapter 6, Framing on Autism, is dedicated to reviewing the literature on the subject of framing about Autism. This chapter introduces the relevant references that will be used for analysis in chapter 7, including Clogston's traditional and progressive models of disability, the concept of media framing and Twitter framing in some previous scholarly works.

Chapter 7, Tweeting Autism in Indonesia: investigating the dominant frames, addresses the way Indonesian Twitter users frame Autism. This chapter provides an analysis of conversations about Autism on Twitter for a 6-month period. The content analysis will be undertaken through Clogston's traditional and progressive models of disability (1994) as a framework, as well as previous literatures in media framing about Autism that have been described in chapter 6.

Chapter 8, the parents' voices on the internet, addresses the representation of Autistics in Indonesia by the non-Autistic community, with a focus on parents. In this chapter, the results from interviews with non-autistics (four parents) will be described and analysed. The discussion in this chapter will emphasise their experiences of using social media regarding Autism, their thoughts regarding the impact of social media for Autistics, and their roles as translators and mediators for their children in Indonesian Autism advocacy.

Chapter 9, Autistic presence, voice and personhood in Indonesia, addresses the findings from the second stage of data collection which is based on the interviews with five Autistics. This chapter investigates how Autism is perceived in Indonesia, a country with great diversities in culture, from the Autistics' point of view. To provide analysis and answers to the main question of this thesis, a discussion about Autistics' experience of social media, their online advocacy on Autism, and their understandings of Autism will be included in this chapter. Moreover, a discussion about social construction of Autism in Indonesia, as well as neurodiversity culture in social media and online communities, will also be addressed. The final part of this chapter will conclude how the internet and social media contribute to Autism narratives in Indonesia.

Chapter 10 will address the conclusion and implications of my thesis, including some important points such as how the internet and social media in Indonesia can be viewed as digital inclusion (or exclusion) for Autistics, how the multiple voices of Autism

illustrate the current state of online Autism advocacy in Indonesia, and how Autism is constructed in Indonesia, in particular its influencing factors including cultural and technological contexts which can contribute to create different narratives about Autism in Indonesia.

Chapter 2. Critical concepts underlying study

2.1. Introduction

As discussed in the introduction chapter, this study focuses on the use of the internet and online communication by Autistics to empower Autistic self-advocacy and promote a better understanding about the diversity of an Autistic presence in Indonesia. This thesis will further analyse the topic by drawing on international theories regarding disability and internet studies, as well as a focus on neurodiversity, the ‘normate’, the social construction of surrounding Autism as an identity, and the role of culture in viewing Autism. The related theories and concepts emanating from this will be described in this chapter.

In the first part of this chapter, neurodiversity will be described firstly as a discourse in understanding and framing Autism as a distinctive culture. Neurodiversity challenges the previous perspective of looking at Autism as a solely neurological disorder, to view Autism beyond the medical frame, which will be explained further in this chapter. This brings us to what constitutes as normal, or “normate” – the term Rosemarie Garland-Thomson refers to as a constructed identity of a human being who can possess certain authorities and power with their bodily configurations and cultural capital (Garland-Thomson, 2007). Garland-Thomson argues that the standards for viewing certain bodies as disabled or “deviant” are varied among different cultures. This chapter will address critical disability studies and critical Autism studies, as both approaches recognise culture as one of the critical aspects in understanding disability. Both approaches were applied to this thesis as the objective of my study is to provide understanding about Autism as a socially constructed idea, influenced by cultural practices and social conditions in Indonesia.

The last concept I will explain in this chapter is the critical role of digital technology. The internet and social media have enabled people with disabilities, including Autism to articulate their own voice, and facilitate Autistic communities to encourage advocacy and awareness of Autism. Debates surrounding the inequality and technological functionality, or the “digital divide” were evidenced from previous

studies about the potential use of the internet and social media for Autistics, will be highlighted in the latter part of this chapter.

2.2. The concept of Neurodiversity and its surrounding controversy

Neurodiversity, according to sociologist Judy Singer, who first used the term in her honours thesis in 1996, represents the politics of diversity, in which she argues that having Autism or being “neurologically different” is similar to other diverse human differences such as gender, race and sexuality (Ortega & Choudhury, 2011). Since then, the idea of interpreting Autism and other neurological impairment as just one of the differences in the human population became globally popular across the internet (Jaarsma & Wellin, 2012). As previously stated in the introduction chapter, the neurodiversity movement also marked the shift in viewing ‘Autism-as-disorder’ which is rooted in a biogenetic approach and medical model of disability, to ‘Autism-as-difference’ narrative which resonates more with the social model of disability. The medical model puts more emphasis on diagnosis and treatment using scientifically validated manuals and protocols such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) which is used as a guide for Autism diagnosis. This marked the emergence of developing and building institutions and the provision of care for disabled people, dissociating them from the society (Krcek, 2013). However, in the 1980s, the social model of disability emerged as a contrasting view to the medical model. This suggests reconstructing disability as a social and political process that the responsibility for “labeling, causing and maintaining disability” should come from society itself (Krcek, 2013). This model makes the important distinction between an individual’s impairment, in terms of biological impairment, and disability, which is society’s lack of accommodation of the impairment. An individual can, therefore, be considered ‘disabled’ because of a lack of accommodation of his or her difference within society. Disability is not seen as an individual attribute but something created through social exchanges and social practices. While the social model of disability was initially conceived of with reference to people with physical impairments, there were later applications of the model to people with intellectual and sensory impairments (Brownlow, 2010).

The more recent notion of neurodiversity offers another, alternative, representation of Autism which seeks to present Autism as a difference rather than a deficit. Such a representation has common links with wider disability literature such as the social model. However, a controversy exists surrounding the concept of neurodiversity, which is still open to debate⁴. Quoting from one of the pro neurodiversity websites, neurodiversity is defined as “the whole of human mental or psychological neurological structures or behaviors, seen as not necessarily problematic, but as alternate, acceptable forms of human biology” (Wolbring, 2007, in Jaarsma & Wellin, 2012). In this broad context of neurodiversity, it can be seen that the movement is aiming for “neuro-equality”, meaning to have equal opportunities, treatment and regard for those who are neurologically different (Fenton & Krahn, 2007). Furthermore, the term neurodiversity emphasises the inclusion aspect for people with neurological disabilities based on universal rights principles (Kapp, 2020). For example, the neurodiversity supporters’ aims are to have full inclusion for basic needs such as education, employment and housing, and to acquire “the right to make one’s own decisions with support as needed” (Kapp, 2020).

Whereas the narrow view on neurodiversity suggested by Baker (2006) is setting a different term between Autism and other neurological differences, in which the former is called neurodiversity and the latter is neurological disability, thus limiting the neurodiversity concept specifically to Autism (Jaarsma & Wellin, 2012). In a newly published book *Autistic Community and the Neurodiversity Movement* (2020), Steven Kapp, the editor of the book who is both an Autism scholar and Autistic neurodiversity activist, states briefly: “Like the far-reaching concept of diversity, the neurodiversity movement as applied to Autism functions inclusively, in that activists include non-Autistic people as allies, and it accepts and fights for the full developmental spectrum of Autistic people (including those with intellectual disability and no or minimal language)” (Kapp, 2020). In this thesis, I will use the term ‘neurodiversity’ to refer specifically to Autism, as the objective of my study is to provide an understanding of

⁴ For example, the various definitions of neurodiversity could be categorised into narrow and broad concepts (Jaarsma & Wellin, 2012). The broad sense concept of neurodiversity constitutes anyone diagnosed with neurological or neurodevelopmental disorders (such as Autism, ADHD, bipolar disorder, developmental dyspraxia, dyslexia, epilepsy, and Tourette’s syndrome) as a normal human difference, not handicapped or pathological (Griffin and Pollak, 2009 in Jaarsma & Wellin, 2012).

how Autism is communicated by means of social media among Autistic people in Indonesia.

Silverman (2008) calls Autism a “contested category”, particularly referring to the controversies surrounding its aetiology, diagnosis and also treatment strategies, all of which can be aversive to the Autism advocacy movement focusing on acceptance of human differences. Following on the different construction between the medical and the social model regarding disability, there is still an ongoing debate surrounding the issue in the Autism advocacy (neurodiversity) movement. Most of the neurodiversity advocates oppose ‘abusive’ treatments, such as overmedication to control behaviour, physical restraint and other interventions that focus on normalisation such as Applied Behaviour Analysis (ABA) (Kapp, 2020; Runswick-Cole, 2014). While the neurodiversity movement’s philosophy seems to oppose many parents’ options to seek behavioural therapies, there is an argument that such ‘interventions’ (e.g. ABA) could hold a role as ‘prosaic technology’ used by parents to support their children for reaching their neurodiverse ends, for example as an artificial platform and tool to support people with Autism to interact with other people (Hart, 2014). Hart borrows the term “making up people” and “looping effect” from Ian Hacking’s theories (2009) to explain how behaviour therapies and everyday practices by parents and therapists can serve as a translation process to make the neurotypical settings more familiar to Autistic – or neurodiverse – children. Drawing from both Hart’s and Hacking’s arguments, behavioural therapies and everyday parenting practices can be seen as translation processes to incite the looping effect for Autistic people, again borrowing Hacking’s term, “to reclaim their identity”. Moreover, neurodiversity advocates largely support interventions that promote well-being and adaptive functioning such as the use of alternative communication systems other than speech (Runswick-Cole, 2014).

According to Hacking (2009), people who possess similar characteristics as Autistics can be found throughout history, but they have not been acknowledged as one until further knowledge is developed. This stage, which Hacking called the looping effect, refers to a situation that, once the classification or category is made (e.g. the Autism spectrum), the knowledge and social practices surrounding the issue will emerge (Hart, 2014). As part of this looping effect, research in social sciences and humanities has

been starting to explore the role of neurological vocabulary in the construction of identities (Ortega & Choudhury, 2011). Silverman (2008) explores the ongoing research on Autism in social studies, which she categorises into four central themes – Autistic cultures, theorising treatment, Autism and subjectivity, and social movements (Cascio, 2015, p. 208).

In a more recent publication, *Re-thinking Autism* (2016), Runswick-Cole states that the neurodiversity movement was once considered an attractive idea because it “offers confirmation and a political identity that allows people to celebrate their sense of self” (Runswick-Cole et.al., 2016, p. 24). On the contrary, the movement itself also has two sides of the coin – creating a powerful connection between the people on the spectrum which can offer an echo chamber of being in the same boat, yet, on the contrary, acknowledging an element of risk in this connection in order to create an “Autism bubble” (Guest, 2019). Guest (2019) addresses this concern as there is a tendency for Autistic self-advocates to become ‘trapped’ in their own communities and became resistant to other opinions.

To sum up the debate surrounding neurodiversity issue, Autistic self-advocate Den Houting (2019) states the three common criticisms of the neurodiversity paradigm. Firstly, the claim that the neurodiversity paradigm limits its framing to view Autism “as a difference and a cultural identity, but not a disability”. Secondly, the state of neurodiversity identity arguably can only be applied to high functioning Autistic people, Autistics with lower support needs. Thirdly, the implication of the neurodiversity paradigm as one that views Autistic people as those who do not require support, as Autism is framed as “just a natural variation” (Den Houting, 2019). In her response to this criticism, Houting considers Autism to be both a natural variation and a disability. That said, Autistic advocates are continuously striving for acceptance and inclusion, while also seeking appropriate support and services for the Autistic community (Den Houting, 2019). In accordance with the previous arguments, Orsini (2012) proposes the idea of “interdependence” to navigate these two seemingly polarised perspectives of Autism: Autism as a debilitating disability and Autism as a neurological difference. He argues that it is important to appreciate the diversity of the Autistic presence, particularly in the context of their citizenship, as “some of them require assistance in their daily lives, while others might require forms of

accommodation that complement, rather than replace, their status as full persons” (Orsini, 2012).

2.3. Critical disability studies

Over the last three decades, the field of interdisciplinary disability studies has emanated largely in Anglo-American traditions, particularly in countries such as the United Kingdom (UK) and the United States (US) (Shakespeare, 1998; Staples & Mehrotra, 2016). Prior to that, disability had been approached from a clinical perspective in applied health sciences, as well as in social sciences such as sociology (as in the study of deviance), medical anthropology and psychology (in the study of abnormalities) (Garland-Thomson, 2013). In its development, more critical approaches were applied when studying disability from social theories, where disabled people are viewed as an element of society who are historically oppressed and where disability is seen as “a social construction and a set of cultural products” (Garland-Thomson, 2013).

The first wave of disability studies started around the criticism of the medical model by taking the non-deficit approach beyond the clinical framing. Kafer (2013) defines the medical model of disability as a framework in which atypical bodies and minds are viewed as “deviant, pathological and defective, best understood and addressed in medical terms” (p. 5). Thus, within this framework, the proper approach to disability is to “‘treat’ the condition and the person with the condition rather than ‘treating’ the social processes and policies that constrict disabled people’s lives” (Kafer, 2013, p. 5). In short, Kafer points out that the medical model build up “a timeline that can only lead to cure or failure” (Eve, 2014). Goggin and Newell (2000) state that some writers in the disability area took note that the medical discourse on disability “ignores the social construction and distribution of impairment” (p. 21). As a result, some notable scholars, such as Mike Oliver, Colin Barnes and Vic Finkelstein, instead propose the materialist social model theories and based their works on neo-Marxist and Gramscian theories (Goodley, 2013). The term ‘materialist’ here refers to material barriers to work, upon which these barriers act as a social disadvantage that excludes disabled people from participating fully in social and political contexts (Goodley, 2013).

As previously proposed in the works of some British writers – mainly based on their personal experience as most of them are disabled people themselves (Barnes in Shakespeare, 1998) – the social model of disability differentiates between disability and impairment (Ellis & Kent, 2011). Driven largely by disability activism since the 1960s and 1970s, the social model of disability has the impact of developing a disability collective consciousness and strengthening disabled people’s movements. This made way for the politics of disability as a minority group activity (Oliver, 2013; Oliver & Zarb, 1989).

In contrast, some scholars emphasise debates regarding the relevancy of the social model of disability to learning difficulties and Autism, as there was a divide between people with physical and sensory impairments, and those with learning difficulties (Brownlow & O'Dell, 2006; Chappell et al., 2001). Drawing from their study in the areas of disability studies and inclusive education, Goodley and Runswick-Cole (2010) discuss the possibility to look beyond the social model of disability and pay more attention to the non-material conditions of exclusion within society and culture. Thus, they argue for more theoretical ideas regarding the intersection of various studies – queer, postcolonial, feminist and disability studies – to identify exclusion practices in children’s education (Goodley & Runswick-Cole, 2010). From feminist and queer studies, Kafer (2013) also identifies problems with the social model, “which risks ignoring the lived realities of pain until ‘cure becomes the future no self-respecting disability activist or scholar wants’” (p. 7) (Eve, 2014; Kafer, 2013). From postcolonial studies, Meekosha and Shuttleworth (2009) state some factors that influenced the re-evaluation of explanatory paradigms in disability studies which eventually lead to the development of CDS. Firstly, considering the social model argues for a distinction between impairment (as a functional limitation) and disability (as a form of discrimination created by the system in society), using the term CDS is a “move away” from the domination of binary understandings within the paradigms (Meekosha & Shuttleworth, 2016). Secondly, the influence of a postmodernist approach and decentring of subjectivity in humanities and cultural studies opens a way for more critical theorising in disability studies. For example, new perspectives in engagement between disability studies and other areas have emerged – including psychological and psychoanalytic which previously have been denounced – to support the individual model of disability (Meekosha & Shuttleworth, 2016). Thirdly, CDS represents a

distancing from the language of disability studies by government institutions and some applied disciplines in higher education institutions (e.g. rehabilitation and special education) which still emphasise normalising ends (Meekosha & Shuttleworth, 2016).

Furthermore, as the development of disability studies expands to be more interdisciplinary in the 2000s, the scholars in this area acknowledge the needs of understanding disability from across disciplinary boundaries such as law, history, bioethics, art and culture to name a few (Garland-Thomson, 2013). This opens a way for the second wave of disability studies which lies more on the cultural work of disability and reflects a criticism towards the dominance of the material condition of disablement (Goodley, 2013). Garland-Thomson (2013) sums up the purpose of CDS as to correct and expand the way that health sciences frame disability. Furthermore, she states that the signature move of CDS is “to consider it a civil and human rights issue, a minority identity, a sociological formation, a historical community, a diversity group, and a category of critical analysis in culture and the arts” (Garland-Thomson, 2013, p. 4).

The cultural context is one of the critical points in CDS, as notable scholars such as Ghai (2012) and Meekosha (2008) challenge the dominant perspective of Anglophone countries in disability studies by bringing up different cultural perspectives from the Global South. It is important to note that the large majority of disabled people – estimated at 80 per cent – live in the Global South (Connell, 2011). However, some disability writers from the South tend to engage in a kind of self-censorship and have difficulties to apply Western concepts in their works because of, presumably, some aspects such as the impact of their historical situation (Meekosha, 2008). The social model has its own challenges to be applied in post-colonial societies, particularly where colonial forms of power still remain, or in a particular situation such as the interrelation between poverty and disability (Rembis, 2016). Disability is therefore visibly multifaceted in the global context (Goggin & Newell, 2000), thus it is important to theorise disability as an “idea that must be framed and understood in context” as emphasised by Shaun Grech in his book, *Disability and poverty in the Global South* (Rembis, 2016). As an example, Grech points out the wide gap between “rhetoric and action” relating to how conventions on human rights, such as the UNCRPD, has little relevancy in providing suitable support in countries with extreme poverty conditions

such as Guatemala (Rembis, 2016). Referring to Indonesia, similar situations happened previously as people with disability is largely related with the deficit model⁵. For decades, being disabled in Indonesia was seen as an impediment (Dibley & Tsaputra, 2019). People with disabilities are seen as being highly dependent and as the objects of pity. Due to their impairments, the best support is to focus on rehabilitation to ‘fix’ their impairments or through giving funds as a form of charity (Dibley & Tsaputra, 2019).

The deficit model opposes the spirit of a more progressive approach in the social model of disability in Law No. 19 of 2011 (on the ratification of the UNCRPD) in Indonesia⁶. By enacting this law, the Indonesian government has already made strong commitments to improving the wellbeing of person with disabilities, claiming equal rights and opportunities for them in all aspects of life (Adioetomo et al., 2014, p.3). However, the global change towards the social model of disability has slowly started to influence disability activism in Indonesia – which has shifted from welfare to rights (Dibley & Tsaputra, 2019).

It is therefore important to explore local discourses and practices in CDS as it is impossible to homogenise and standardise disability due to differences in its definition and other aspects in cultural contexts (Grech & Soldatic, 2016; Rembis, 2016). For example, traditional cultural beliefs – such as appropriate behaviour during pregnancy, karma and also religious beliefs – are likely contributing to parents’ understanding of Autism and their parenting practices in Indonesia (Hersinta, 2012; Riany et al., 2016). It is also worthy to note that there is another aspect of cultural relations surrounding the politics of neurodiversity which largely emerge from the internet (Meekosha, 2003). In this case, the internet provides a space for people on the spectrum, particularly those with Asperger’s syndrome, to socialise and communicate, to build a community and develop their own culture. From her study on Autistic culture online,

⁵ The deficit model – often combined with or referred to as the medical model – emphasises on the ‘deficiencies’ and the intrinsic flaws of the person with disabilities; rather than consider their strengths and abilities or the environmental factors that constrain them (Inckle, 2019).

⁶ On 30 March 2007, Indonesia ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Adioetomo, et al., 2014). By ratifying the UNCRPD, it means that person with disability, including Autistics, should be viewed as “people who have a right to live in a society that does not erect barriers to their participation based on their functional status” (Adioetomo et al., 2014).

Davidson (2008) observed how the internet is used by Autistic people to connect with “similar Others”, creating “a sense of belonging to a particular cultural group” (Davidson, 2008a).

Interestingly, disability studies also opens the opportunity for scholars to develop a critical perspective through the lived experience of disability, oftentimes via the presence of disability in themselves or in the family (Garland-Thomson, 2013). To give an example, in his essay, Reaume (2014) is drawn to experiences by his maternal grandfather who was traumatised by war in order to emphasise the objective of CDS, “... to reinterpret what it means to be considered disabled, bringing people who live this experience to the process as the primary agents of change in word and deed” (Reaume, 2014, p. 1249). Another example is Joseph Straus, the author of *Extraordinary measures: Disability in music*, who discovered his way to explore the intersection between disability studies and his discipline when he was on a train reading a book about Autism; he has an Autistic son. At that time, he came across another scholar who asked him if he was interested in disability studies (Garland-Thomson, 2013).

Another example of a critical perspective through the lived experience of disability was given by Maija Nadesan who describes her intense interest with Autism in the introduction of her book *Constructing Autism* (2005). As a mother of an Autistic son, she developed a great interest in Autism topic, and found that many Autism references are medically and scientifically based, including narratives in autobiographies written by parents of Autistic children. Many of those autobiographies represent Autism as a “biologically based psychiatric condition that has to be therapied, remedied, assaulted in an effort to ‘save’ afflicted children locked inside an Autistic cage” (Nadesan, 2005, p. 2). She realised that there was a gap in the existing literature on Autism, and she started to view Autism, or particularly the idea of Autism, as socially constructed (Nadesan, 2005); this is an important point that I will return to later. Such engagement, between Autistics and non-Autistics, supposed to bring critical perspectives on Autism in scholarly works, resulted in, borrowing the term from Mark Osteen, “empathetic scholarship” (Davidson & Orsini, 2013; Osteen, 2007). This kind of scholarship refers to empathy or “eudaimonistic kinship” that is also addressed the inclusion and accommodation of Autistic difference and personhood (Davidson & Orsini, 2013; M.

Osteen, 2007) which is part of a more particular, developing division in disability studies called critical Autism studies (CAS).

2.4. Critical Autism studies and the social construction of Autism

Critical disability studies resonates with the Autistic community, the idea that Autism is also socially constructed – Nadesan (2005) refers to the role of social conditions and practices as the “production, interpretation and remediation of Autism” while not rejecting the biological basis for the condition (Nadesan, 2005, p. 2). Previously, the dominant constructions of Autism were pathological, based largely on a medical model of understanding disability (O’Dell et al., 2016). In the medical model, Autism is viewed as having a condition that is pathological, in which “a diagnosis and cure should be sought” (Krcek, 2013). Later, the neurodiversity movement challenged this dominant view from its roots from the social model of disability, by claiming that autism is a variation among humans; not a disease or disorder, just a difference (Jaarsma & Welin 2012, Runswick-Cole 2013, Krcek 2013). That said, most advocates within the neurodiversity movement are proponents of the social model of disability, as this model describes well the experiences of many Autistic people (Den Houting, 2019).

However, it is worthy to note that the history of Autism cannot be separated from its pathological or biological basis. Referring to Hacking’s argument of making up people, Nadesan (2005) argues that “the idea of Autism could not have emerged as a distinct disorder because within the diagnostic categories of 19th century (and earlier) thought, Autism was unthinkable” (p. 3). The idea of understanding Autism as a spectrum of difference – one that goes beyond the deficit narratives of Autism – has driven some scholars in this area to start developing the field of CAS. The term was first coined in 2010 in Davidson and Orsini’s work on Autism and neurodiversity and was later explored in their co-edited volume *Worlds of Autism* (2013). These scholars argue that a medical approach is not the only way of thinking and researching Autism (O’Dell et al., 2016). CAS is complementary to CDS, focusing mainly on Autism issues and recognising Autism as both “a diagnostic category and lived experience that shifts through different cultural contexts” (O’Dell et al., 2016, p. 170).

Referring again to the idea that Autism is socially constructed, CAS scholars emphasise the importance of an interdisciplinary approach in understanding how culture and lived experiences of Autistics contributes to certain interpretations of Autism (O'dell et al., 2016; Woods et al., 2018). This is in accordance with Siebers' argument (2016) about the theory of complex embodiment – as a socially constructed identity, disability should be located in a specific time and place and a complex form of embodiment (Siebers, 2016). According to Siebers, both the effects of a disabling environment – the representations of body – and the lived experience of the body mutually transform each other. That is, how people think of a body is informed by the lived experience and, conversely, how people live with the body is informed by the social prejudices and ideologies that represent the body (Siebers, 2016).

To sum up, Davidson and Orsini (2013) highlight the three main aspects of a critical approach in studying Autism – exploring power relationships that construct Autism, enabling narratives that challenge the dominant negative medical Autism discourse, and developing theoretical and methodological approaches that are emancipatory and inclusive, and which value the highly individual nature of Autism and the complexity of the (dis)order (Davidson & Orsini, 2013; Woods et al., 2018). This thesis will address these three aspects in later chapters, by focusing on Indonesian Autistic voice that makes its presence on social media. Furthermore, the Autistic voice is considered an important factor in the emerging field of CAS, and led to the birth of the Autistic-led journal *Autonomy, the Critical Journal of Interdisciplinary Autism Studies* in 2011 (Woods et al., 2018). Mitzi Waltz (2014) asserts the critical aspect in CAS' working definition, "The 'criticality' comes from investigating power dynamics that operate in discourses around Autism, questioning deficit-based definitions of Autism, and being willing to consider the ways in which biology and culture intersect to produce 'disability'" (Waltz, 2014, p. 1337).

Thus it is also important to note that CAS acknowledge that different perspectives on Autism and cognitive normalcy arise in different cultural contexts which, in the end, will lead to the production and legitimation of different knowledge about Autism (O'Dell et al., 2016). However, the literature of social science on Autism in English language still focuses greatly on Anglophone countries such as the United States, Canada, United Kingdom, Australia and also Sweden, whereas published research

from other countries, particularly from the Global South and developing countries, is still very few in number (Cascio, 2015; O'Dell et al., 2016). Currently, Southern perspectives are emerging in social studies and humanities, and are therefore considered as an important resource for disability studies (Connell, 2011). The critical role of cultural contexts – which hold a great influence on how Autism is perceived, valued, understood and socially constructed across different nations – will therefore be an important feature of this thesis.

In 2015, a special issue of *Culture, Medicine and Psychiatry* highlighted the theme of conceptualising Autism around the globe by including papers describing experiences of Autism conceptualisation in Brazil, India, Italy and the United States, with an aim to fill the growing need of broader cross-cultural Autism literature (Cascio, 2015). The same issue provides various contexts in viewing Autism, such as at the level of national policy, within the home, and surrounding the health interventions and practices in different cultural settings. Furthermore, the cultural aspect was addressed not only in regard to geographical context but also in the marked and distinct culture within Autistic individuals (Cascio, 2015). Davidson (2008) investigates how Autistics use the internet to connect with “similar Others”, wherein that space they can get social support as well as organise and advocate “for recognition of Autistic cultural difference” (Davidson, 2008a, p. 791). Thus, the internet becomes a medium for the Autistics to reach out to others and share their points of view, and to communicate the meaning of Autism from a first-hand experience (Neil, 2008).

This also raises the question in this thesis – how Autism is interpreted in different cultures, such as Indonesia, where there are cases in which the internet plays a critical role in catalysing new expression among Autistic adults. In Indonesia, there are 171 million internet users out of 264 million Indonesian citizens (“Indonesia has 171 million internet users: Study,” 2019). With an estimated 23% of the population being people with disabilities, there is a growing network of NGOs and community-based organisations that are working on disability rights (Bexley, 2015). Currently, they have started to increase their presence in social media. The following part will address the development of the internet and social media – and the impacts of online communication platforms for people with disability – before moving to the final part of this chapter about the potential use of the internet and social media for Autistics.

2.5. The internet, social media, and disability

The internet emerged in the 1960s, and has been associated with the Advanced Research Projects Agency Network (ARPANET) which was established in the United States at that time (Edwin & Ross, 2017; Tsatsou, 2014). The word internet – the abbreviation for inter-networking – was introduced in 1974 and refers to the fact that it constitutes a “network of networks”, each with their own design and unique structure (Tsatsou, 2014). Further development of the internet was led by the open-source movement in the 1980s which worked on more democratic development and the use of digital communication networks (Tsatsou, 2014). In 1989, the development of hypertext language and the release of the World Wide Web by Tim Berners-Lee and the European Organisation for Nuclear Research (CERN) in Geneva marked the next milestone for further development of the internet (Tsatsou, 2014). By the end of the 1990s, social networking sites⁷ (SNS) started to emerge as one of the most popular forms of web-based services for enabling connection among its users, with some of the earlier examples of SNS being Friendster (2002), MySpace (2003), and Facebook and YouTube (2005) (boyd & Ellison, 2007).

Boyd and Ellison (2007) define SNS as “web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system” (boyd & Ellison, 2007) (p. 211). Based on this definition, Albarran (2013) defines social media as “the technologies or applications that people use in developing and maintaining their social networking sites” (p. 2), which involves the posting of multimedia information, location-based services, gaming and others (Albarran, 2013). Basically, social media was developed for connecting people – either connecting between friends, or connecting people with the same interests to form a community (Albarran, 2013).

The advancement of social media platforms currently has many impacts in various aspects of people’s lives. Social media has become an essential part of daily lives, with people spending more time to access it. Scholars have started to explore various areas

⁷ Baym (2011) states that Boyd and Ellison (2007) prefer to use the term “social network sites” to “social networking sites” to emphasise the use of these sites for “replicating connections that already exist offline than to build new one” (Consalvo & Ess, 2011) (p. 386).

in social media research; developing definitions, investigating its impacts, and discovering communication patterns and preferences related to social media use (Albarran, 2013; Khang et al., 2012). Online communities and forums, blogs, SNS, and instant messaging platforms were the most frequently researched social media types in communication journals during the years 1997–2010 (Khang et al., 2012). Haller (2015) states that social media such as Facebook, YouTube and Twitter are simple to use; with pre-set templates and shorter text, people can easily present themselves online. As such, visual communication now becomes more important than textual communication (Miller et al., 2016); for example, YouTube is utilised by the D/deaf community to show their creative endeavours and to communicate with others in the D/deaf community by posting their own videos in sign language (Haller, 2010). Alper and Haller (2017) show that Pinterest, an image-based social media platform, can be used by people with aphasia – a communication disability that comes from a stroke or traumatic brain injury – for conversation prompts by using the photos in that platform to communicate (Ellis & Kent, 2017). Other social media such as Facebook and Twitter also offer a way for disability activists to organise disability rights actions and to promote disability events to a larger audience (Haller, 2010). This example illustrates what Finkelstein (1980) proposed as “technological empowerment” which refers to the benefits of communication and assistive technologies for people with disabilities by enabling access that eliminates preceding barriers (Roy & Lewthwaite, 2016).

However, accessibility issues for people with disability in using social media remain (Haller, 2015). For people with disability, technology such as mobile phone and the internet can be liberating, but on the contrary they also have the potential for controlling in certain aspects (Goggin & Newell, 2000). For example, a lack of accessible websites can be excluding for people with disabilities, making them as the “other” (Goggin & Newell, 2000). Until early 2010, most YouTube videos did not have captions, thus blocking D/deaf people from accessing any content that requires hearing⁸ (Haller, 2010). Despite accessibility issues, social media also has ownership

⁸ In July 2020, YouTube announced they will discontinue their community caption feature starting on 28 September 2020 (YouTubeHelp, 2020). While YouTube creators can still use their own captions, automatic captions or third-party tools and services, they can no longer use community transcriptions or translations to use on their videos. This creates a number of protests from Deaf and hard of hearing creators.

issues. Goggin and Newell (2000) argue that technology is supposed to be inclusive and accessible but, in reality, technology is still controlled by the majority or dominant group. For example, SNS such as Facebook have been criticised for commodifying people's friendship networks by using this network as business opportunity (Ellis & Kent, 2011).

Goggin and Newell (2003) also investigate the possibility of how disability is socially constructed in new media (Roy & Lewthwaite, 2016). The gap between disability and ability is consistently ingrained in technological networks as technical barriers can exclude some of the disabled users in participating in mainstream interactions (Goggin & Newell, 2005; Ellis & Kent, 2011). Beyond ownership and access and the technical divide, Roy and Lewthwaite (2016) also address another digital divide, that of a social divide which is produced in social media such as Facebook. For example, powerful normative social pressures could emanate from peer surveillance in those online networks (Roy & Lewthwaite, 2016). It is possible that, in such situations, disability can be seen as "extra visible", with the risk of "exposing disabled people to negative public scrutiny" (Roy & Lewthwaite, 2016, p. 492). Thus, in consideration of discussing technology to be beneficial for people with disability, Goggin and Newell (2005) propose that the discussion should consider two aspects (Ellis, 2017). The first one is the critical role of technology in assisting people with disability, while the second is how technology can influence "the way disability is conceived, experienced and framed in society" (Goggin & Newell, 2005; Ellis, 2017).

2.6. The potential use of the internet and social media for Autistics

Verlanger states that people with disability are often the earliest adopters of new technologies (Ellis, 2017). One the example is Mel Baggs (then Amanda), an Autistic female who presented her disability in "a radically different way, beyond the deficit and super cripple stereotypes" via her 2007 YouTube video, *In my language* (Ellis, 2017). By presenting her unique means of expression, Baggs "advocates for the agency and power of Autistic people, particularly non-speaking people, who are often excluded from mainstream disability narratives" (Fritsch, 2019). In that case, both the internet and social media are viewed as a medium and a way to lessen the boundaries of Autism's "triad of impairments" – communication, interaction and imagination (Frith, 2008; Pinchevski & Peters, 2015). Thus, the internet "was the *conditio sine qua*

non for the Autistic community, a medium that opened up new opportunities for exchange while freeing them from the ambiguity and sensory overload of the face-to-face” (Pinchevski & Peters, 2015, p. 11). The significant connection between the internet and Autistics is expressed clearly in Judy Singer’s popular claim about how the internet’s impact on Autistics is similar to the spread of sign language’s impact to the D/deaf (Davidson & Orsini, 2013). Communicating via the internet provides a shared language for Autistics, or borrowing Hacking’s argument: “the Internet helps people with ASD communicate more like neurologically typicals” (Pinchevski & Peters, 2015, p. 12).

However, the digital divide is also found within the story of Autistics and the use of technology. Pinchevski and Peters (2015) assert that pathology has its own risk of political economy, which refers to a class distinction within the Autism spectrum, namely the classification into “high- and low-functioning” Autism (Pinchevski & Peters, 2015). However, this distinction is arguable, as some previous research and literature found that Autistics who were considered non-verbal or having limited speech – classified as “low functioning” – could achieve a high score on the non-verbal assessment of intelligence and could communicate through digital technologies (Neil, 2008; Pinchevski & Peters, 2015). Nevertheless, the idea of functionality also requires solution, as those who are on the “higher function” end of the spectrum such as Asperger’s syndrome perhaps also have adequate or more cultural capital to compete with other neurotypicals compared to Autistics at the opposite side of the spectrum (Pinchevski & Peters, 2015). Houting (2019) admits that the voice of Autistic people with the highest support needs is considered a minority within the advocacy community, albeit being some of the most influential voices. Consequently, more accessibility, opportunities and support are needed for Autistic people with the highest support needs in order for their voices to be heard (Den Houting, 2019).

Castells argues that the internet provides the networking to establish new social processes and to create new communities based on similar interests and emerging identities which can lead to some kind of “new tribalism” or, in Ian Hacking’s term, “making up” people (Castells, 2000; Kirmayer et al., 2013). These online communities were started from various discussions – the internet users who exchange information, news, sharing their creative projects or personal stories to initiate protests or

movements (Kirmayer et al., 2013). In such cases, the previously isolated individuals can have different understandings about themselves once they communicate with other people experiencing similar conditions (Kirmayer et al., 2013). As stated by Kirmayer et al. (2013): “That certain experiences, affective states, and beliefs may be reinforced or amplified, both through the social ‘looping effects’ associated with identification and sociality, and through the triggering of embodied responses to certain images and ideas” (p.175-176).

In their study about the importance of the internet for people on the Autism spectrum, Davidson and Orsini (2013) address on how online experiences can make Autistics feel more understood, empowered and connected with each other. Based on their participants’ responses, the internet is not only providing a “safer” space for people who have difficulties in sensorial and emotional process in offline social interaction, but also serves as the training ground for developing skills to interact in the real world (Davidson & Orsini, 2013). Furthermore, the social media landscape develops very rapidly with specific features and forms for certain purposes; for example, Second Life provides many virtual sites for Autistic communities such as the Autistic Liberation Front (ALF), the Autism Awareness Center and Naughty Auties (Danilovic, 2009). Through its virtual world, Second Life provides new forms of social networking that allows its user to create a new ‘virtual’ selves that can surpass some of the physical and social boundaries usually found in one’s identity and community (Danilovic, 2009). In this regard, for Autistics and their use of the internet, the digital network is “transforming human functioning, personhood, and identity by providing new modes of social presentation and positioning, new media for expression, and new ways of narrating the self” (Kirmayer et al., 2013, p. 167).

2.7. Conclusion

This chapter has discussed a number of critical concepts that will provide as a framework throughout this thesis: the neurodiversity concept, the critical disability studies and critical Autism studies, and the internet and social media which provide digital affordances for Autistics to communicate, create self-narratives and build network among peers.

To conclude this chapter, I quote Grech and Soldatic's arguments (2006) about the importance of listening and learning from the voices and perspectives of disabled and marginalized people – as well as articulating their voices – from certain context without inferring or generalizing. This idea of listening in disability could play an important role in understanding the “power relations” between the disabled and non-disabled (Goggin, 2009). The new modes of listening through convergent media such as blogs and other digital media are considered to have potential in creating new kinds of public spheres (Goggin, 2009). In this study, I emphasise these new modes of listening to seek contribution of theoretical findings, particularly for understanding the power relationships that construct Autism in Indonesia and to gain understanding about the diversity of Autistic presence in that country.

Hence, this study includes the voices of various stakeholders in the discussion part later of this thesis. Starting from chapter 7 I will address the majority and minority voices drawn from the public conversation about Autism on Indonesian Twitter. Both of these voices will be discussed in details later in chapter 8 (the voice of the parents) and 9 (the voice of the Autistics). By employing this I intend to provide a critical analysis of how online space can transform Autistic's personhood and identities in Indonesia – from investigating how Autism and Autistics are represented on Indonesian Twitter (in chapter 7) to discussing how Autistic personhood emerges in these spaces (in chapter 9).

But, beforehand, in the next chapter I will explain the selected methods and data collection procedures that will be used in this thesis. As mentioned briefly in the introduction chapter, I employ a case study research supported by dual methodologies; by doing content analysis from Twitter messages and conducting interviews from Autistics and non-autistics. The method of Grounded Theory will be applied to contextualise the different data and multiple constructions during the research process. A further and more thorough discussion over the methodologies will be found in the following chapter.

Chapter 3. Methodology

3.1. Chosen research strategies

3.1.1. Case studies as a research strategy

This chapter will give more description about the selected methods that will be used throughout this study. As outlined in Chapter 1, this study aims to provide an analysis of Indonesian Autistic personhood in social media and their practice of using social media as a means of self-narrative and self-advocacy. In doing so, I use critical disability studies and critical Autism studies as the theoretical approaches for the overall research project. Consequently, research in critical Autism studies – which mainly comes from the social sciences and humanities – calls for sensitivity in order to provide an understanding of the complexity of the Autism spectrum (Orsini & Davidson, 2013). As discussed in the previous chapter, to study the nature and culture of Autism within the critical Autism approach requires inclusive and non-reductive methodological approaches. Taking off from that point, I apply case studies with a qualitative approach, as they offer the ability to deal with various sources of evidence such as documents, artefacts, interviews and observations (Yin, 2009).

Stake (2003) argues that, despite a methodological choice, a case study is “a choice of what is to be studied” (Denzin & Lincoln, 2008). Historically, the case study approach emerged from the need to understand complex social phenomena, thus it has mostly been chosen as a research strategy to answer the ‘how’ or ‘why’ questions, and “allows investigators to retain the holistic and meaningful characteristics of real-life events” (Yin, 2009; Kolbacher, 2006). It is worth noting that the objective of the case study is not to represent a sample or make a statistical generalisation, but to generalise theories or make an analytical generalisation while focusing on the process of social context (Hartley, 2004; Kohlbacher, 2006). As this study is aiming to provide an in-depth understanding of the narrative of Autism being discussed in Indonesian social media, I decided to apply the case study approach as I expect to discover certain patterns and linkages to theory. Moreover, I also apply an inductive analysis for generalising theoretical propositions in this study.

Daymon and Holloway (2011) suggest that the theoretical concepts generated from case studies can be verified in other settings in future studies, using either qualitative or quantitative research (Daymon, 2011). In this thesis, the case studies were five Autistic people using social media in Indonesia, with an aim to understand and communicate findings about their identities. The decision to include five cases is to provide in-depth and various portrayals of each Autistic in their practice of using social media in order to understand their identities when conducting self-advocacy. By doing so, I intend to ‘give voice’ to the Autistics who are involved in this study, rather than to use them solely as respondents or informants; this also follows the application of a critical approach in Autism studies.

To select the cases in this study, I applied a particular stage for selecting a candidate case, firstly by observing Twitter accounts and content related to Autism in the Indonesian context. This selection process was also applied to conduct the first stage of my analysis in this study – to investigate the dominant frame of Autism conversation on Twitter through a content analysis method. Twitter was chosen because of its popularity in Indonesia; the country has been ranked in the top five of the largest Twitter users since 2010 (Carley et al., 2016; Lim, 2013). The content analysis method will provide the answer to the preliminary research question of this study – to further explore the public’s understanding and discussion about Autism in Indonesia. That said, the first stage of data collection and analysis in my study will provide a general overview of how Autism is understood and perceived in Indonesia, while also locating Autistics’ accounts and content on Twitter. Further explanations about the content analysis procedure and data collection will be explained in more detail in chapter 6 while the data collection will be described further in the final part of this chapter.

As mentioned in chapter 1, there is a lack of previous studies related to Autism and social media topics in the Indonesian context, particularly from critical disability studies, and therefore most of the theoretical concepts in this study were taken from previous research in non-Indonesian contexts; these include critical disability studies, critical Autism studies and the social construction of Autism. In the analysis and discussion parts of this thesis, the findings will be linked to the wider, global literature of those aforementioned theories, particularly around the neurodiversity approach in the global Autism movement which emerged from the internet. Interestingly,

Eisenhardt (1989) notes that it is possible, when applying case studies, that the researchers will find the opposite result from their expectations, therefore it will open ways for a new development of thinking (Hartley, 2004). Thus, it is worth investigating if the selected case studies in Indonesia might offer different explanations of how social media use can contribute to the interpretation and narrative of Autism in that country.

However, some scholars argue that the objectiveness of the case study is more situated in capturing the uniqueness of the case being studied rather than using them as a basis for wider generalisation (Gomm et al., 2000). Consequently, case study research mostly requires a narrative approach rather than a framework of variable analysis (Gomm et al., 2000). To fulfil the aim of a case study approach for generating theory and discovering new categories and concepts, Daymon and Holloway (2011) suggest that a case study approach needs to combine with another approach, such as grounded theory. In this study, I therefore opted to combine the case study approach with a grounded theory approach. The latter approach will act as the overall method of synthesising the different data and analyses, as I explain further below.

3.1.2. The grounded theory approach for synthesizing strategy

Starting from the need for an approach to generate new theories within sociological research, Glaser and Strauss (1967) developed the notion of grounded theory as “a kind of theory generated from the data collected” (Länsisalmi et al., 2004). Since its inception by Glaser and Strauss (1967), grounded theory has been acknowledged as a social constructionist approach with critical commitments, mainly in the humanities and social sciences (Craig & Tracy, 2014). The method in grounded theory refers to qualitative data analysis, with its objective to build theories from data. Glaser (1995, 1998) stated that grounded theory could provide “new insights into the understanding of social processes emerging from the context in which they occur, without forcing and adjusting the data to previous theoretical frameworks” (Länsisalmi et al., 2004). Thus, what differentiates grounded theory with other qualitative approaches lies in its focus to uncover phenomena and processes in researching without any predetermined theoretical or conceptual framework (Länsisalmi et al., 2004).

In the context of this thesis, a grounded theory approach is applied to explore and understand the phenomenon studied in providing a critical analysis of how online space can transform Autistic's personhood and identities in Indonesia. Furthermore, in doing this study, I adopt the "constructivist viewpoint", as proposed by Corbin and Strauss (2008). The constructivist approach in grounded theory has been developed by Charmaz (2000) who argues that "data do not provide a window on reality. Rather, the "discovered" reality arises from the interactive process and its temporal, cultural, and structural contexts" (Mills, et.al., 2006). By adopting this viewpoint in my research, I create multiple constructions during the research process, including to analyse both the Twitter and interview data.

At the first stage, I construct concepts and arguments from Twitter data about Autism representation and Autistic portrayal in Indonesia. As guidance to categorise the tweets, I constructed a codebook by using a deductive coding scheme. In the later stage of the research I apply an inductive approach to search for the possibilities in tacit meanings in the tweets and identifying key issues from the tweets collected (in chapter 7).

In the second stage, I bring out more in-depth, personal narratives constructed by my participants. From the interviews, I sketch a picture of how my participants make sense out of their experiences in using social media to create self-narratives, promote self-advocacy, and provide different meanings to understand Autism as their identities. In the third stage, I draw on different stories from another group of participants – the parents of Autistics – about their views on Autistic self-advocacy and the important role of the internet and social media to voice out Autistics' narratives. Borrowing Corbin and Strauss' arguments, as researchers we make an effort to construct knowledge through our analysis of those multiple constructions (Corbin, 2008). In the context of my study, from my analysis, I aim to construct new concepts and insights about the role of the internet and social media to produce a different frame of Autism in Indonesia.

However, to ensure the development and density of the concept being studied, it is strongly suggested that research using the grounded theory approach can imply a constant comparative analysis with a specific coding scheme throughout its process (Länsisalmi et al., 2004). In some cases, research applying grounded theories uses

triangulation which combines various types of data collected, such as interviews, participative observation and document analysis (Länsisalmi et al., 2004). Moreover, Länsisalmi et al. (2004) explain that “theoretical sampling” is needed in research projects which apply grounded theories. This means that the selection of samples for data should be guided by the development of concepts used in the study. In that case, this thesis employs two different types of data collection, including content analysis of social media documents (Tweets) and interviews from two different groups (Autistics and parents). Strauss and Corbin (1998) describe the use of “nontechnical” literature (such as reports and internal correspondence) as a potential source of data for providing information about the context within which the participant operates (Mills, et.al., 2006). In this study, I used a number of nontechnical literature such as reports, internal correspondence and social media postings for additional data that is related with the topics of this study and the context of my participants’ area of interest. The procedures of data collecting and participants selecting will be described in the following sections; while the procedures of constructing a codebook and sample selecting for the content analysis conducted in this study will be explained in chapter 7.

3.2. Data collection procedures

This study applied a qualitative approach to data collection procedures. In obtaining data for this study, I conducted three different stages of data collection – online content analysis of Twitter messages followed by in-depth interviews with two different groups, firstly with Autistics and then with non-Autistics represented by parents. The overall data collection process started in November 2017 and ended in August 2019. The procedures of each stage will be described below.

The first stage performed a content analysis using textual and social data analytics software (DiscoverText) and a Twitter API (Application Programming Interface) search to map the conversations and to observe active accounts about Autism and the neurodiversity movement on Indonesian Twitter for 6-month periods (November 2017 to January 2018 and March–May 2018). Firstly, keywords and hashtags over the previous 3 years in this area were observed to explore the local narrative frames of Autism and the neurodiversity movement, resulting in some frequently used keywords

(in Bahasa) such as ‘Autism’, ‘Autistic’, ‘special needs’ and ‘neurodiversity’. Before the data collection stage, a codebook was set to categorise Tweets. This process will be explained further in chapter 6, where the results from this stage’s data collection is presented.

The second stage involved semi-structured interviews with five Autistics as well as observations of social media content created by them. A semi-structured interview was chosen because of its flexibility to develop the formulation of the questions when obtaining the individual views of the participants (Flick, 2011). This form of interview is ideal to initiate a dialogue with the participants as they are expected to reply freely and extensively, sharing their stories and experiences related to the topics (Flick, 2011). For this purpose, a set of interview guides was established, consisting of open-ended questions about participants’ experiences and perceptions related to social media use and presence, their online Autism advocacy, as well as their understanding of Autism and the neurodiversity concept (see Appendix B). The interview settings were either online or offline depending on the convenience to the participants, resulting in a mixture of communication methods – synchronous such as via chat app, asynchronous such as via email, or through face-to-face interviews. Age criteria for informants in this research was limited to over 18 years of age, as this age group is classified as young adulthood (UN, 1982).

For the third stage, a series of interviews were conducted with four non-Autistics – parents of Autistic persons – to gain more perspectives on social media use by Autistics from a different group (see Appendix A). These four parents were recruited from several online groups on parenting for Autistic children. This final interview stage is expected to give further explanation about which direction parents’ advocacy movements in Indonesia are heading toward. I prepared an interview guide consisting of open-ended questions about parents’ experiences in using social media and online Autism advocacy in Indonesia, as well as their opinions about social media use for Autistics (see Appendix C).

These interview guides were constructed from literature reviews, which will be discussed in more depth in the following chapters (chapter 4 and 5). Both chapters will discuss the historical context of Autism and the emergence of Autism advocacy in a global context (chapter 4) and in Indonesian context (chapter 5).

Chapter 4. Autism awareness and the online advocacy movement

4.1. Introduction

As explained in the introduction chapter, one of the objectives in this thesis is to explore the phenomenon of the changing landscape in Indonesian Autism advocacy – from parents’ advocacy to Autistic self-advocacy. Previous studies indicate that the majority of parents support the neurodiversity paradigm and have become allies to the global neurodiversity movement, thus increasing the acceptance of Autistic identities, while another group of parents opted for the pro-cure movements, or opposing the neurodiversity movement (Ortega, 2009; Kapp, 2020).

This chapter will address the literature reviews on the historical aspect of Autism and the emerging of Autism advocacy movement in global context. A section about the use of the internet as a platform for disability movements and advocacies in Indonesia will be addressed in the last part of this chapter before continuing to chapter 5 about autism and advocacy in Indonesia. I will begin by examining how Autism is defined and understood – from the clinical, social and cultural aspects of Autism. The role of the media and internet in shaping public understanding of autism and inciting both a parental Autism movement and Autistic self-advocacy movement will also be addressed in this chapter.

4.2. Definitions and historical aspect of Autism

As explained in chapter 1, the definition of Autism was first introduced in clinical studies. Autism spectrum disorder, or ASD, is usually detected in early childhood and is defined as a complex neurological (brain) disorder that affects three areas of early development – language, socialisation and behaviour (Blank & Kitta, 2015; Reilly, 2013). In particular, Autistic children have difficulties in initiating social interactions, engaging or maintaining eye contact, as well as involving in imaginative play, differentiating linguistic play with literal speech, and recognising emotional expressions (Fenton & Krahn, 2007; Frith & Happé, 2005). However, the symptoms can be indistinct and often coexist with other conditions such as gastrointestinal dysfunction, sensorimotor differences, sleep disturbances, intellectual disability, seizures and anxiety (Tucker, 2015; Reilly, 2013).

Regarding definitions and historical aspects of Autism, as briefly mentioned in the introduction chapter, the first publication introducing the term ‘Autism’ was Leo Kanner’s paper (1943) entitled *Autistic disturbances of affective contact* (Silberman, 2015). In his paper, Kanner, an Austrian–American child psychiatrist, described his experiments of 11 young patients who seemed to be in their private worlds and paid no attention to people around them (Silberman, 2015). He used the term ‘Autism’ from the Greek word *autos* which means ‘self’ because these children showed unique conditions such as repeating behaviours while agitating to changes; some of them were unable to speak, but all had the common characteristic of self-isolation (Silberman, 2015). One year after Kanner published his paper, Hans Asperger, an Austrian paediatrician, published similar cases to Kanner. Asperger described his observations of some children and adolescents who were on the “borderline” – those who have normal or superior intelligence but showing specific learning difficulties and inappropriateness in social behaviour (Wing, 1997). Later, in 1962, a number of scholars published an article about Asperger’s findings which coined the term Asperger’s syndrome, and in 1991 Uta Frith introduced it to a wider audience as a part of the Autism spectrum in her book *Autism and Asperger’s syndrome* (Molloy & Vasil, 2002; Wing, 1997). However, a more recent publication by Herwig Czech (2018) about Asperger’s involvement with the Nazi euthanasia program – by referring severely disabled children to a special clinic in Vienna to be killed as a study in eugenics – now creates provoking questions regarding bioethical challenges in using the term (Baron-Cohen, et al., 2018).

Once claimed as a rare neurological disorder, Autism has been increasingly recognised as a more common developmental disorder since the turn of this century. For example, in the US as well as in other countries, Autism cases are seen to be ‘booming’, increasing at least ten times more than over previous decades (Baker, 2006). Consequently, Autism has become the focus of increased public attention, including in the media and within authorities. Particularly in the 2000s, the topic and stories of Autism – its prevalence, causes, symptoms and treatments – were in the headlines of popular news magazines such as *Newsweek* and *Time*⁹ (Clarke, 2012). The beginning

⁹ *Understanding Autism* was the cover story published by *Newsweek* on 31 July 2000, while *Time* magazine published *Inside the world of Autism* as their cover story on 15 July 2002.

of this century has also seen Autism research becoming a priority for the US National Institutes of Health (NIH) – since 2000 they have increased research grants for Autism by an average of US\$51 million annually (Silberman, 2015).

To date, the cause of Autism has remained unclear, although Frith & Happé (2005) mention a number of previous studies indicate the possibilities of both environmental trigger factors and genetic vulnerabilities which may predispose some cases (Frith & Happé, 2005). However, the heterogeneity of the spectrum makes it difficult to provide significant validations (Frith & Happé, 2005). In further studies about the causes of Autism, other factors were brought as contributing aspects to its increasing prevalence, from mercury in vaccines¹⁰, to the rising awareness of early diagnostic testing and improvement of services from healthcare providers, to the widening of the Autism diagnostic criteria (Baker, 2006; Mann, 2019). In the book *Autism matrix*, Eyal (2010) questions whether Autism is a “real disorder” that became a global epidemic or whether it is a socially constructed disorder caused by the inclusiveness of the spectrum. Furthermore, he emphasises the critical role of therapies and institutional factors, as well as the role of parental motivation, for developing and changing the category of Autism (Eyal, 2010). He concludes that contemporary Autism is a “network effect”; a result of related changes between the shifting ideas about aetiology, the advancement of therapies, and the widening of categories led by deinstitutionalisation of mental retardation in the late 1960s (Eyal, 2010; Timmermans, 2012).

Interestingly, both the internet and popular media possibly have a role in spreading the emphasis on a genetic cause for the “Autism epidemic” (Eyal, 2010). Some examples – including Steve Silberman’s Wired article that claimed “there was an Autism pocket in Silicon Valley” and Simon Baron-Cohen’s theory of “assortative mating” – are quite popular, despite these kinds of explanations and theories needing further validation before they can be confirmed (Eyal, 2010). To conclude this brief history of Autism, the definition and understanding of the spectrum as a lifelong condition are still highly problematic, particularly as Autism is a behaviour-based diagnosis with no “clear”

¹⁰ The link between MMR vaccines and Autism became a controversial issue in 1998, when Andrew Wakefield’s fraudulent research was published in the British medical journal *The Lancet*. The article was retracted in 2010 after Wakefield et al. were held guilty of ethical violation and scientific misrepresentation (Rao & Andrade, 2011).

marker which can be clinically obtained (Hanbury, 2012). Consequently, as a diagnosis with unclear prognosis and with a lack of standardised treatment, Autism still faces a significant public challenge (Baker, 2006).

4.3. The rise of parental Autism movement

The complex nature of Autism has provided the impetus for the parental Autism movement (Langan, 2011). Parents feel the need to seek information and to solve the 'problem' of Autism, and also to educate the public about their children's condition. As such, they become the spokesperson for the needs of their children (Ho, et al., 2014). Historically, parents' voices inside the Autism community have been diverse (Antunes & Dhoest, 2018). Some parents speak on behalf of their personal experience as parents, while others speak as clinical experts, with an academic or professional expertise in various disciplines, e.g. psychology, psychiatry, sociology, anthropology and literature (Langan, 2011).

There have been three different phases regarding parents' voices in the Autism community; the first phase was in the 1960s to the 1980s, the second phase was in the 1990s to the current one started in 2010 (Langan, 2011; Antunes & Dhoest, 2018). In the first phase, Autism was seen as a rare condition and, consequently, there was still a stigma surrounding that condition at that time, driving the parents to focus on seeking social support. But, as the research surrounding Autism developed and the diagnosis of Autism became more common in the 1990s, the popular issue that emerged in this phase was the 'blaming frame'. This blaming frame was brought to attention by the media and also by parents who stated that Autism was an epidemic issue caused by external conditions, including vaccines. However, starting in 2010, a new wave of parental voice has emerged, focusing on supporting and accepting Autistic diversity, thus embracing a shift from the medical model to the social model (Langan, 2011; Antunes & Dhoest, 2018). This includes the voice of academics such as Roy Richard Grinker, a social anthropologist from the US, and also a parent of an Autistic daughter. In his book, *Unstrange minds: Remapping the world of Autism*, Grinker stated his critique toward environmental causes and the blaming frame which was popular in the 1990s. He argues that, in Western society, Autism is now being viewed as a kind of human difference while, in many other cultures, "Autism is only beginning to emerge from being hidden, stigmatized and denigrated" (Grinker, 2007; Langan, 2011).

However, in her study of Autism and social movements in France, Chamak (2008) emphasises a different interpretation of Autism among parents' associations and Autistics. The parents' associations in that country seem to redefine Autism as no longer a psychiatric disease, but as a "handicap which can be counterbalanced by intensive educational and behavioral methods" (Chamak, 2008). To counter this, Autistic individuals have started to voice out on behalf of themselves, demanding acceptance of their differences, arguing that "their difficulties should not be stigmatized as a mental disease" (Chamak, 2008). With the support of online network platforms, the Autistic self-activists are starting to take a more proactive role in shaping their virtual community and their position within it (Davidson, 2008). This self-advocacy movement among Autistic persons – which would later become known as the neurodiversity movement, as previously discussed in chapter 2 – claims that Autism is not a disease to be cured, but rather a human specificity or difference. The movement acknowledges that Autistic people have different ways of socialising, communicating and sensing, which must be equally respected (Jaarsma & Welin, 2012).

4.4. Autistic activism: The emerging of self-advocacy and the neurodiversity movement

Self-advocacy movements by Autistic adults emerged formally after the first publication of the diagnostic criteria in 1989 (Ward & Meyer, 1999). Autistic self-advocacy associations such as the Autism National Committee (AUTOCOM) and Autism Network International (ANI) started to appear at the beginning of the 1990s as a result of Autistics' encounters at conferences and with support from the Autism parental associations (Chamak, 2008; Ward & Meyer, 1999). However, although these associations and the wider parental community provide some support, for example in connecting their Autistic children through pen-pal contact lists, Autistic communities often face great resistance from some parental groups (Chamak, 2008). According to studies by Chamak (2008) and Bagatell (2010), over the years there has been much friction between parent and self-advocacy associations. Consequently, Autistic self-advocates have had to struggle to make their voices heard (Chamak, 2008; Bagatell, 2010).

The debate surrounding the two polar oppositions – the parents and clinical experts who are considered as the ‘outsiders’ versus the Autistics – has increased since the early 2000s (Langan, 2011). The roots of the debate came from the former group’s tendency to reinforce the stereotypical images of Autistic individuals as asocial, unemotional and, particularly, uncommunicative (Davidson, 2008b; Davidson, 2009). Consequently, they deny the voice of individuals on the spectrum (Brownlow & O’Dell, 2006). To emphasise these conflicting views, Orsini and Smith (2010) mark the distinction between “Autism activism” which is focused on therapy and cure, and “Autistic activism”, which focuses on the rights and recognition of Autistic people (Orsini & Smith, 2010; Runswick-Cole, 2014).

For example, some parent-funded campaigns were sending messages about ‘curing Autism’ or ‘becoming normal’, ideas which are opposed to self-conscious identity politics movements like the neurodiversity movement (Hart, 2014). In 2007, the New York University Child Study Center launched a publicity campaign, dubbed the Ransom Notes, which sparked massive criticism among activists (Orsini, 2012). In the print and TV ads that were part of the campaign, Autism is described as an “abductor of innocent children and an unstoppable epidemic” (Orsini, 2012). Ari Ne’eman, the leader of Autistic Self-Advocacy Network (ASAN), stated that the campaign was “highly offensive” for relying “on some of the oldest and most offensive disability stereotypes to frighten parents” (Orsini, 2012).

Chamak (2008) makes a comparison regarding the relationship between parents’ and Autistic persons’ associations in Western countries. She argues that, compared to France, the conflict between the two groups is stronger in the US and Canada regarding their different traditions of protest and social reform (Chamak, 2008). Interestingly, in a study on Autism and neurodiversity in the US and Canada, Orsini (2012) indicates that both parents’ advocacy and Autistic self-advocacy do seem to agree at some point, particularly in the context that they need to increase the reach of care and support for Autistic people and their families. However, they still have different views regarding the nature of Autism. Hart (2014) terms this “the Autism-as-disorder” versus “the-Autism-as-difference” debate, with one side being mostly represented by parents of ‘low-functioning’ children and the other side being represented by ‘high-functioning’ Autistic self-advocates. The first group is more aligned with a medical model of

disability which views disabled people as defective, abnormal or deviant; in contrast, the second refers more to the social model which views disability as “socially produced, not simply an individual deficit that needs to be overcome” (Orsini, 2012).

Another interesting point was brought by Brendan Hart (2014) who argues that parents have a critical role in opening the way for Autistic self-advocates. Historically, parents, as well as others who are considered experts in Autism, had been advocating for people who were previously institutionalised – known as ‘mentally deficient’ and ‘socially incapable’ – and had also been challenging the notion that Autism was a result of defective parenting styles (Hart, 2014; Langan, 2011). Moreover, parents today have maintained this critical role, doing what Hart calls “radical translations” (Hart, 2014). Radical translations refer to the inclusive activities that parents do for their children, for example engaging children in daily life activities (Hart, 2014). While doing so, they translate their children’s behaviours and utterances. Through ethnographic research in the US and Morocco, Hart (2014) found that some parents of ‘low-functioning’ Autistic children use behavioural therapies, which might be opposed to the neurodiversity approach. But, in doing so, they are aiming to achieve their child’s full personhood, thereby achieving neurodiverse ends (Hart, 2014), including acquiring the skills for independent living and, crucially, advocating for themselves.

For disabled people – including the Autistics – self-advocacy is viewed as an important stage to open the way for more inclusive practices and cultures; this is particularly so in the Autistics’ case, as previously they were represented by parents and health professionals (Waltz et al., 2015). Self-advocacy is also regarded as a demand for self-determination from being treated unequally (Bagatell, 2007), and “a way of interacting with outside agencies and institutions” (Aspis, 1997; Waltz et al., 2015; Aspis, 2002). On the other hand, others view self-advocacy as some form of individual resistance from persons who have difficulties in negotiating their positions or who are under institutional control (Baggs, 2005). Drawing from Judi Chamberlin’s model of effective self-advocacy practices by people with mental health difficulties (1990), Waltz et al. (2015) analyse the roles and practices of Autistic self-advocacy in the Netherlands. Chamberlin’s model describes some stages in the development of the psychiatric patients’ movement which include (Waltz, et al., 2015, p.1175):

- Writing and publishing individual narratives by former patients.

- Creating former patients' groups (distinct from mixed groups that included professionals).
- Consciousness-raising in forms of sharing personal experiences and insights.
- Developing national coalitions.
- Building collective self-help action projects, such as organising support groups, advocating for hospitalised patients, lobbying for changes in laws, promoting public speaking, publishing newsletters, and developing creative ways of dealing with ex-patients' experiences.
- Participating in forums where decisions were made, such as commissions and conferences.
- Developing self-help alternatives to mainstream mental health services.
- Strengthening individual self-advocacy skills through collective advocacy.

In terms of the Autistic self-advocacy context, the internet acts as a primary space for self-advocacy, with various platforms – such as online groups, blogs, vlogs and self-produced films – being used to communicate Autistics' presence to the world (Waltz, et al., 2015). Ward and Meyer (1999) also argue that Autistics may possess good skills related to technology and written communication, which can lead to opportunities in using the internet to advocate on their behalf (Brownlow & O'Dell, 2006; Ward & Meyer, 1999). As discussed in chapter 2 about the potential use of the internet for Autistics, the new technology provides a network for Autistic individuals to share personal experiences and form a coalition. This relates to the later stages in Chamberlin's model outlined above. For example, Autistic self-advocacy organisations such as ASAN and Aspies for Freedom have used the internet to organise collective advocacy for protest movements to combat both misrepresentation by the media and oppressive actions from residential services (Waltz et al., 2015).

However, beyond the advantages and positive impacts of the internet, not every Autistic individual can benefit from the new technology. A previous study from Pinchevski and Peters (2015) shows that the internet creates a class distinction which highlights the problem of the digital divide within the spectrum due to the functionality differences between the so-called high-functioning and low-functioning Autistics. Even among the people who are at the higher end of the spectrum, problems regarding social media use still present. For example, in maintaining an online relationship, Autistics often face difficulties due to their social skills such as understanding social

rules to apply and evaluating trustworthiness when developing friendships (Burke, et al., 2010).

4.5. The internet as a platform for disability movements and advocacies in Indonesia

The general use of social media for disabled users is similar to non-disabled users. Both groups are mainly using social media for social interaction with friends and families, enjoying entertainment content, and also for work-related tasks and personal reflections. Hollier (2017) states that social media provides benefits by providing accessibility for disabled users to join social conversations and to create employment opportunities (Ellis & Kent, 2017). Due to their popularity and accessibility, online platforms such as Facebook and Twitter are chosen for conducting advocacy and organising disability rights actions, and also for sharing disability-related news and finding a network of disability rights advocates (Ellis & Kent, 2017). In Indonesia, more disability activists have started to use social media over the last decade to create awareness of disability issues and advocate for disability rights.

Historically, as the popularity of the internet began to rise in the 1990s in Asia – including in Indonesia – this new medium of communication was viewed as a more democratic medium, as it eliminated the distinction between producers and consumers (Hill & Sen, 2005). Previous studies about the internet and online activism in Indonesia indicate that this new medium had a distinct role in the Indonesian political movement at the end of the 1990s, with online activism becoming more prominent among Indonesian civil society in the 2000s (Hill & Sen, 2005; Lim, 2013; Nugroho, 2011). In Indonesia, the number of users – in particular of popular blogging platforms and social media sites such as Facebook and Twitter – started to grow rapidly from 2008 in line with the growth of mobile phone users in that country (Lim, 2011). However, large disparities were found among internet users in Indonesia in terms of access, with the largest numbers of users centralised in urban and more populated areas in the western part of Indonesia (Edwin & Ross, 2017). Despite that, social media provides a space for Indonesians to communicate and express themselves; this leads to participatory forms of content creation and the building of online communities (Lim, 2011).

There are three key reasons for the popularity of online social networking platforms in Indonesia today – the relatively affordable price of mobile phones, the strong sense of community in Indonesian culture, and the tendency to follow trends regarding new technologies and celebrities (Nugroho, 2011). Indonesian culture is “highly receptive in online socializing” – most Indonesian users utilise Facebook for sharing life moments and Twitter for exchanging news and activities (Nugroho, 2011). In a study about Indonesia’s internet blueprint, Triastuti (2017) states that 92.9 percent of Indonesian internet users are actively using Facebook, and there are 385 tweets posted every second from Indonesia, making the country the third largest nation in terms of Twitter users (Triastuti, 2017). In addition, from his study on community activism and social media in Indonesia, Nugroho (2011) states that Indonesian civil society groups and communities are very active on social media, particularly on Facebook and Twitter. The characteristics of these social networking platforms are considered particularly convenient to facilitate civil society to achieve their goals, either for mobilising help in an emergency situation¹¹ or for organising rallies (Nugroho, 2011).

Regarding the disability movement, the internet opens up numerous opportunities for online participation and activism. With digital technology such as screen readers and text-to-speech software installed on mobile phones and computers, blind and deaf people can access online platforms and participate in online forums and discussions (Bexley, 2015). Since the 2000s, the internet has facilitated people with disabilities to build connections and networks across the nation. As explained in chapter 1, an Indonesian organisation of blind people called Kartunet launched a social activism site in 2006 to educate the public about inclusiveness. The internet is a key tool in facilitating activism as they build online information and networks focusing on disability issues, and also use social media to spread disability awareness campaigns (Kartunet, n.d.).

In 2011, Angkie Yudistia, an Indonesian Deaf activist, started to build Thisable Enterprise, a company whose mission is to empower people with disabilities. She said that social media can be a powerful tool to campaign for disability rights and to build

¹¹ To give an example, in 2010 during the Mount Merapi eruption, an Indonesian civil society organisation called Jalin Merapi utilised Twitter and other online platforms to disseminate information and coordinate voluntary action (Nugroho, 2011). Two other notable cases in Indonesian social media activism were the Coins for Prita and the Gecko versus crocodile movements in 2009, when Facebook and Twitter were widely used to support a libel case and fight against corruption (Lim, 2013).

a network for disabled people (personal communication with Angkie, 2015). In *Linimassa* – translated ‘the timeline’, a documentary series about the social media movement in Indonesia – Angkie was depicted in a scene using Facebook and Twitter for sharing her personal stories and advocating for disability issues. She relies more on Facebook due to its benefits in providing visual features and effectiveness in distributing messages, particularly compared to traditional media like television and magazines (Laksono, 2012). She also emphasises the fact that 80% of her close-circle friends have a Facebook account; this makes the social networking platform a great tool for having conversations with others (Laksono, 2012). In addition, she has developed an e-commerce website (www.thisable.org) for selling homemade skincare products made by disabled communities; this has developed into an enterprise website for the disabled community, providing services such as assistance with job applications and a learning centre for disabled people. In 2017, her company began a partnership with several Indonesian companies, including the famous technology start-up company Go-Jek, to facilitate job opportunities for people with disabilities (Mayasari, 2018).

The Asia Foundation, a non-profit international development organisation that works with the Indonesian government and communities, reported a growing network of non-governmental organisations (NGOs) and community-based organisations that are working on disability rights in Indonesia (Bexley, 2015). Since 2014, organisations such as Kerjabilitas, Solider and Accessible Indonesia, have also made their presence in social media (Bexley, 2015). Kerjabilitas – translated as ‘workability’ – launched in 2015 for people with disabilities in Indonesia and is the first online career service (www.kerjabilitas.com), while Solider (www.solider.id) is an online information exchange for the community and serves as a platform for people to get involved in advocacy for disability rights (Bexley, 2015). Accessible Indonesia is a tour service for people with disabilities that uses social media such as Twitter, Facebook and Instagram to provide information about their services and disability-friendly public access to buildings and transport. In the same year, the Asia Foundation has also worked with the Indonesian government in a programme called Program Peduli to promote social inclusion for citizens who face stigma and discrimination, including people with disabilities. Using social media platforms, they collaborate with non-profit

organisations and communities, offering a shared platform to promote activities by using the hashtag #IDInklusi (or ‘inclusive Indonesia’) (Bexley, 2015).

Another example of how social media is deployed for building awareness and campaigning on inclusiveness for people with disabilities is Surya Sahetapy’s YouTube channel. Surya is a 25-year-old Deaf activist who actively uses social media – Twitter, Facebook, Instagram and YouTube – to advocate on behalf of the Indonesian Deaf community. His background as an actor – as well as having parents who are both celebrities – contributes to his popularity. Surya, who once starred as an abled, hearing, character in an Indonesian drama movie, also creates a series of vlogs (video blogs) on his YouTube channel. His popular YouTube channel has more than 34,000 subscribers, and one of his popular vlogs gives a message about the importance of learning and providing sign language – and other means to communicate – to give more access for the Deaf. The video, which got 43,000 likes and more than 3,000 comments in its first 6 months, emphasises his initial message:

... to express your mind and heart is not only limited by using your verbal sounds, but it could be in many forms of communication, including written text, sign language, gestures, and other means (Sahetapy, 2018).

To conclude, it could be seen that social media platforms provide and create online space for persons with disabilities to have their conversations and communicate their stories which, in the offline world, might go unheard. As told by Anto Darmanto, an Indonesian blogger and a disabled person, “Blogging is a means to express myself. I use blog as a promotional tool and a place for sharing my stories with others” (BU, 2011). Darmanto, as well as other prominent figures with disabilities like Angkie Yudistia and Surya Sahetapy, have important roles in raising the public profile of people with disabilities and thereby voicing disability issues in Indonesia through their social media posts.

It is worth to note that in disability advocacy movement in Indonesia – including Autism advocacy – the popular terms *berkebutuhan khusus* (Indonesian term for ‘special needs’) and *difabel* (an Indonesian acronym term for differently abled) have been largely employed by some disability advocates and news media. Although the official term used in ‘Undang-Undang Republik Indonesia No. 8/2016 tentang Penyandang Disabilitas’ (Law Number 8/2016 on People with Disabilities) is

penyandang disabilitas, or people with disabilities (Arif, 2016). In an Indonesian context, the term *difabel*, *diffabel* and *diffability* are considered as grassroots terms¹² used to counter the hegemony of the elitist term previously used legally in the 1980s, *penyandang cacat* (Suharto, et al., 2016). The usage of different terms in Indonesia to refer disability can be traced back to the cultural and religion aspects. As a country with the world's largest Muslim community (Edwin & Ross, 2017), Islam plays an influential role in people's understanding of disability. For example, the terms *difabel* and *diffability* – which promotes that people with impairments are differently able – is reflecting the concept of inter-human equality, an ideology invoked by Indonesian transformist Moslems (Suharto et al., 2016). Looking from the terminology's historical aspect, the terms *difabel* and *diffability* are used by Indonesian disability activists to, borrowing Linton's (1988) term, "claim disability" as a positive identity to combat the stigma and reject the negative views towards people with disability. Further discussion about the stigma surrounding Autism, as well as how social and cultural context affects the way Autism is perceived, will be addressed in the following chapter.

¹² In a study about disability terminology in Indonesia, Suharto et al. (2016) state that disability advocate Mansour Fakhri invented the term *difabel* or *diffable*. Fakhri used the new term to replace the previous one, *penyandang cacat*, which has been reproduced by a dominant hegemony, thus contributing to a marginalisation toward people with disability. The previous term has contributed to people with disabilities to be faced with stigmatisation and discrimination, as *cacat* refers to "physical (or mental) dimension of an object or person; there is an assumption that something that is 'cacat', including humans, has no value, is useless and deserves to be discarded" (Suharto et al., 2016).

Chapter 5. Autism in Indonesia

5.1. Introduction

In the last chapter I showed that the historical aspect of Autism in global context was started in 1943, and how Autism has been increasingly recognised as a more common developmental disorder since the turn of this century. However, it was not until in the beginning of the late 1990s when the public history of Autism in Indonesia was started. Hence, Autism can be considered a relatively new topic in that country. It is also indicated by the limited amount of academic research about Autism in Indonesia (Tucker, 2013b), particularly from a media and disability studies perspective, apart from a very few published studies in media discourse (Satvikadewi, 2014), public awareness campaigns (Ulima & Dhani, 2012) and online parents community (Purnamasari, et al., 2019).

To give some examples, publications about Autism in Indonesia are mostly found in the areas of health and medicine (Hariyani et al., 2019; Hartini, et al., 2016; Wignyosumarto, et al., 1992), psychology (Kuntoro, et al., 2017; Sidjaja, et al., 2016), cultural anthropology (Riany et al., 2016; Tucker, 2015), and education (Padmadewi & Artini, 2017).

This chapter is intended to give a brief description of the general history and development of Autism in Indonesia as well as the importance of considering cultural influences to understanding Autism in that country – before moving to the next chapters to discuss the thesis' findings. Considering the absence of academic literature on the history of Autism in Indonesia, some of the sources and references in this chapter were collected from various articles published by Indonesian news media, and also documents and reports from Indonesian academic institutions and government agencies. The following sections in this chapter will address firstly on how Autism is situated in Indonesia – particularly from the socio-cultural context – including the stigma surrounding Autism and how Autism is represented in Indonesian popular media. In the final part of this chapter I will discuss the emergence of parents-based Autism movements and Autistic self-advocacy in Indonesia, before moving to the conclusion part.

5.2. How Autism is situated in Indonesia

To date, there has been no exact data on the rate of Autism prevalence from reliable sources. The most recent data is provided by the Ministry of Education and Culture, which states that the prevalence of children with Autism is growing by 15% every year – with 638,000 Autistic students registered in Indonesian special schools in 2008 (Riany et al., 2016). Another report from the Ministry of Women Empowerment and Child Protection in 2008 estimates there are 2.4 million Autistic people in Indonesia with a growing rate of 500 persons each year (Ekaputri & Afriansyah, 2020). Prior to that, the Ministry of Health (2009) reported there were 475,000 children diagnosed with Autism in Indonesia in 2004 (Riany et al., 2016). Looking at these statistics, it can be seen that the data and information regarding Autism in Indonesia are mostly focused on children. The absence of data and further reference to Autistic adults in Indonesia as outlined above was a driving force in my research – as Autism has been identified among children in Indonesia since the beginning of the 1990s.

Social and cultural context affects the way disability is perceived. As discussed in chapter 2, it is impossible to homogenise and standardise disability due to differences in its definition and other aspects in cultural contexts; therefore in critical disability studies, it is important to explore local discourses and practices (Grech & Soldatic, 2016; Rembis, 2016). In a study about how Autism is perceived in various ethnic communities, Perepa (2014) indicates that some parents from African and Asian groups tend to address the ‘deficit’ social behaviours associated with Autism. These parents use the deficit model for selecting particular behaviours to be taught to their children (e.g. eye contact). On the contrary, some British parents who use the social model, argue that society should make allowances to understand the difficulties in particular behaviours for Autistics, such as maintaining eye contact (Perepa, 2014). These differences in interpreting social behaviours of Autistics show that culture is one of the factors that influenced how people understand and identify Autism – and also influenced people’s understanding of the social construction of disability in general.

As discussed throughout this thesis so far, Autism in Indonesia, is largely related with the deficit model – as for decades, being disabled in Indonesia was seen as an impediment (Dibley & Tsaputra, 2019). In their study about cultural beliefs and

Autism in Indonesia, Riany, et.al (2016) found that mothers would feel ashamed, frustrated and expect stigma from the community – if they had a child with Autism. Tucker (2013) also addresses the social stigma surrounding the families with Autistic members in Indonesia; according to one of the informants in her study, Autism was seen as *aib keluarga* (trans. family shame) – particularly before the era of Autism awareness movement emerged in the late 1990s. At that time, having an Autistic child was seen as a burden and the topic of Autism was considered as a sensitive issue; as such, families tend to ‘cover up’ the situation (Tucker, 2013b).

In a report by The Centre for Disability Studies at Universitas Indonesia, Irwanto et.al (2010) describe the general condition of people with disability in Indonesia. The report, which used data and references from various national surveys and media reports in Indonesia, states that existing surveys related to disability data in Indonesia are therefore yet to specifically represent the prevalence of disability in the mental, emotional and intellectual domains – particularly Autism, ADHD and other intellectual disabilities (Irwanto, et al., 2010). The same report also states that stigma and discrimination toward mental and emotional disability were largely found in Indonesia. For example, cases of confinement (*pemasungan* – being held captive to a wooden block) of children or adults who are having mental and emotional disability are often found in society (Irwanto et al., 2010).

The deficit model opposes the spirit of a more progressive approach in the social model of disability in Law No. 19 of 2011 (on the ratification of the UNCRPD) in Indonesia¹³. By enacting this law, the Indonesian government has already made strong commitments to improving the wellbeing of person with disabilities, claiming equal rights and opportunities for them in all aspects of life (Adioetomo et al., 2014, p.3). However, the enforcement of the law remains as a challenge as Indonesia still needs to develop reliable data on disability, including Autism. For example, in Indonesia’s 2009 National Socioeconomic Survey, the listed category of disabilities is still limited to sensory, physical and mental disabilities; this does not properly represent the

¹³ On 30 March 2007, Indonesia ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Adioetomo, Mont, & Irwanto, 2014). By ratifying the UNCRPD, it means that person with disability, including Autistics, should be viewed as “people who have a right to live in a society that does not erect barriers to their participation based on their functional status” (Adioetomo et al., 2014).

prevalence of disability in the mental, emotional and intellectual domains, particularly Autism, ADHD, and other intellectual disabilities (Irwanto et al., 2010).

In 2008, Melly Budhiman, a child psychiatrist – who is also the founder of the pioneering Autism organisation, YAI (Yayasan Autisma Indonesia or Indonesian Autism Foundation) – wrote about her concerns about Autism in Indonesia. Melly is one of the prominent figures in the Autism arena in Indonesia as she was one of the first health practitioners who brought the topic to light when she began writing about Autism in the media in 1994 (DetikHealth, 2013). According to her, Autism was identified in Indonesia in the middle of the 1980s (Tribunal, 2008), but there has been an absence of comprehensive data on Autism prevalence and the lack of support to get sufficient services for Autistics in Indonesia (Budhiman, 2008).

For example, the only published study which mentions the prevalence of Autistics in Indonesia is outdated, as it was conducted 25 years ago. In that paper, a clinical study of Autistic children in Yogyakarta conducted in 1992, it was stated that 12 in 10,000 (0.1%) children born between 1984 and 1991 in Indonesia had an Autism diagnosis (Wignyosumarto et al., 1992). One of the challenges in providing comprehensive data about Autism prevalence is due to different approaches to the measurement of disability prevalence in Indonesian¹⁴.

As mentioned briefly in the previous chapter, the term ‘special needs’ (*berkebutuhan khusus*) is a popular term for referring Autism, or addressing children and adults with Autism. Again, this is due to the historical aspect of disability conception in Indonesia which was largely focused on a person with functional impairments. According to the *Report on people with disability in Indonesia* (2014, p. 3), the term for a disabled person is labelled with a prefix *ber-* in Bahasa which means ‘has’ or ‘to own’ disability(ies) (e.g. *ber-kebutuhan khusus* means having special needs). However, since the enactment of Law No. 4 of 1997 on Persons with Disability (*penyandang*

¹⁴ Disability is categorised in different ways by different government bodies. For example, in the 2010 population census – the official national survey conducted by Badan Pusat Statistik (BPS, translated Statistics Indonesia) – disability was defined into six-category classification which includes difficulty in: seeing; hearing; walking/climbing stairs; remembering or concentrating, or communicating with others due to physical or mental conditions; and self-care (Cameron & Suarez, 2017). Another categories was provided by the Ministry of Education and Culture, which recognises Autism as being one of six disability categories in its own right – alongside hearing impairment, developmental disorders, blindness, physical disability and mental disorder (JICA, 2015).

disabilitas) in Indonesia, the term persons with disability is considered as a legal terminology (Adioetomo et al., 2014). Following this law, Autism organisations such as YAI are currently using the term *penyandang Autisme* (person with Autism) in their campaigns and communication messages.

It is important to note that public knowledge about Autism in Indonesia is not the same across the whole country. This happens due to a number of factors: the large disparities in socio-economic status, the dispersed nature of its geographical location, and gaps in accessing health information and services between people in rural and urban areas. There are cases of Autistic children who receive adequate therapies and treatments and have enough support to learn the required skills for daily living; however, this mostly happens in urban areas (Post, 2015). On the contrary, there are cases in rural and remote areas where families keep their Autistic children bound in chains or as mentioned in the earlier paragraph – being held captive to a wooden block (*dipasung* in Bahasa) or locked in a room. This happens because of the stigma toward mental and emotional disability, and also due to the lack of knowledge among the parents and families – who do not know how to deal with Autism – nor do they have adequate financial support to provide treatments for their children (Wike, 2015).

As mentioned earlier, culture has a critical influence in the construction of disability, including Autism. In Indonesia, local culture has a significant impact on the labels used for Autistic children or people with mental disabilities. For example, among some Javanese families, some symptoms in Autism such as ‘being in a world of one’s own’, crying or laughing with no apparent reason, wandering, and sensory hypersensitivity has led to them being labelled as crazy or severely disturbed people, or alternately being viewed as a person who is possessed by a spirit (*kesurupan* or *kesambet* in Bahasa) (Tucker, 2015). As such, in a rural area in West Java where many children showed symptoms of Autism, the children are treated by *dukun* or *tabib* (shamans) as their symptoms are associated with evil or supernatural powers (Budhiman, 2008). This kind of situation is not uncommon in Indonesia, due to the difficulties in accessing health services and information, particularly for the villagers (Budhiman, 2008).

Despite the lack of healthcare services, in 2007 YAI states there are 140 organisations, clinics and therapy centres which provide services and information on Autism in Indonesia (Wike, 2015). Considering the increasing diagnosis of Autistic children in

Indonesia, in 2015 the Ministry of Education and Culture established 29 Autism centres around the country (JICA, 2015). However, since most services are provided by the private sector, those who are in the lower level of economic status have difficulties in accessing it (Riany, et al., 2017). Melly Budhiman describes a similar situation as above, namely that any formal support for parents of Autistic children is mostly only available in urban areas, particularly areas centred around big cities on Java island such as Jakarta, Yogyakarta and Bandung (Egutkina, 2013). She adds that all therapies needed to be paid by the parents; consequently, paying for the full range of therapy is considered a financial struggle, even for a middle-class family (Egutkina, 2013).

On the other hand, alternative and traditional therapies such as homeopathy, massage therapy, reflexology treatment, animal therapy (e.g. horse riding and interactive therapy with dolphins), yoga and music therapies are also found throughout the country (Tucker, 2013b). Holistic-based treatments, such as massage and cupping therapies combined with prayer, are also popular among some parents of Autistic children (Hersinta, 2012). Currently, technology-based interventions such as using a mobile or computer apps (eg. Alternative and Augmentative Communication or AAC) have also been developed by Indonesian universities and organisations to reduce the cost and facilitate the demand for interventions and therapies. One such example is Cakra, a learning app using an ABA-based method which was launched by a group of university students from Surabaya in 2016 (Wandari, 2016). The latest one is Spokle – a mobile application that delivers speech and language therapy resources to its users – which was launched in 2017 to help parents to teach communication skills to their children (Ulung, 2017). In her book *Giving Voice* Meryl Alper (2017) describes the critical factors of parents' economic and technical capital for using ProLoquo2Go (the Alternative and Augmentative Communication app designed to be used on the iPad), as the technology is not cheap and requires intensive trainings for the parents to teach their children (Schmidt, 2017). The household-level economic disparities causes a class distinction among families, middle and upper-class parents may have more capacities to support their children – due to parents' unequal access to economic, cultural and social capital (Alper, 2017). This resonates with the situation in Indonesia, where the use of technology such as communication and learning apps for Autistics is still limited due to social and economic inequalities.

The lack of infrastructure and services to support people with Autism is still viewed as a great problem in Indonesia, particularly for those who live in rural areas (Sidjaja et al., 2016). Generally, health services and intervention supports for people with disability in Indonesia are under recognized by the government institution and public themselves due to four key reasons (Kusumastuti, et al., 2014). Firstly, due to budget shortages in healthcare priority services. Secondly, the cultural belief among Indonesians that having a child with disability is disgraceful, particularly for those with mental and emotional disabilities. Thirdly, the people's preference, particularly in rural areas – as described in the previous paragraph — to go to traditional or native healers. Fourthly, the mind-set among some people with disabilities to pursue social support rather than to be independent and productive (Kusumastuti et al., 2014). The second reason – the cultural belief about childhood disability – can lead to further stigmatisation and discrimination towards both the parents and the children (Kiling, et al., 2018). For example, children with disability may face exclusion from getting education services, and also have higher possibilities in experiencing institutional neglect, physical violence and bullying (Kiling et al., 2018).

5.3. Cultural and societal impacts of Autism: The stigma

The term stigma is used to refer to an attribute that is deeply discrediting that does not fit the normative expectations of society (Goffman, 1968). There are three different types of stigma which refer to the impacts of having physical, character or behaviour differences, and also as the impact of 'belongingness' to a certain race, nation or religion. The first type of stigma is a detestation of the body as a result of various physical deformities. The second refers to the flaws in individual character which may be identified as "undesired differentness" from what people had anticipated. The condition of mental disorder, imprisonment, addiction, homosexuality, and radical political behaviour are some of the examples of the second stigma. The third type is the tribal stigma of race, nation and religion which can be transmitted through lineages (Goffman, 1968).

As a result, stigma could be seen as a form of spoiled social identity for individuals or groups who possess these attributes (Goffman, 1968; Obeid et al., 2015). They have the possibility of being stereotyped, often resulting in negative outcomes such as poor

self-esteem and difficulties with employment. In the case of Autistic people, they may experience higher levels of negative outcomes such as social exclusion and bullying (Obeid et al., 2015). In contrast, while at present the general public is more familiar with the symptoms of Autism, the stigma and the exclusion that society attaches to it are implacable, particularly considering that most people with Autism do not look different than other ‘typical’ people (Grinker, 2007). Due to the absence of visible markers of Autism, an uninformed person may view Autistic people who look ‘normal’ to be “acting voluntarily in ways that violate social norms” (Gray, 2002; Obeid et al., 2015).

Previous studies in the US and UK indicate that Autistic people experienced stigma towards their conditions – and so do their parents (D. E. Gray, 1993; Obeid et al., 2015; Tang & Bie, 2015). Similar cases are also found in Indonesia, where the stigma surrounding an Autistic child will attach to the family. For example, Goffman (1968) identifies a term called ‘courtesy stigma’ or stigma by association, which refers to people directly connected to individuals with disabilities, for example a member of the family (Gray, 2002; Phillips, et al., 2012). This means that the family, such as the parents, carry part of the stigma – in this case Autism – that marks disability in ableist societies. Consequently, the experience of parents of Autistic people also includes their lives as parents of people with disabilities, and is not only based on how their sons and daughters are treated by society (Antunes & Dhoest, 2018).

Another study on Autism in developing countries indicates that cultural factors play an important part in reflecting health-related stigmas (Tang & Bie, 2015; Weiss, et al., 2006). In addition to that, some cultures are known to have negative views toward Autism such as India, Korea, Nicaragua, Hong Kong and China (Riany, et al., 2016; Tang & Bie, 2015). Particularly in China, it was found that there are two factors which might contribute to heightening the public’s low awareness of Autism and thus increase the discrimination toward them (Tang & Bie, 2015). Firstly, the scarcity of resources and facilities for Autistic children in China and, secondly, the cultural pressure to have a normal child (McCabe, 2007; Tang & Bie, 2015). This also influences cultural stigma in Indonesia – having children were viewed to be the source of a family’s pride as they bring happiness and wealth (Riany et al., 2016; Wike, 2015). If the expectation is not met due to their children’s disabilities, there is a possibility

that the child will be stigmatised (Riany et al., 2016). For example, within the Javanese community, the birth of a child equals a great expectation that the child will bring happiness and lead a better future than his or her parents (Wike, 2015). When the child is diagnosed with Autism, the expectations of the parents to have a ‘typical’ or ‘normal’ children are unmet; this can bring shame and sadness to the family (Wike, 2015).

According to Riany, et. al (2016) traditional cultural beliefs such as *karma* and *taboo* influence how people understand the cause of Autism in Indonesia. These two aspects are viewed as important aspects in pregnancy and the process of giving birth. Karma refers to “something occurring in the present which is understood to be a consequence of what has happened in the past” (Riany et al., 2016). There is a negative stigma relating to beliefs that having a child with disability is a result of karma. Other traditional beliefs, such as avoiding breaking the *taboo* during pregnancy – for example, avoiding eating or consuming certain foods and drinks or forbidding a pregnant mother to go outside the house during *Maghrib*¹⁵ time – are considered acceptable among Indonesian families (Hersinta, 2012; Riany et al., 2016). Breaking the *taboo* means there are negative consequences that the parents have to bear in the future, including having children with disabilities or diagnosed with serious illness.

In Indonesia, Tucker (2015) indicates that a number of labels are used when referring to Autistic symptoms and behaviours such as ‘naughty’ (largely caused by hyperactivity and difficulties in controlling impulsive behaviour), and ‘stupid’ or ‘crazy’ (due to sudden outbursts or meltdowns caused by sensory hypersensitivity and other problems). Moreover, the parents often find these labels to be stigmatising and inaccurate as they recognise some good potential in their children (Tucker, 2015). The parents of Autistic children also face challenges in admitting their kids to regular school because of these negative labels; their children are deemed as ‘troublemakers’ because of their difficulties in social and communication skills, despite their ‘normal’ physical appearances (Priherdityo, 2016). A clinical observation among some families

¹⁵ *Maghrib* time is the time for doing prayer (*shalat* in Bahasa) after sunset in Islam. There is a belief based on some *Hadiths* – the traditions or sayings of the Prophet Muhammad – that people are advised to close their front doors during *Maghrib* to keep their children safe from devils and Jinn (Nashrullah, 2020).

in Indonesia indicates that stigma and misunderstandings about Autism in Indonesia may lead parents to neglect their child with Autism (Riany et al., 2016a).

However, in certain urban areas of Indonesia, Autism has been regarded with a “high-status diagnosis” – as access to the right diagnosis, treatments and education for Autistics is somewhat limited to those who can afford it (Tucker, 2013b). As such, there is less social stigma related to Autism than other mental disabilities. For that reason, there are cases of parents with children who have been diagnosed with a psychotic disorder such as schizophrenia who have asked the psychologist to change the diagnosis to Autism because it is less stigmatising (Tucker, 2013b). Previous studies have found that greater knowledge about Autism is associated with lower stigma, although this is still debatable (Obeid et al., 2015). It is possible that by increasing the knowledge of Autism, we could reduce the stigma accompanying it. However, it has been acknowledged that the information about Autism from the media could also provide stereotypical images of Autistic people (Obeid et al., 2015; Tang & Bie, 2015) a notion which I will discuss in the following section about Autism in Indonesian popular media.

5.4. Autism representation in Indonesian media

In the last 10 years, Autism-related topics have been starting to proliferate in Indonesian media, presumably related to the rising global awareness of Autism. As mentioned in chapter 4, the controversy regarding the vaccine issue in 1998 also contributed in increasing the media coverage about Autism. In Indonesia, this issue has caused a large number of opposing responses from parents to have their children vaccinated (Prawira, 2014). Despite that, the increasing amount of media exposure on Autism makes the topic more familiar to the public. Autism has been emerged in various popular culture forms – particularly in the US and UK – which makes it a highly productive idea (Murray, 2011; Tucker, 2013b). This global trend is also evident in Indonesia, where Autism themes and stories have been presented in the memoirs of parents of Autistic children, news articles, magazine features, television talk shows and different genres of movies portraying Autistic characters.

For example, during 2008–2013, various angles on Autism topics were covered by some leading national newspapers (*Kompas*, *Tempo* and *Jawa Pos*), by women’s and

parenting magazines (*Femina* and *Parenting Indonesia*) and also by national television (RCTI and SCTV) (Satvikadewi, 2014; Tucker, 2013b). At the beginning, the topics covered were mostly in the area of medical or clinical issues, e.g. the causal factors, symptoms, treatments, services and prevalence of Autism (Satvikadewi, 2014). But in recent publications and coverage in the news media, more diverse issues have started to appear (see Table 1), including Autism acceptance and neurodiversity topics:

Table 1. Examples of the topic of Autism in Indonesian news media (2008–2018)

Year	Media	News title
2008	<i>Kompas</i> (newspaper)	<i>Hari Autis Dunia: "Pandemi" Autisme?</i> (World Autism day: The ‘pandemic’ of Autism?)
2008	<i>Kompas</i> (newspaper)	<i>Boom! Autisme terus meningkat</i> (Boom! Autism continues to increase)
2009	<i>Kompas</i> (newspaper)	<i>Pemerintah diminta berperan tangani autis</i> (The government is expected to handle Autism issues)
2011	Antara (news agency)	<i>Christine Hakim meluncurkan film tentang Autisme</i> (Christine Hakim launches a movie about Autism)
2012	Kompas.com (news site)	<i>Autismaze ubah persepsi keliru tentang anak autis</i> (‘Autismaze’ changes the misperception about Autistic children)
2013	<i>Jawa Pos</i> (newspaper)	<i>Politikus makin autis</i> (Politicians are turning Autistic)
2013	<i>The Jakarta Globe</i> (news site)	Life with Autism is full of challenges
2014	Liputan6.com (news site)	<i>Kontroversi vaksin MMR dan Autisme</i> (MMR and Autism vaccine controversies)
2015	Brilio.net (news site)	<i>Autisme bukan lelucon, stop bercanda pakai kata Autis</i> (Autism is not a joke, stop using the word Autism as a joke)
2016	Beritagar (news site)	<i>Neurodiversity, keragaman saraf dan Autisme</i> (Neurodiversity, <i>keragaman saraf</i> and Autism)

2016	<i>National Geographic Indonesia</i> (magazine)	<i>Dunia sunyi para pencari jati diri</i> (The silent world of the soul seekers)
2017	<i>The Jakarta Post</i> (newspaper)	Balinese foundation treats Autistic children with organic food
2017	<i>Magdalene</i> (web magazine)	Coming out as Autistic
2018	<i>The Jakarta Post</i> (newspaper)	The bright side of living with Autism

On the other hand, the media also contributes to popularising the misuse of the term which has the potential to stigmatise Autistic people. For example, in 2012 *Jawa Pos* (see Table 2) published an opinion article titled *Politikus makin autis* (translated as *Politicians are turning Autistic*) (Afandi, 2012). In this article, the writer coined the term “politically Autistic” which means a “leadership style that does not care for others – leaders who are busy with their own affairs and immersed in their own world, obsessed with their dreams and do not care about the voice of the public or the interests of the voters” to describe the invidious behaviour of many Indonesian political leaders (Afandi, 2012). This tendency to use the word autist and Autistic to label obstructive behaviour or character is not uncommon in Indonesia. Tucker (2013) takes note of how the terms are used casually by Indonesian youngsters – particularly in Java – to describe ‘anti-social’ behaviour and to depict a person who is self-absorbed in their world while using their gadgets. They use the word Autism as a form of slang or folk speech to describe anti-social behaviour and/or as an “idiom for isolation or stunted development”. In a book about Indonesian female students studying in Australia, a mother of two Autistic children writes about her experience when she moved to Australia to study. She was surprised that Autism in Australia has a different meaning, is categorised as disability, rather than being perceived as a disease, a mental disorder

or as being a ‘peculiar’ kid or, worse, using the term for people who are addicted to games on their mobile gadgets or computers (Melati, 2018).

In a study about Autism discourse on Indonesian Twitter, the word ‘autist’ (*autis* in Bahasa) has various meanings; it’s not just limited to the actual meaning related to pathological conditions or clinical terms (Satvikadewi, 2014). Moreover, the study also indicates an “over reduction” and “over exaggeration” of the actual meaning of the word *autis* which is indicated by people using the word in a totally different context. For example, the word is often used mostly in a conversational way as a substitute for another words or terms such as ‘mad’, ‘stupid’, ‘highly creative’, ‘extremely focused’ and ‘game addictive’ (Satvikadewi, 2014). The study also indicates that there are Twitter users who are non-Autistics but identify themselves as Autistics or *autis* due to the attribution of different meanings to the word (Satvikadewi, 2014).

The misusing of the term *autis* drove a large protest from many parents of Autistics in Indonesia – due to the possibility for creating another stigma for those who bear the label. As such, parental organisations and Autism communities in Indonesia have been actively campaigning against misusing the terms *autis* to label negative behaviour. For example, in commemorating Autism awareness day in 2015, YAI and MPATI have been actively circulating the message “Autism is not a joke” in their public campaigns – to counter the popularity of misusing the term¹⁶.

In addition, since 2004 some memoirs written by parents of Autistic children have also been published in Indonesia, thereby supporting the efforts on Autism awareness in that country (Tucker, 2013b). Mostly written by the mothers, these memoirs are not only considered as ‘inspirational stories’ of parental hardships in raising the children but also provide information and insights on symptoms, interventions and daily life experiences of living with an Autistic member in the family. Some previous studies discuss the role of parents as the major source of published life narratives. Life writing

¹⁶ The “Autism is not a joke” campaign was launched nationwide in Indonesia, as the phenomena of misusing the term *autis* became widespread – which also used largely by some news media and in other forms of popular culture in Indonesia. In 2015, a public petition was made to protest an Indonesian pop band – who uses the word *autist* for describing a person who immersed in their own world and showing antisocial behaviour (Aloha, 2015; Wardoyo, 2015).

in the form of family memoirs and biographies does not only provide the stories of parenting a child with Autism, but also shows the various cultural and social understandings of the condition (Ho, et al., 2014). Furthermore, these narratives reflect more personal voices compared to the medical narratives which usually dominate the discussion on Autism (Ho et al., 2014).

As previously discussed in chapter 1, the first ‘autie-biography’ in Indonesia was written by Oscar Yura Dompas, an Autistic 25-year-old student from Jakarta. In his book *The Autistic journey*, Oscar shares his life story – from when he was diagnosed with brain damage at the age of four, which was later identified as Autism – to his teenage years. The book tells the story of his experiences as a teen on the spectrum, including his stories of experiencing teen romances and having difficulties in controlling anger in his high school days. Oscar, who later continued his study overseas to study English, published his second book, *The life of the Autistic kid who never gives up*, in 2008 in both Bahasa and English.¹⁷

In addition, Autistic characters have been represented in Indonesian movies and fiction books, thus making Autistic traits more familiar for the mainstream audience. In 2003, a drama genre movie titled *Biola tak berdawai* (translated as *The stringless violin*) portrayed an 8-year-old boy with multiple disabilities – Autistic, brain damage and stunted physical growth – in a main supporting role. Despite receiving negative reviews due to its illogical scenes, ridiculous action, and a dull plot, the movie successfully gained some awards, including the Asia-Pacific Film Festival Award for Best Actress category (Diani, 2003). However, while it generates positive values for touching the audience’s emotional side and giving the audience “something to think about” (Diani, 2003), the title of the movie itself is depicting disability as an impairment and dysfunctional. As quoted by Bhisma, a male, able-bodied character in

¹⁷ The title of Oscar’s second book *The life of the Autistic kid who never gives up* may suggest an inspirational framing of Autistic within his biography. Quoting journalist and disability rights activist Stella Young: “Inspiration porn is an image of a person with a disability, often a kid, doing something completely ordinary – like playing, or talking, or running, or drawing a picture, or hitting a tennis ball – carrying a caption like “your excuse is invalid” or “before you quit, try” (Ellis & King, 2015, p. 150). However, I met several disability activists in Indonesia in 2018 who stated they do not object to inspirational representation in the media. One senior disability activist, Sri (not her real name) commented, she dislike the term (inspirational porn). She views that there is nothing wrong with the portrayal of people with disabilities as inspirational, particularly in Indonesia: “Indonesians need to get ‘inspired’ to combat the stigma toward disability. Being portrayed as ‘inspirational’ is one of the ways to construct a positive image of people with disability” – Sri.

the movie, “such children – with disability – are like violins without strings: beautiful, but they cannot be played” (Diani, 2003). This image type – known as the ‘sweet innocent’ or ‘charity cripple’, that is, portraying disabled people as “perfect in every way except for the disability” – has existed since the early years of the cinema industry (Norden, 1994). Portraying disabled children to emphasise a poignant tale of a humble, gentle and ‘pure’ person who needs gracious protection from able-bodied people (Norden, 1994) is likely to be considered as a popular strategy in attracting movie audiences, particularly by incorporating such a plot with a heart-touching, drama genre movie.

Another example of an Indonesian movie which portrays an Autistic character can be seen in the 2007 film *Perempuan punya cerita*, distributed internationally with the title *Chants of the lotus* (Tucker, 2013a). The movie contains four separate stories about women. One of the stories, *Cerita pulau* (translated as *Island story*) tells the story of an Autistic female adult who becomes a rape victim. In the story, the female character, Wulan, is described as having a fascination for light, depicting the Autistic trait of sensory perception. Wulan is manipulated and brutally raped by a group of young men who lure her with a flashlight (Tucker, 2010). The movie’s plot makes the audience aware of disability and Autism as a difference; that Autism should not be regarded as “something foreign, frightening or vacant, but as something unique, special, and valuable” (Tucker, 2010). It is worth noting that *Cerita pulau* seems to convey the message of social stigma and discrimination facing by woman with disability. Indonesian film critic Eric Sasono highlights this problem – in particular the social stigma and discrimination commonly faced by women as a second-class gender in Indonesia – in his review about the movie:

The story of Cerita pulau illustrates the social pressures experienced by women, which leave them with no space. Women have no choice; they are excluded from many aspects in society – from medical institutions, law enforcement agencies, financial power, to having roles in family lives (Sasono, 2010).

In addition to the two movies mentioned previously, Autistic characters have become more prevalent in Indonesian cinema, particularly since 2003. Autistic characters have seen either as the supporting or main role in more recent productions. For example, in 2011, Autism was represented in three movies and a documentary work, including in

a thriller genre movie *The perfect house*, in a blockbuster movie *Simfoni luar biasa* (translated as *The extraordinary symphony*) featuring the famous Filipino singer Christian Bautista (Tucker, 2013b), and in the first documentary on Autism in Indonesia titled *Love me as I am*. In more recent years, Autistic characters have become more prominent in Indonesian drama genre movies. For example, an Autistic character is portrayed in *Rectoverso* (2013), a popular movie based on the Indonesian best-selling novel by Dee Lestari, in *I'm a star* (2013), a teen drama movie which starred Autistic actors and actresses, and in three other drama movies titled *My idiot brother* (2014), *Malaikat kecil* (translated as *Little angel*) (2015) and *Dancing in the rain* (2018) (Hardian, 2018).

Table 2. Movies portraying Autistic characters in Indonesian cinema

Year	Genre	Movies title
2003	Drama	<i>Biola tak berdawai (The stringless violin)</i>
2007	Drama	<i>Cerita pulau</i> in the film <i>Perempuan punya cerita (Island story in the film Chants of the lotus)</i>
2011	Thriller	<i>The perfect house</i>
2011	Drama	<i>Simfoni luar biasa (The extraordinary symphony)</i>
2011	Documentary	<i>Buah hati (international title: Love me as I am)</i>
2013	Drama	<i>Malaikat juga tahu</i> in the film <i>Rectoverso (The angel also knows in the film Rectoverso)</i>
2013	Drama	<i>I'm a star</i>
2014	Drama	<i>My idiot brother</i>
2015	Drama	<i>Malaikat kecil (Little angel)</i>
2018	Drama	<i>Dancing in the rain</i>

Sources: Tucker (2013); Hardian (2018); writer's observations

5.5. Parental Autism movement in Indonesia

However, public awareness about, and advocacy for, Autism in Indonesia has been behind that of other more developed countries. In her study of how Indonesian Javanese families treat and interpret Autism in their local cultures, Tucker (2015)

points out that the history of Autism in Indonesia mirrors a broader global history where localised parental movements initiate public awareness. For example, since 2006, many local websites have been writing about Autism awareness in Indonesia (Tribunal, 2008) – some of these were initiated by parents of Autistic children. *The Jakarta Post* mentioned some of the earlier parenting websites, such as dunia-ibu.org (trans. mother's world) and Putrakembara (trans. wandering son) (Tribunal, 2008). The first one is a parenting website featuring a mailing list forum for mothers – it provides information for parents of Autistic children such as lists of schools and therapy centres for Autistics, while the second is a website, also with mailing list forum, created for Autistic children and adults, their families and other caregivers.

Historically, advocating for Autism in Indonesia has mostly been advanced by communities and groups made up of parents and health practitioners such as YAI, MPATI and Putrakembara. Since the late 1990s, the parents of Autistic children started to try to bring Autism into public awareness in Indonesia – especially in urban areas – making the subject more familiar to the public. They inaugurated public discussion and provided group support and information through online group discussions via a Yahoo mailing list (Tucker, 2013b). This was also a time when Indonesia began to more fully embrace the popularity of the internet and the power of online communication (Tucker, 2013b).

One of the first online Autism community is Putrakembara – as mentioned earlier in the introduction chapter – which started in the forms of a website and online mailing list group. The Putrakembara website and online mailing list forum, for example, was initiated in January 2000 by a group of parents who have children diagnosed with Asperger syndrome (Marijani, 2012). The website and its online, mailing list forum provide various information and topics, ranging from practical information about Autism, to treatments and interventions, education issues and health problems. According to Leny Marijani, the moderator and administrator of Putrakembara, the website and online forum were created not only to provide information about Autism in the Indonesian language – at that time most information available was in English – but also with an aim to be a support group for parents and families of Autistic children. Lenny, who has a son with Asperger's, admitted that she was surprised when she received such an enormous responses from subscribers to the mailing list at that time,

particularly considering that in the early 2000s internet connection was still limited in Indonesia (Yang, 2015). By 2012, according to Leny, around 14 parents' support groups were established from the mailing list network members around different cities and islands in Indonesia, including for Indonesian parents who reside outside of the country such as in Qatar (Yang, 2015). To date, the Puterakembara mailing list forum is still active, although the website has not been updated; the last post was dated in 2014. Currently some of the online forum's members moved to the newer WhatsApp group chat platform as this offers more interactive discussion among parents.

During 2007 and 2008, Puterakembara collaborated with YAI to organise Autism campaigns and events, including the national campaign on Autism awareness. In 2007, they conducted an annual public campaign called *Peduli Autisme* (trans. caring for Autism). The campaign is designed to spread the message that Autism is a serious problem – a problem which the public and the government need to be aware of (Ulima & Dhani, 2012). For the first campaign they chose the theme *Autisme: Sadari, Kenali, Atasi sedini mungkin!* – translated as Autism: Recognising, identifying and treating it, immediately! – as they wanted to emphasise the importance of early intervention for Autistic children (Ulima & Dhani, 2012). Dyah Puspita, a psychologist and the founder of Mandiga – the pioneering school in Jakarta which provides education for Autistic students – hoped that the campaign would provide a better understanding of Autism for Indonesians. She states that, “the public awareness about Autism was very poor in Indonesia and many parents denied their children had the illness” (Tribunal, 2008). Indeed, it has been recognised that there is very little understanding of Autism – or other disabilities – in Indonesia. As mentioned earlier, this is particularly so for those people living in small cities and rural areas who have limited access to media and other health information compared to their counterparts in the big cities (Riany, et al., 2016).

5.6. Autism self-advocacy in Indonesia

As previously mentioned in chapter 1, Oscar Yura Dompas was the first Autistic in Indonesia to create a website about his daily life experiences. Oscar's website was first initiated by his father, Jeffrey Dompas, who wanted to create a writing outlet for his son to journal his daily life experiences (Etty, 2010). According to his mother, Ira Dompas, writing a journal helped Oscar to express his emotions (Etty, 2010). In 2005, Oscar made a request to his parents to publish a book based on his web postings and,

in April that same year, the book – *The Autistic journey* – was published to commemorate Autism awareness month (Marijani, 2006). Today the website (oscardompas.com) is no longer active, as Oscar currently prefers social media platforms such as Facebook to post his thoughts and activities randomly.

Moving forward 8 years later, Ananda Sukarlan, an internationally known Indonesian pianist and composer, started to share thoughts about his Asperger’s syndrome on social media, using his Facebook account and his personal blog under the pseudonym Andy Starblogger (Sukarlan, 2014a). Within the same year, a Twitter account on behalf of an Indonesian Autistic youth advocacy group, Pemuda Autisme Indonesia (PAI), translated in English as Indonesian Autism youth, emerged online (Hersinta, 2019). Besides Twitter, PAI also has Facebook and blog accounts, and created a discussion thread in Kaskus, the largest Indonesian online community forum at that time, about Autism. Its Twitter account, @perkumpulanPAI, had a total 920 tweets and only gained 26 followers during the year of 2014–2015. In the biography section, it is stated that the account is intended for people on the spectrum and supports the neurodiversity approach with the statement “Accept the difference!” (Hersinta, 2019). Information from PAI’s blog contains longer narrative, despite it only having seven postings during its short existence, from April 2014, Autism awareness month, to only a year later. The organisation’s goals are to communicate the aspirations of Autistic people and to help them to create public understanding on Autism so they can obtain acceptance (Stellune, 2014). The blog was written in Indonesian, and all postings generally delivered information on Autism, from basic information to more specific topics such as emotional difficulties experienced by Autistics, and various modes of alternative communication for Autistics who have difficulties in oral communication (Hersinta, 2019).

The aforementioned three examples from Indonesia resonate with the wider global cases of other Autistics’ form of online self-expression and self-narrative. Recent studies have highlighted the important role of blogs and social media as a tool to share perceptions from Autistics’ lived experiences and self-advocacy. However, as discussed in this chapter, parental based advocacy are still going strong in Indonesia, both offline and online – particularly through social media platforms such as Facebook, Twitter and Instagram, and also blogs. The term “sharenting” refers to the

activities when parents share information about themselves and their children online (Blum-Ross & Livingstone, 2017). The ethics and practicalities of “sharenting” are questioned, including who is being represented when parents share stories of their children online (Blum-Ross & Livingstone, 2017). The question of representation on Autism will be highlighted in the two following chapters. Chapter 6 will address the literature reviews on disability models of representation in the media before moving to chapter 7 about the discussion of Autistic portrayals and representations on Indonesian Twitter.

Chapter 6. Framing on Autism

6.1. Introduction

The previous chapter introduced the changing representations of Autism in Indonesian media and emphasised the role of parents – particularly in the cultural construction of Autism in by challenging the social stigma and initiating public awareness about Autism in Indonesia.

In order to answer the first research question of this thesis: “How Autism is represented and understood in Indonesia through online platforms?” I employ a content analysis on Twitter to investigate the dominant frames in conversations about Autism on social media, in this case, Twitter. The reason to focus on Twitter will be explained in the last subsection of this chapter. Moreover, this chapter will address some references related to media and framing, which will be used for data analysis in the next chapter.

This chapter consists of literature reviews, particularly about theories and concepts in disability models of representation in the media, as well as news framing on Autism and Twitter framing. The first literature is Clogston’s traditional and progressive model of disability; I apply this model to investigate the dominant frames shaping Twitter conversations about Autism in an Indonesian context. The second literature review will discuss previous studies of news framing about Autism – particularly for determining the categories on type of issues that are being discussed in the conversation about Autism – which I used for constructing a predefined frame for the codebook for this study in chapter 7. The third literature review will explore framing on social media – particularly Twitter – to understand how framing can be applied in social media.

6.2. The Traditional and Progressive Models of Disability

In the area of news coverage regarding disability issues, Clogston creates five models of representation, which he divided into two categories (Haller, 1995). Firstly, the traditional model which is largely based on the medical model of disability, focusing on the disabled individual’s differences from others in society and, secondly, the

progressive model which is based on the social model, focusing more on how society deals with a population that includes those with various disabilities (Clogston, 1994).

In his 1991 study on disability news coverage in the US, Clogston indicates a large amount (60% of newspaper coverage) of issues are based on the traditional model (Clogston, 1994). Some issues that portray the traditional models could be in the form of medical treatment and/or institutionalisation, government and private support programs, charity telethons and/or victimisation of disabled people. This traditional model was further categorised into three frames by (Clogston, 1994; p. 47):

- Medical model: This model emphasises the individual's physical disability as an illness. The individual is portrayed as dependent on health professionals for cures or maintenance. Also included in this model are stories that focus on any physical aspects of an individual's disability.
- Supercrip model: This model focuses on the individuals because of the physical characteristics of their disability, portrayed either as 'superhuman' or 'amazing' because they function 'normally' in spite of their disabilities.
- Social pathology or economic model: In this model, disabled people are portrayed as disadvantaged clients who look to the state or society for economic support, which is considered a gift, not a right. The individuals are portrayed as passive recipients of government or private economic support.

In contrast, the progressive model mainly portrays disabled people more inclusively. For example, disabled people are viewed as a minority group demanding equal rights and full participation in society (Clogston, 1994). From the same study by Clogston (1991) of the US newspaper coverage, 40% of the coverage portrayed progressive issues such as discrimination, access issues, integrated education, employment issues, or portrayed the disabled person as a consumer (Clogston, 1994). He further classifies the progressive model into two frames (1994, p. 47):

- Minority/civil rights model: This model shows disabled people as members of a minority group dealing with legitimate political grievances, usually involved in disability rights or political activities, and actively demanding political change.

- Cultural pluralism model: This model shows disabled people are considered to be multifaceted individuals whose disability is just one aspect of many. No undue attention is paid to the disability. The individual is portrayed to be the same as others without disabilities.

In addition to Clogston's models of representation, Haller (1995) has created three media models; the business model, the legal and consumer model. The business model, which fits into the traditional model, emphasises 'the cost factor' – how society and businesses tend to view disabled people and their accessibility as costly (Burns & Haller, 2015). Meanwhile, the legal and consumer model represent the progressive model, with the first model focusing on disabled people as having legal rights and the latter model viewing disabled people as an 'untapped consumer group' that can bring profits for society and businesses (Burns & Haller, 2015).

As described in the previous chapter, popular issues related with Autism in Indonesian media coverage have been largely about medical or clinical issues, as well as issues of economic support and access for autistic people. Nugroho et.al. (2013) state that Indonesian media continues to cover disability (acronym for 'different ability') issues mainly in the medical context; while portraying people with disability as the "victim, weak and helpless subject begging for empathy" is commonly found in Indonesian television shows and movies (Nugroho et al., 2013, p. 82). This reflects the way Clogston's traditional model depicts disabled people – as a "group of poor, powerless unfortunates who depend on society for physical and economic assistance" (Clogston, 1994, p. 46). Example words found in Indonesian news articles that apply a traditional model narrative to describe Autistics are *penderita Autisme* (trans. Autism sufferer) or *menderita Autis* (trans. suffering from Autism). However, as discussed in chapter 5, Autism organisations and Autistic persons have started to emerge in social media, including Twitter, to advocate about Autism acceptance in Indonesia – thus reflecting more on the progressive model. In this chapter, both the traditional and progressive models will be used for further analysis in the discussion part. I apply this typology to investigate how issues related to Autism and Autistic were represented and portrayed in Indonesian Twitter, along with other framework from literatures about news framing on Autism – which will be explained in the following section.

It is worth to note that Clogston's model of disability coverage is generated from his analysis in traditional news coverage (Clogston, 1994). However, I argue that the majority of Twitter contents are reflecting issues driven by the mainstream media, as suggested by Lim's findings in Indonesian Twitter (2011). Hermida (2013) and Weller et.al. (2013) also address the benefits of Twitter as a digital network for disseminating and reception of news. Hence, the application of Clogston's frames for content analysis on microblogging platform such as Twitter is considered relevant – as the practice of “ambient journalism” is present on Twitter (Hermida, 2013). The use of Clogston's model for this study will allow me to investigate the majority voice and to frame the prominent topics that emerged on Twitter discussion about Autism in Indonesia.

6.3. Media framing on Autism

Framing is the process of selecting and emphasising certain issues from everyday reality and organising that ‘reality’ into news coverage in order to promote a specific interpretation to the audience (Entman, 2007). Furthermore, framing in news content generally has four basic functions – to define problems, to identify causes, to convey a moral judgment, and to suggest remedies or improvements (Entman, 2004). News frames are also considered as the elements that journalists deliberately select and apply to deliver information to an audience, “in a way that complex issues can be more easily consumed” (Holton, et al., 2014, p. 192). Some scholars in previous studies argue that framings can have an impact on individual responses to certain issues, as well as drive public opinion and affect public policy (Iyengar & Simon, 1993; Wendorf Muhamad & Yang, 2017)

Clogston's models of disability have been deployed by a number of scholars in their studies of media content and disability, including Haller (1995), Haller & Zhang (2014), Burns & Haller (2015) and Goggin & Newell (2004), among others (Goggin & Newell, 2004; Kent, et al., 2018; Mellifont & Smith-Merry, 2015). In a study of newspaper coverage of Autism in the US and the UK over a period of 15 years, it was found that two-thirds of the news coverage used stigmatising cues such as addressing labelling, psychiatric symptoms, social skills deficits and physical appearances (Holton et al., 2014). This approach by the mainstream media has the effect of creating a “a threatening space” for Autism; Autism was heavily depicted in loss frames,

focusing more on negative outcomes (Holton et al., 2014). For example, news about the lack of infrastructure for Autistics and financial struggles faced by families with an autistic member was widely represented in the print media (Huws & Jones, 2011). Consequently, Holton et al. (2014) suggest that a social media platform can be more inclusive in terms of providing more individual points of view on Autism, particularly from people who are related to Autistics or the Autistics themselves.

Media frames can be categorised as either generic or issue-specific frames (Ben, 2013). While the generic frames refers more to broad and structural themes such as conflict, human interest, economic impact, responsibility and morality, the issue-specific category is more subjective (Ben, 2013) and has been called “emphasis framing” (Cacciatore, et al., 2015). One example of the generic frame is how US-based newspapers mostly emphasise human interest and economic consequences frames when delivering Autism news (Holton, et al., 2014). Here, the economic consequences frame is supporting the medical model by viewing Autism as an economic cost factor imposed on a family (Wendorf Muhamad & Yang, 2017). In health framing, there are two approaches commonly applied in the study of mental disability coverage. The first approach supports the gain and loss frame and the second one the episodic and thematic frame. For example, a study on stigmatisation and Autism news framing in the US and UK by Holton et al. (2014) applies the gain and loss frame to explain the health benefits/rewards of taking certain activities, and the risk/disadvantages of avoiding a particular health action. The same study also applies the episodic and thematic frame to categorise a particular case study (episodic) or more broader issues (thematic) in Autism news (Holton, et al., 2014).

A number of studies on media framing – newspaper and television – on Autism in countries such as in the US, UK, Australia and China also indicate that there are news biases in depicting Autism more globally. Media in these countries tends to focus on autistic children and their ‘special talents’ in the news coverage, despite Autism being a lifelong developmental disability (Bie & Tang, 2014; Dodd, 2005; Huws & Jones, 2011). For example, in a UK television show *Richard & Judy*, both presenters interviewed Daniel Tammet, a 26-year-old autistic and referred to him as ‘the boy with a rare gift of genius’ (Huws & Jones, 2011). These “infantilisation” and sensationalised descriptions of Autism in news media can be misleading as these do not represent the

heterogeneity of autistic individuals (Huws & Jones, 2011). These representations are constantly reinforced and repeated by parent-run and charitable organisations, the popular media and the news industry (Stevenson, et al., 2011). Consequently, this kind of portrayal can contribute to creating unrealistic expectations of autistics' capabilities, and also highlights the lack of attention and resources for autistic adults (Bie & Tang, 2014; Huws & Jones, 2011). Moreover, this infantilisation and sensationalisation of portraying Autistic also reflect public attitudes towards Autism – that will be described further in the following chapter.

Previous studies by Davidson & Henderson (2010) and Gray (2002) find that a high level of stigma also exists in public conversations surrounding Autism (Gray, 2002; Tang & Bie, 2015). This is reflected in the news media; for example, Holton et.al. (2014) found stigmatising cues were presented in more than two thirds of the coverage about Autism in the US and UK national newspapers. Likewise, in China, stigmatising cues such as viewing Autism as problems and shame were also presented in Chinese leading newspapers, particularly during the period of 2003-2012 (Tang & Bie, 2015). From the same study, Tang & Bie (2015) indicate two factors which might contribute to the public's low awareness of the Autism condition, thus increasing discrimination towards Autism. The first factor refers to the scarcity of resources and facilities for Autistic children in China, and the second factor refers to cultural pressure to have a 'normal' child (Bie & Tang, 2014; Tang & Bie, 2015). Prior to that study, there had been no health education programs in China that aimed to reduce the stigma of Autism (Tang & Bie, 2015).

Among various topics related to the issue of Autism in news media, the issue of vaccines was considered important in news framing of Autism as the issue sparks great controversy among a mainstream audience (Kang-Yi, et al., 2013; McKeever, 2013). As discussed in chapter 4, the controversy was brought into the light after an article published in February 1998 in *The Lancet* suggested a possible link between Autism and the MMR vaccine (Jang, et al., 2019). The public controversy resulted in great attention from news media, particularly in the US where Autism was included as one

of the top five disorders/diseases in the health news coverage at that time¹⁸ (McKeever, 2013).

In news framing, there are two approaches used to analyse content – inductive or deductive (Gamson, 1992 in Wendorf Muhammad & Yang, 2017). Gamson (1992) refers to the inductive approach as “examining stories with an open view and allowing for frames to emerge” (Wendorf Muhamad & Yang, 2017), while the deductive approach “involves analyzing content with predefined frames to verify the presence or absence of certain frames” (Wendorf Muhamad & Yang, 2017). For this study, I started with the deductive approach first – by constructing predefined frames from a number of previous literatures about news framing on Autism. These references were used as a framework for this codebook, which will be explained further in chapter 7. In the discussion section, I applied the inductive approach to analyse the tweets for exploring the possibilities of new frames to emerge.

According to Holton et al. (2014), newspaper journalists have mainly focused on medical issues such as the causes and potential cures for Autism over the last several decades; they have not often included Autistics’ points of view. Consequently, to improve news media’s coverage of Autism, it is suggested that news producers refer to online media platforms in order to listen to other voices and acknowledge the audience’s expectations of the news (Holton et al., 2014).

However, as mentioned in the previous section, a number of scholarly works in Twitter and journalism studies highlight the tendency of the microblogging platform to amplify popular issues from the mainstream media (Hermida, 2013; Lim, 2011; Weller, et al., 2013). As such, it will be interesting to see if in this study, Indonesian Twitter users will repeat and reinforce media frames on Twitter in discussing Autism-related topics and portraying Autistics. In the next section, some previous studies on social media framing will be discussed to give a more thorough description of how to employ framing on Twitter.

¹⁸ The wave of anti-vaccine sentiments received a large attention from the mainstream public and the media. This is also perpetuated by celebrities such as Jenny McCarthy who became a celebrity spokesperson against vaccine, and appeared in various popular talkshows such as *Larry King Live*, *Good Morning America*, and *Oprah*; bringing that misconception to the public (Kata, 2012).

6.4. Framing on Twitter

Communication platforms such as blogs and social media are opening up as easily accessible spaces for information sharing. These platforms provide arenas where individual viewpoints can be shared (Hermida, 2013, Holton et al., 2014). Hara and Sanfilippo (2016) affirm that the participatory nature of social media is not limited to scientists and journalists when publishing science and medical information but is also opening the access to the general public for them to be “participating in knowledge co-construction online” (Jang et al., 2019). Therefore, social media platforms can provide an arena for discussing topics and issues beyond the mainstream voices and stigmas which are often found in news media coverage (Holton et al., 2014).

Burch et. al. (2015) emphasise Twitter’s critical role as an outlet for news and information framing – as it can also serve as a platform for shaping public opinion and cultural perception (Burch, et al., 2015). In particular, Twitter is largely used for daily chatter, conversation, sharing information and reporting the news (Hermida, 2013). Previous studies about journalism and Twitter state that the microblogging platform has increased opportunities for news-sharing by journalists, due to the rise of its popularity (Lasorsa, Lewis, & Holton, 2012). As such, Twitter has developed as a digital network for real-time news; the microblogging company launched their official Twitter reporting guide in 2011 (Hermida, 2013). Twitter can facilitate the dissemination and reception of news into short fragments of information online, thus creating a stream of conversations from its users (Weller et al., 2013). Hermida (2013) refers to this practice as “ambient journalism” – a “telemediated practice powered by networked, always-on communications technologies and media systems of immediacy and instantaneity” (Weller et al., 2013).

Currently, framing from the perspective of Twitter users has been done in a number of previous studies. For example, Meraz and Papacharissi (2013) investigate networked framings in a 2011 Egyptian uprising event, Burch et.al. (2015) study the frames employed by Twitter users during the 2011 Vancouver riots, and Moody-Ramirez and Cole (2018) examine victim blaming frames in the US case of violence against Black men. As explained in the previous section, in news media, framing involves selection by the media to emphasise certain aspects in order to highlight the importance of these issues to the audience (Entman, 1993, 2007; McKeever, 2013). Compared to

traditional media, most social media tend to have fewer text – e.g. Twitter with 280 character limit – and probably less richness in its content (Kim & Cooke, 2018). However, it is possible to identify frames in tweets, as Twitter has certain features – such as hashtags and hyperlinks to other online sources – that can be used by Twitter user to amplify and frame their message (Kim & Cooke, 2018). Recent studies on social media framing show that Twitter and Facebook enable its users – either groups or individuals – to use frames to bring attention to specific issues (Kim & Cooke, 2018; Meraz & Papacharissi, 2013; Moody-Ramirez & Cole, 2018). In the context of advocacy movements, for example, organisation members and activists can utilise frames to mobilise people and connect groups to form a network for their activism (Nisbet, 2010).

This utilisation of Twitter for framing issues is referred to by Nisbet (2010) as a “bottom up model of framing” (p. 75). He argues the importance of studying social media framing, as user generated content in digital media (e.g. blogs, online video and social networking sites) allows citizens to participate in constructing alternative frames (Nisbet, 2010). Moreover, these “bottom up” alternative frames have the possibilities for “gaining greater influence in the discursive contest” (Nisbet, 2010, p. 48). This reflects the case of neurodiversity movements in social media – which discussed earlier in chapter 4 – as Autistic self-advocates have started to distribute the idea of neurodiversity as an alternative frame of viewing Autism through the online platforms.

Twitter also has some advantages regarding its news storytelling platform, as it creates an opportunity for “collaborative filtering and curating of news” (Schonfield, 2010; Meraz & Papacharissi, 2013). For example, the addressivity and conversational markers on Twitter such as retweet (@RT), hashtags (#), reply or mention could be used to maintain interactivity and to build interpersonal conversations, as well as to increase social awareness streams (Meraz & Papacharissi, 2013). As such, these markers can be used to give a voice to marginalised issues and publics (Meraz & Papacharissi, 2013).

Twitter has always been popular in Indonesia. The nation was ranked as the country with the highest Twitter penetration in 2010’s ComScore report (Lim, 2013). By 2013 Indonesia was acknowledged as the “Twitter nation” by CNN and was ranked as the fifth most tweeting country a year later (Lim, 2013; Carley et al., 2016). In 2015,

Indonesia had 24.34 million active Twitter accounts, which currently places the country in third place globally (Herman & Mononimbar, 2017). The popularity of the microblogging platform makes it particularly attractive for activism and for building networks among activists. As previously explained in chapter 4, Indonesian disability activists have used Twitter, along with other online networking platforms such as Facebook, to build awareness and to network with other peers, as well as to advocate for disability rights. For example, Ananda Sukarlan, the famous Indonesian music composer mentioned in the previous chapter, uses Twitter actively to share awareness and campaign about disability issues, including Autism.

In a publication about framing and the impacts of digital technology in a political communication context, Entman and Usher (2018) argue that the disruption of digital technology could potentially affect the communication flow between elites, the traditional media, and individuals. In the age of social media, there are five important features of technology – online media platforms (e.g. Google, Facebook and Twitter), analytics (data about audience behaviour), algorithms, ideological media (e.g. Fox News, Breitbart.com, MSNBC in the US) and rogue actors (e.g. hackers and bots, malicious autonomous programs on the internet) (Entman & Usher, 2018). These five features can enhance and diminish communication flow in the distribution of the framing process. For example, social media and online search platforms implement algorithms to influence users' experience and their perceptions; they can also decrease institutional media's gatekeeping capacity (Entman & Usher, 2018). Digital analytics can provide instant feedback on popular news items to news organisations and, likewise, media companies can also use the 'rogue actors' (e.g. bots) to spread the news via social media networks (Entman & Usher, 2018). This argument should be taken into account as this study utilises digital analytics software and Twitter API searches to collect data, and both programs/platforms using algorithms. Consequently, there are possibilities for influencers' accounts to promote certain issues by using algorithms to maximise traffic on Twitter.

In conclusion, previous literatures about media framing and Twitter framing can be applied in this study – to explore both the dominant and the alternative frames about Autism from the perspective of Twitter users in Indonesia. The next chapter will

investigate these frames and explore further main issues surrounding the context of Autism by conducting a content analysis on Twitter.

Chapter 7. Tweeting Autism in Indonesia: Investigating the Dominant Frames

7.1. Introduction

The previous chapter introduced theorisation about media framing and the application of media framing to Twitter. An understanding of framing is important to this thesis as it provides frameworks to investigate the content analysis of Twitter messages. This chapter applies those frameworks to outline the main themes and issues regarding Autism and the portrayal of Autistic people on Twitter.

Among other social media platforms, Twitter was chosen for this study – to map the main issues raised in conversations about Autism and also to investigate active accounts of Autistic advocates and neurodiversity proponents in Indonesia. This is due to a number of reasons; firstly, Twitter messages, or tweets, are categorised as public messages – unless the users mark their tweets as private – so it can provide information about the views of people on various topics (Reavley & Pilkington, 2014)¹⁹. Secondly, as discussed in the previous chapter, the microblogging platform is one of the most popular social media platforms in Indonesia, with 24.34 million active Twitter accounts in 2015 (Herman & Mononimbar, 2017). Thirdly, prior to writing this thesis, I found some active Twitter accounts on behalf of Autism organisations and Autistic self-advocates have started to join the conversations on Twitter, particularly to advocate about Autism-related topics in Indonesia.

The process of constructing the codebook and the method of collecting data from Twitter will be explained in the data collection procedure, before moving to the analysis and discussion part. The data analysis and discussion part will be divided into subsections – each subsection will provide discussion for answering the research questions in this chapter. The analysis was conducted by categorising tweets into different categories within the frame of a particular issue as described in the codebook. The top four frames – that frequently appear on Twitter findings – then were analysed further to investigate the prominent issues about Autism on Indonesian Twitter.

¹⁹ In conducting this content analysis on Twitter for my thesis, I refer both to Twitter's terms and conditions and AoIR's (Association of Internet Researchers) ethical guidelines 3.0 (2019) as the guidelines for ethical practices.

Clogston's models of representation, which has been discussed in the previous chapter, was used for further analysis in the discussion part to investigate the Twitter users' framing of Autism and the portrayal of Autistics on Indonesian Twitter.

The chapter concludes with a summary of the social media findings and how these findings can contribute to the public understanding of Autism in Indonesia. The results from the analysis indicate that the frame of understanding Autism on Twitter is still dominated by a traditional model which focuses on the disabled individual's differences from others in society. On the other hand, a minority voice from Autistic people also appears on Twitter, representing the progressive perspective, namely viewing Autism as a part of human difference.

7.2. Data collection procedure

Prior to data collection and analysis, a codebook was constructed as a guide or framework to analyse the tweets used in this study, with the aim to answer the following questions:

RQ 1: What are the main issues about Autism discussed on Indonesian Twitter?

RQ 2: How do Indonesian Twitter users frame the issues of Autism?

RQ 3: How are Autistic people portrayed on Indonesian Twitter?

Each tweet collected was coded and categorised under two categories – the age group of the Autistic profile/s mentioned in the tweet and the Autism issue/s which were framed; these issues are further categorised into 10 specific topics (see Table 3). This framework was developed from previous studies about news framing on Autism (newspaper and television news framing) and also from studies about online content analysis (health and social issues in social networking platforms) discussed in the previous chapter. The analysis procedure of this chapter is divided into two stages. Firstly, the basic content analysis or first level analysis – in the form of word or phrase-frequency analyses, keyword-in-context lists (KWIC), and some basic data visualisations (Weller et al., 2013). The first stage is intended to answer RQ 1. Secondly, the framing analysis or second level analysis is done to answer the remaining questions (RQ 2 and RQ 3).

Table 3. Content analysis item descriptions on Indonesian Twitter

Categories	Sub-categories and descriptions
Age group	Defined as the representation of Autistic profiles (age group) in the tweets or content of the tweets (pictures, article/news) (adult, teen, children)
Issues framed	Defined as what issues for the specific topic on Autism are represented in social media: <ul style="list-style-type: none"> • Infrastructure and access • Medical and science (e.g. scientific advancements in Autism-related research and content about Autism risks, diagnosis, causes and treatments) • Charity • Personal or family story • Celebrity story • Social and/or legal case • Policy • Art and/or cultural activity (e.g. art, films and fiction about Autism or cultural/artistic/athletic achievements of Autistic people) • Politics or political commentary • Misuse of the word Autism (e.g. erroneous use of the term to refer to introverted personalities or unsocial behaviours)

Source: Bie & Tang (2014), Jones & Harwood (2009), Kang (2013), Tang & Bie (2015).

In data collecting stage, certain keywords related to Autism in Bahasa were used, including *Autisme* (Autism), *autistik* (Autistic), *autis* (autist) and *keragaman saraf* (neurodiversity) to search for tweets in the first 3-month period (1 November 2017 to 31 January 2018). The keywords Autism, autist and Autistic are common terms when talking about Autism, while neurodiversity is a specific term which is drawn out from references and academic literatures about Autism advocacy on the internet. Tweets were collected using DiscoverText and Twitter API keyword searches. During the process, tweets that were irrelevant – either not related to Autism issues or not in an Indonesian context – were omitted to obtain an appropriate and clean dataset for analysis. The filtering process was done manually to exclude tweets that did not relate to Indonesia, e.g. when using the aforementioned keywords, both DiscoverText and Twitter searches generated data from countries which use the same term or similar language with Bahasa such as Dutch or Malay.

However, at the end of the first 3-month period, the result was not significant as only 60 tweets related to Autism were found. Considering this small result, I decided my

search needed to be re-defined for the second 3-month period (1 March to 31 May 2018); this time period was chosen to coincide with the international Autism awareness month of April²⁰. As such, from further observation of related tweets in March, a different term in addressing Autism, namely *berkebutuhan khusus* (special needs), emerged. This term was then added to the initial keywords in data collection process for the remaining two months of the second period. This resulted in a larger amount of tweets (n=2541); however, after implementing a filtering process in order to eliminate any content not related to Autism and ensure a de-duplicating (eliminating duplicated tweets) process was done, the final number of tweets for both 3-month periods came to 451. The results can be seen in Table 4.

This total number of tweets (n = 451) is the sampling data used for analysis to answer the aforementioned research questions, which will be discussed in the following section.

Table 4. Total tweets on Indonesian Twitter using keywords per 3-month period

Time period	Tweets using the keywords <i>Autisme</i> (Autism), <i>Autistik</i> (Autistic), <i>Autis</i> (Autist) and <i>keragaman saraf</i> (neurodiversity)	Tweets using the keyword <i>berkebutuhan khusus</i> (special needs)
November 2017 to January 2018	60	NA
March to May 2018	122	269
Total tweets	451	

7.3. Data analysis

7.3.1. Main issues about Autism discussed on Indonesian Twitter

The first research question asked what main issues about Autism are being discussed on Indonesian Twitter. As explained in the previous section, I use the framework from previous studies by Tang and Bie (2015), Kang (2013), Bie and Tang (2014), and Jones

²⁰ Since 2007, *bulan kepedulian Autisme sedunia* (Autism awareness month) has been celebrated widely in Indonesia. Its aim is to provide support and increase acceptance for people with Autism. Some leading Autism organisations in Indonesia such as YAI and MPATI have been using this moment to increase public awareness by conducting public events; recent events include Walk for Autism and Light It up Blue (LIUB) events. However, members of Autism communities globally have started to facilitate protests against Autism Speaks – who initiate both Autism awareness month and LIUB – due to their use of biomedical discourse and fear-based rhetoric in their campaigns (Parsloe & Holton, 2018).

and Harwood (2009) to develop 10 subcategories of issues for this study (see Table 3). The first category addresses infrastructure and access issues, e.g. issues about the need and access for facilities, places and services about Autism. The second category describes issues that are medical- or science-related, e.g. scientific advancements in Autism-related research and content about Autism risks, diagnosis, causes and treatments. The third category refers to charity issues, e.g. fund-raising, donation and community support, and Autism-related events. The fourth category refers to a personal or family story, e.g. conversations regarding personal stories of an Autistic or of a family member with an Autistic relative. The fifth category describes a celebrity story, e.g. conversations about a celebrity who is diagnosed with Autism or has an Autistic family member. The sixth category addresses issues relating to a social or legal case, e.g. Autistic people as either the perpetrator or victim of a crime or involved in a legal case, and the seventh category refers to policy issues, e.g. conversations on policy and regulation relating to Autism. The eighth category describes an art and cultural activity, e.g. art, films and fiction about Autism or cultural/artistic/athletic achievements of Autistic people, while the ninth category refers to politics or political commentary, e.g. conversations on Autism which are related to a political situation. The politics/political commentary category appears later; when doing the data collection and coding process I found some tweets that referred to the political situation in Indonesia – which I added later to the framework. The last category addresses the misuse of the word Autism, e.g. the erroneous use of the term to refer to introverted personalities or unsocial behaviours.

After the coding process was done, I searched and calculated the most frequent issue that appeared in tweets from the sampling data. The result can be seen as follows:

Table 5. Frequency of issues in Autism-related tweets on Indonesian Twitter

No	Issue	Count	Percentage %
1	Art and cultural	95	19
2	Charity	82	16
3	Medical and science	76	15
4	Infrastructure and access	68	14
5	Social and/or legal case	44	9
6	Politics or political commentary	32	6
7	Personal or family story	31	6
8	Misuse of the word Autism	15	3
9	Celebrity story	8	1.6
10	Policy	2	0.4

As seen in Table 5, the most prominent frames – or the top four categories – that frequently appear on Twitter are art and cultural activity, charity, medical and science, and infrastructure and access. This finding is similar to previous studies about newspapers’ Autism coverage outside Indonesia, in the US, Australia and China (Bie & Tang, 2014; Jones & Harwood, 2009; McKeever, 2013). These studies indicate that the most frequent Autism issues covered in newspapers are issues related to funding and donations, science and medical research, education and infrastructure, and also popular media such as articles related to books, television programmes and movies with Autistic characters (Jones and Harwood, 2009, Bie and Tang, 2014, McKeever, 2013).

In this analysis part, five tweets were selected as examples for each top 4 category. The samples were chosen based on ‘top tweets’ – tweets that were most retweeted and received most ‘likes’. This process was done by using the Top Meta Explorer feature in the DiscoverText search.

- **Art and Cultural Frames**

The first category is art and cultural activity; this was found in tweets related to arts and cultural events held in Indonesia to celebrate Autism awareness month, for example art and cultural performance, painting and photography exhibitions. As seen in Table 6, it was identified that some descriptions of Autistic people in these tweets include individuals who had special or outstanding talents and skills – indicated by using the words “amazing” and “extraordinary” – despite having Autism. This reflects the supercrip model in Clogston’s traditional model, where disabled persons are portrayed as “amazing” because they function “normally, in spite of their disabilities” (Clogston, 1994). The word extraordinary is also used to praise the effort of the community in providing space for Autistic students to express themselves.

Tweets in this category also contain information about popular movies and television series portraying Autistic characters such as TV shows *Atypical* and *The good doctor*, and the movie *Please stand by*. This form of popular culture is seen as a useful reference for understanding Autistics as people who have a different way of thinking to others, as shown in the last tweet in Table 6. Since most of the tweets are in Bahasa,

I provide the free translation of tweets in Bahasa (the original tweets in Bahasa are written in italic).

Table 6. Examples of tweets on Indonesian Twitter following the art and cultural activity frames

Tweets
<p><i>How Creative Are the Children with Special Needs in Autism Awareness Festival</i> http://bit.ly/2JTznZZ: <i>Children with Autism could have achievements. They prove it with performing in Autism Awareness Festival (kumparan.com)</i></p>
<p>RT @979FeMaleRadio: <i>FeMalicious, apakah Anda pernah mengenal atau bertemu dengan ABK (Anak Berkebutuhan Khusus) yang membuat Anda kagum?</i> #JoyParenting #HappyMorning #IndyKinos</p> <p>RT @979FeMaleRadio: <i>FeMalicious, have you ever met with ABK (Children with Special Needs) that amazed you?</i> #JoyParenting #HappyMorning #IndyKinos</p>
<p><i>This child has symptoms of Autism... but he has extraordinary skill than typical kids... the <i>adzan</i> [call to prayer in Islam –ed] that he recites sounded more melodious than the sound of other chants. May Allah SWT gives him health and ease in life. Do not be discouraged brother cc @fahiraidriss</i></p>
<p>RT @akbarfarraz: <i>The way <i>gfja</i> [the name of an art gallery, –ed] and <i>Spectrum</i> gives photography lesson to ABK (special needs children) to give them some space to express themselves as who they are rather than forcing them to be what “normal people should be” is really extraordinary. Thanks for the inspiring exhibition!</i></p>
<p><i>Menurut saya, TV series ini bagus sekali. Kita bisa tau bagaimana perspektif tentang dunia ini dari seorang autis. Bagaimana susah nya ia mengerti dunia ini tanpa cemoohan.</i></p> <p>In my opinion, this TV series (Atypical) is great. We can understand how the perspective of this world from an Autistic. How difficult it is for him to understand the world without being mocked.</p>

The supercrip frame also appears in other tweets in art/cultural category – besides the examples in the table – such as tweets emphasising extraordinary skills as outlined previously or in those covering the opening of a local government facility for Autistics as seen below:

Pemprov @DKIJakarta ingin menunjukkan apresiasi kepada anak berkebutuhan khusus, karena mereka punya bakat istimewa.

Local government of @DKIJakarta wants to show appreciation to special needs children, because they have special talents.

Anak Berkebutuhan Khusus Lukis TransJ, Wakil Gubernur DKI Sandi: Semoga Jadi Inspirasi.

Special needs children paint TransJ buses, Jakarta's Deputy Governor hopes they can inspire others.

The use of the second model, supercrip framing, can be seen clearly in these tweets – portraying Autistics as children with special needs who have special talents that can inspire other people. This “inspirational supercrip” frame is criticised for reinforcing the idea that disabled people’s achievements “are amazing for someone who is less than complete” (Haller & Zhang, 2014). However, in their study about the impact of American mass media for person with disabilities, Zhang & Haller (2013) argue that the supercrip model can be more empowering compared to the other models. People with disabilities may experience positive feedback from the supercrip model, as this portrayal can affect their self-identity positively (Zhang & Haller, 2013). As discussed in the previous chapter, the inspirational supercrip portrayal is likely viewed as a positive image for people with disability in Indonesia. This portrayal is also found to be favourable by Twitter users, as indicated in this tweet:

Gak tau ya lagi suka banget film film yg anak kecil walaupun berkebutuhan khusus tapi mereka berbakat pintar kaya wonder, gifted.

Don't know why but I currently love movies about children with special needs. They have special needs but they also have extraordinary talents such as having 'wonder' brains, gifted.

On the other hand, the supercrip model, which is highly represented in news media and in the entertainment industry, can lead to a biased public understanding of Autism, for example, creating false expectations and reinforcing a ‘savant’ stereotype for Autistic people (Draaisma, 2009; Tang & Bie, 2015). However, some news media accounts on Twitter, such as @BeritaKBR (a radio news network organisation) have put some effort into questioning the stereotyping of the Autistic savant, while still focusing on the children. The news organisation conducted an interview with Melly Budhiman, a child psychiatrist who is also a prominent figure in Autism, to confirm the false stereotyping surrounding Autistics as savant people with lack of emotional empathy:

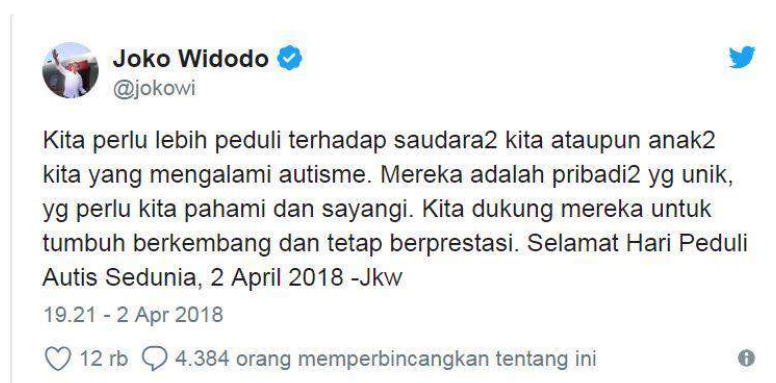
Anak Autisme biasanya cerdasnya diatas rata-rata dan tidak memiliki emosi dan tidak bisa merasakan kasih sayang? Bener gak sih? Kita tanyakan ke Ketua Yayasan Autisma Indonesia, Melly Budhiman di #SaatnyaBertanya! #KBRPagi, sekarang.

Is it true that children with Autism usually have very high intelligence, but lack of emotion and affection? We will ask those questions to Melly Budhiman, the chairperson of YAI, in #SaatnyaBertanya! #KBRPagi, now. – @BeritaKBR.

- **Charity frame**

The second prominent category – the charity frame– contains information related to charitable donations and community events in support of both Autistic individuals and Autism organisations (Tang and Bie, 2015). This frame frequently appears on Twitter and is related to various events during the Autism awareness month celebration in April. In the tweets that fit the charity issue, most of them depict the Autistic person as individuals that need to be understood, as well as an understanding of the need for support and charity, as seen in the following examples (see Table 7). This includes the tweet from the President of Indonesia Joko Widodo, as he made a statement on Twitter to commemorate Autism awareness month (Figure 1 and translated below). This tweet received a large number of responses – 12,000 likes and more than 4000 conversations relating to the thread:

Figure 1. Most prominent tweet on Indonesian Twitter following the charity frame



We need to care more about our brothers, sisters and our children who have Autism. They possess unique personalities that we need to understand and care about. We support them to grow and to have

great achievements. Happy Autism Awareness Day, April 2, 2018 – @jokowi.

Table 7. Examples of tweets on Indonesian Twitter following the charity frame

Tweets
<p>Thank you for the participation of our friends # walk4Autism and #grandindonesia who have facilitated our event, until we meet at the next event #walk4Autism #walkforAutism #walkforAutismJKT</p>
<p>RT @RSColumbiaAsia: <i>Autisme bukanlah penghalang bagi mereka untuk berkarya. Mari cintai, pahami serta berdayakan wanita dan anak perempuan dengan Autisme.</i> Happy World Autism Awareness Day!</p> <p>RT @RSColumbiaAsia: Autism is not a barrier for people with Autism to work. Let's love, understand and empower women and girls with Autism. Happy World Autism Awareness Day!</p> 
<p><i>Ternyata Cosmoners, Anak Berkebutuhan Khusus ini harus diberikan tempat untuk lebih berkembang terlepas dari terapi dan pendidikan formal yang sudah diterima agar merasa eksistensinya dihargai.</i></p> <p>Cosmoners, as a matter of fact children with special needs have to be given space to develop themselves, so they can view their existence were appreciated, despite therapies and formal education they had received.</p>
<p><i>Melalui #walk4Autism ini YAI mengajak masyarakat berpartisipasi dalam kampanye ini sehingga dapat melihat sendiri dan menyadari bahwa individu autistik adalah bagian dari kita, yg dapat mandiri, mempunyai kemampuan & dpt bekerja sama. #jakartawalk #Autismawareness</i></p> <p>With this # walk4Autism event, YAI invites the public to participate in this campaign so that they can see for themselves and realise that Autistic individuals are part of us, who can be independent, have the ability & can work together. #artartawalk #Autismawareness</p>
<p>Nuha (Person with Autism)</p>

Some Support World Autism Awareness Month, add a #Twibbon #walkforAutism #walk4Autism #Autismawareness #Autismawarenessmonth #walk4Autism2018 #walkforAutism2018 #jakartawalk #LightItUpBlue



From the previous examples in the charity frame, we can see different ideas emerging. Most tweets focus on giving support and offering opportunities to certain groups such as Autistic children, women and girls (see Table 7, row 2 and 5, for examples); while another tweet (see row 4) invites public participation to join an event (YAI’s Walk for Autism event) for campaigning Autism acceptance. These tweets reflect more of Clogston’s progressive model, particularly the minority/civil rights model, as the messages bring issues of awareness and inclusiveness, as well as give support for Autistics to have independent lives. It is also worth to note that there was likely a misunderstanding about portraying Autistic, as the tweet from @RSColumbiaAsia (a regional network of medical facilities) uses a picture of a Down syndrome girl to represent an Autistic girl, which possibly could lead to confusion for the readers.

However, the traditional model is also seen in a tweet from @CosmopolitanFM – a local radio station account – who emphasises on Autistic children (refers here as special needs children) as passive recipients for parents’ support, “so they can view their existence were appreciated” (Table 7, row 3). This tweet reflects more on social pathology model, where people with disabilities are portrayed as disadvantaged and economically dependent on state and society (Clogston, 1994; Haller & Zhang, 2014).

Some content regarding the issue of charity also relates to popular keywords which frequently appear in a large number of tweets such as “Autism awareness month”, “walk4Autism”, “awareness day”, “Autism day” and “Autism Speaks”, the US-based organisation that runs research and funding for Autistics. Popular hashtags – including #walk4Autism, #walkforAutism, #walkforAutismJKT, #jakartawalk, #walk4Autism2018 and #walkforAutism2018 – refer to the popular event held by YAI. Hashtags, which are represented by the number sign (#), are commonly used in

a tweet or other social media messages to denote that a message is relevant to a particular topic (Guo & Saxton, 2014). In this case, the popular hashtags are used to serve the information and action function for the tweets. The action function of the messages is to get followers to attend the tagged event, while the information function promotes updated information and live reports related to the event.

- **Medical and science frames**

The third prominent category – the medical and science frames – describes tweets about assessment, intervention, therapies, remedies, news related to science and research about Autism, and also technological support and medical inventions related to Autism. The example tweets in this category emphasise issues about symptoms, the prevalence of Autistic people in Indonesia, mobile apps for therapy, and also address the ‘deficit’ traits among Autistic children which are often seen as behaviour problems (Table 8).

Table 8. Examples of tweets on Indonesian Twitter following the medical and science frames

Tweets
<p>RT @BBCIndonesia: <i>Penelitian unkap gejala-gejala Autisme sejak bayi</i></p> <p>RT @BBCIndonesia: Research revealed symptoms of Autism in infant</p>
<p>RT @earnigh: <i>Memiliki anak berkebutuhan khusus itu memang membutuhkan kesabaran luar biasa, apalagi jika anak itu mengalami gangguan emosi</i> #InvisibleDisabilityAwareness</p> <p>RT @earnigh: Having a child with special needs does require tremendous patience, especially if the child has emotional disturbances, behavioral disorders, personality disorders, developmental disorders, and other disorders #InvisibleDisabilityAwareness</p>
<p><i>Spokle App, aplikasi mobile bantuan untuk orang tua dengan anak berkebutuhan khusus</i></p> <p>Spokle App, a mobile application to support parents of special needs children</p>
<p>#LiveTweet shinta: <i>sering kali anak yang menderita Autisme/autistik dinilai aneh karena sibuk sendiri dan bertingkah laku yang tidak wajar</i> #KlinikRPK #RPKFM</p> <p>#LiveTweet shinta: most of the times, the children suffering from Autism/Autistic are seen as weird, because they are immersed with themselves and showing inappropriate behaviour #KlinikRPK #RPKFM</p>

RT @kpp_pa: Sahabat Perempuan dan Anak, tahukah anda bahwa setiap 2 April merupakan Hari Peduli Autisme (World Autism Awareness Day)? Merujuk pada Incidence dan Prevalence ASD (Autism Spectrum Disorder), penyandang Autisme di Indonesia diperkirakan sebanyak...

RT @kpp_pa: Friends of Women and Children, did you know that every April 2nd is the World Autism Awareness Day? Referring to the Incidence and Prevalence ASD (Autism Spectrum Disorder), Autistic people in Indonesia are estimated as many as ...



Clogston’s medical model is represented heavily in the medical and science category by addressing issues of symptoms, treatments, early detections and dependencies on health professionals. This includes tweets from news media accounts (@BBCIndonesia, the official account of BBC news office in Indonesia and @963RPFKM, the official account of Radio Pelita Kasih) and government institution account (@kpp_pa, the official account of KPPA, the Ministry for Women Empowerment and Child Protection). It is worth to note that some of the tweets used traditional terminology to address Autistic (e.g. *anak yang menderita Autisme* or “children suffering from Autism”) and focus on traditional message (e.g. addressing deficit behaviours that require “tremendous patience” from the parents or caregivers). There were also tweets that perceive Autism as a disorder that can be cured (not included in the example in Table 8):

"AUTISM IS CURABLE" *Ya. Autisme dapat disembuhkan. Itu bukan kata saya. Itu kata Kak Kresno, saudara...*
<http://fb.me/2ZzeiRL61>

“AUTISM IS CURABLE”. Yes. Autism can be cured. This is not my statement. That is according to Kak Kresno’s word, fellows ...
<http://fb.me/2ZzeiRL61>

The tweet quotes a local psychiatrist’s book titled *Autism is curable*²¹ which indicates an opinion that Autism is something that can be cured, despite the fact that Autism is a lifelong disability of biological origin (Dodd, 2005).

- **Infrastructure and access frames**

The next prominent issue is the infrastructure and access frames; it’s the fourth most prominent Autism-related issue discussed on Twitter. Tweets in this category are largely discussing the lack of health expert in handling Autism and the lack of access for special needs children (including Autistic). The conversations in this category also allude to the government’s responsibilities to provide infrastructure and services for Autistic children. The tweets emphasise the lack of inadequate support and access for Autistics, and the efforts from the government and the parents to provide facilities and support (see Table 9). However, it is worthy to note that all the example tweets in this frame came from the media, mostly from online news sites (indicate by tweeting the headline and the shortened link at the end of the tweet) and one tweet from a local radio station (see Table 9, row 4).

Table 9. Examples of tweets on Indonesian Twitter following the Infrastructure and access frames

Tweets
<p><i>Masih Minim, Anak Berkebutuhan Khusus Melanjutkan Studi ke Perguruan Tinggi</i> http://dlvr.it/QQk8G7</p> <p>Only A Few Special Needs Children Can Study in University http://dlvr.it/QQk8G7</p>
<p><i>Risma Resmikan Pusat Anak Berkebutuhan Khusus, Berharap Einstein Baru</i> http://dlvr.it/QQk8G7</p> <p>Risma Opens the Centre for Special Needs Children, Hoping There Will Be New Einstein http://dlvr.it/QRsr1D</p>
<p>RT @republikaonline: Tenaga Ahli Autisme di Indonesia Masih Terbatas https://t.co/q8EmsBGmXq</p> <p>RT @republikaonline: Autism Experts in Indonesia Are Still Limited</p>

²¹ The book *Autism is curable, benar Autism dapat disembuhkan* (trans. *Autism is curable, it is true that Autism can be cured*) was published in 2016 by Dr Kresno Mulyadi, SpKJ, and Dr Rudy Sutadi, SpA, MARS. The first author is a psychiatrist and the second author is a paediatrician – both are known as health practitioners who deal with Autistic children in Indonesia. Years before they published the book, both authors have faced criminal charges in different cases. Dr Kresno was charged of fraud in 2006 (Burhani, 2006) while Dr Rudy was imprisoned in 2004 due to a number of charges, including falsifying papers and sexual harassment of minors (Tucker, 2013b).

<https://t.co/q8EmsBGmXq>

90.4 | *Dari pengalaman ketiga srikandi ini, mereka memberanikan diri untuk mendirikan Rumah I'm Star yaitu rumah kerja untuk Anak Berkebutuhan Khusus.*

90.4 | Based on the experience from these three *srikandi* (trans. wonder women, in this tweet refer to mother of Autistics) they made an effort to establish “I’m Star”, a job training centre for children with special needs.

Pemprov DKI, lanjutnya, berkomitmen untuk memfasilitasi lebih banyak lagi dan menampung keperluan ABK (Anak Berkebutuhan Khusus). <http://www.hidupkatolik.com/2018/05/14/21319/karya-abk-di-transjakarta/>

<http://www.hidupkatolik.com/2018/05/14/21319/karya-abk-di-transjakarta/>

Jakarta Provincial Government, he added, is committed to facilitate and accommodate the needs of ABK (Children with Special Needs) .<http://www.hidupkatolik.com/2018/05/14/21319/karya-abk-di-transjakarta/>

<http://www.hidupkatolik.com/2018/05/14/21319/karya-abk-di-transjakarta/>

In this category, the progressive model is presented in some tweets, emphasising the accessibility rights for Autistics, particularly for focusing on access to education and facilities from the government. However, Autistic people are mostly portrayed by the media as ‘children’ or ‘children with special needs’ in addressing the issue for infrastructure and access (e.g. “Only A Few Special Needs Children Can Study in University”).

The supercrip model is also presented in a tweet (Table 9, row 2). The tweet represents Autistics as savant, and appears in a headline news “Risma Opens the Centre for Special Needs Children, Hoping There Will Be New Einstein”. The news covers the event of an opening ceremony for a newly built Autism therapy centre in Surabaya – a provincial city in East Java. At the opening ceremony, Risma – the Mayor of Surabaya – shared her high hopes that Autistic children could have extraordinary achievements like the famous scientist Albert Einstein. Her statement had been quoted by numerous mass media in Surabaya (e.g: “During the Opening Ceremony, Risma Motivates Special Needs Children to be Like Einstein”). This description related to the ‘supercrip’ model, referring to them as people who have extraordinary skills or who are ‘savant’ despite their disabilities. This stereotyping image of portraying Autistic as savant is commonly found in Indonesian Twitter – as described in a tweet from a private hospital Twitter account:

Autis Savant atau Savant Syndrome: tipe anak ini memiliki tingkat kecerdasan yang luar biasa. Yuk kenali karakteristik & fakta

menarik mengenai Autis Savant di:
<https://t.co/twdske7ns3#rscolumbiaasia> #infokesehatan #Autisme
#savantsyndrome #healtharticle #columbiaasiaindonesia

Autism Savant or Savant Syndrome: This type of children have an extraordinary level of intelligence. Let's recognise the characteristic & interesting facts of Autistic Savant at:
<https://t.co/twdske7ns3#rscolumbiaasia> #infokesehatan #Autisme
#savantsyndrome #healtharticle #columbiaasiaindonesia

The savant syndrome, popularised by the fictional character in the 1988 movie *Rain man*, is an outstanding cognitive skill above the population norm. A previous study by Draaisma (2009) found that many fictional Autistic characters are represented as savants with a special talent, despite savantism being rare among Autistic people (Draaisma, 2009).

7.3.2. Indonesian Twitter users' framing of Autism

The second research question asked how Indonesian Twitter users frame the issues of Autism. Despite there being different views regarding an understanding of Autism, most of the tweets perceive Autism as a neurological and developmental disorder that can be detected from an early age. The conversations around Autism are also mainly medical-based, discussing treatments and offering problem-solving strategies such as intervention and therapy programs. This again reflects more on Clogston's medical model in the traditional categories, where people with disabilities are portrayed as dependent on health professionals for cure and maintenance (Clogston, 1994). The finding in this study also resonates with a previous study by Satvikadewi (2014) about the discourse on the term Autism on Indonesian Twitter which indicates that one of the understandings about Autism constructed on Twitter refers to Autism as a disorder, disease or illness. In her study, this medical frame is indicated through a series of tweets using particular medical-related terms such as "Autistic sufferers", "DSM V" and "Autism disease" which represent the meaning of Autism as a condition that shows symptoms of illness (Satvikadewi, 2014).

However, despite the fact that Autism is a developmental disorder which begins in childhood and has a tendency to persist to adulthood (WHO, 2019), in my findings Autism is still largely perceived by Twitter users as a disease and illness to be cured,

and therefore one that should be prevented (see Table 10, row 2, for example). Nevertheless, there are also other points of view reflected in some tweets – namely seeing Autism as a different condition and a unique way of thinking (see Table 10, row 3). This point of view reflects the progressive model, particularly the cultural pluralism – as the tweets emphasise the differences of Autistics and how people should appreciate human differences.

Another interesting finding relates to the issue of religion. There are tweets which share stories and interviews from both famous ulemas – Muslim scholars or experts who are recognised as having specialist knowledge of Islamic sacred law and theology – and Muslim preachers about how to deal with Autism and how to handle Autistic children. In particular, one of the topics from the interviews with a Muslim preacher is about “how to take care of Autistic children as a mandate from Allah”. As such, religion forms one of the frames for Twitter users to discuss the meaning of dealing with and having a family member with Autism. For example, having Autistic children is viewed as both a test and a gift from God.

This resonates with previous findings of parents of Autistic children in Indonesia and also of parents from Muslim and South Asian backgrounds in the US. Parents regard their children as gifts from Allah the Almighty and they feel blessed that He chose them to be special parents (Jegatheesan et al., 2010, Hersinta, 2012). In this case, religion acts as the primary frame that helps parents understand the meaning of having Autistic children²² (Hersinta, 2012; Jegatheesan et al., 2010). To conclude the answer for RQ2, these four frames were appeared on tweets discussing Autism:

Table 10. Indonesian Twitter users’ framing of Autism

Twitter users’ framing of Autism	Examples of tweets
Autism as a disorder	<i>Autisme adalah gangguan perkembangan saraf yang kompleks dan ditandai dengan kesulitan dalam...</i>

²² Regarding the influence of religion in understanding disability, it is worth to note a reference from the late Mansour Fakhri, an Indonesian disability rights activist (1953-2004). Fakhri’s emphasis on Islamic view provide a unique understanding on disability in Indonesia: “The value of a human in the eyes of Allah lies in the individual’s faith and obedience to Allah, not in their physical, intellectual and mental features” (Suharto et al., 2016). This view seems to reflect in some tweets I found during the data collection period.

	<p>Autism is a complex development neurological disorder, indicates by difficulties in...</p>
	<p><i>Apakah anda tau Autisme atau Autism Spectrum Disorder (ASD) tak hanya mencakup Autisme?</i></p> <p>Do you know that Autism Spectrum Disorder (ASD) includes not only Autism?</p>
<p>Autism as a disease/illness</p>	<p><i>Penyakit mental ini mulai berkembang saat anak-anak, dan sangat sulit untuk didiagnosa karena belum ada pengobatan atau tes darah untuk memastikannya. Jenis-jenis Autism antara lain, Autistic disorder, Asperger syndrome, dan Atypical Autism.</i></p> <p>The mental illness starts to develop in childhood, and it is hardly difficult to diagnose because there is no treatment or blood test to confirm it. Autism has a number of categories, namely Autistic disorder, Asperger syndrome, and Atypical Autism.</p> <hr/> <p><i>Seandainya kita memiliki Grand Design pencegahan dan penyembuhan Autisme di Indonesia. Bisa jadi ini adalah upaya bersama untuk mengurangi Lost Generation Indonesia 15-20 tahun yang akan datang. Semoga bisa didengar sama pemangku kebijakan.</i></p> <p>Hoping we could have a Grand Design to prevent and cure Autism in Indonesia. This could be our effort to reduce the Lost Generation Indonesia for 15-20 years to come. Hopefully the policy makers can listen to this suggestion.</p>
<p>Autism as a different condition</p>	<p><i>Menurut saya, TV series ini bagus sekali. Kita bisa tau bagaimana perspektif tentang dunia ini dari seorang autis. Bagaimana susah nya ia mengerti dunia ini tanpa cemoohan.</i></p> <p>In my opinion, this TV series (Atypical) is great. We can understand how the perspective of this world from an Autistic. How difficult it is for him to understand the world without being mocked at.</p> <hr/> <p>The most interesting people you'll find are ones that don't fit into your average cardboard box. They'll make what they need; they'll make their own boxes (Dr Temple Grandin).</p>
<p>Autism as a gift and test from God</p>	<p><i>Memiliki anak berkebutuhan khusus, termasuk autistik, memang ujian...</i></p>

	Having a child with special needs is indeed a test...
	<p>90.4 Menurut Ibu Unun, Anak Berkebutuhan Khusus ini merupakan mitra taat orangtua. Bagaimanapun juga anak-anak spesial ini adalah karunia dari Tuhan YME.</p> <p>90.4 According to Mrs Unun, children with special needs is a pious partner for parents. However, these special children are a gift from God the Almighty.</p>

7.3.3. The portrayal of Autistics on Indonesian Twitter

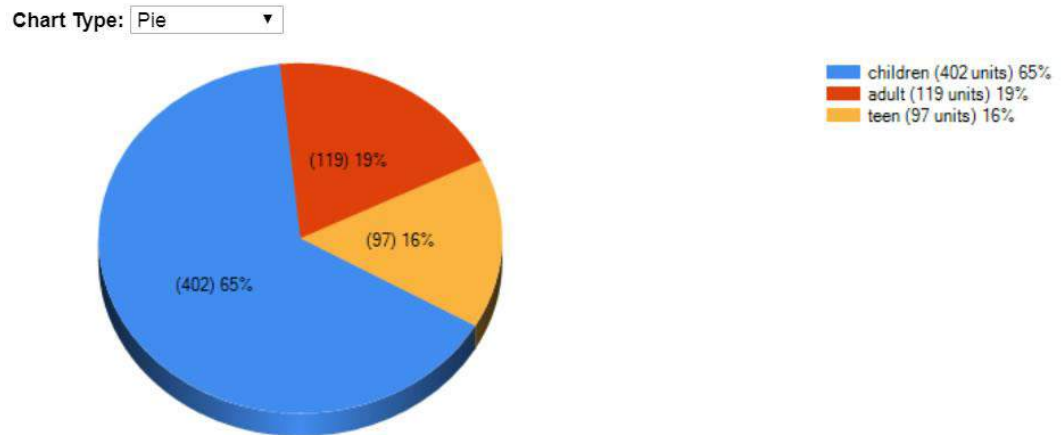
The third research question asked how Autistics are portrayed on Indonesian Twitter. From the majority of the tweets, it was found that it is mostly Autistic children who are discussed (65%), while other age groups (adult and teen) are only represented in smaller numbers (see Figure 2). Previous studies on Autism representation in British and Chinese newspapers also find similar evidence portraying Autism as a condition that primarily affects children (Huws & Jones, 2011, Tang & Bie, 2015). This over-representation of Autistic children also presents in the US, where stories about Autistic children are the top issue in television news coverage (Kang, 2013). This biased portrayal of Autistics could lead to a tendency to view Autism “as a condition that only affects infants and children” (Tang & Bie, 2015).

In a study by Stevenson et.al. (2011) Autistic children are portrayed in 79% of most of the contemporary US news media regarding Autism. This media portrayal contributes to a broader culture of “infantilising Autism” (Mann, 2019; Stevenson, et al., 2011). The same study states that infantilisation of Autism is driven by two factors. Firstly, from the stereotype of the “eternal child” in disability history. Secondly, due to the ‘unique’ development of the concept of Autism – which largely depicted as “a child-bound disability” by a number of parent-driven Autism societies, Autism fundraising charities, and also mass media portrayals in news and entertainment content (Stevenson et al., 2011).

Similar evidence of this phenomenon is also found in Indonesia; as explained in the previous chapter, most data and published studies about Autism in Indonesia are focused on children. More references and data about Autistic adults in Indonesia are

significantly needed, as their presence – as children – was identified around 30 years ago at the beginning of the 1990s.

Figure 2. Representation on Indonesian Twitter of Autistics by age group



In addition, I used the cloud explorer feature in DiscoverText to reveal the most popular keywords being tweeted when searching for frequent terms used in addressing Autism and Autistics (see Figure 3).

Figure 3. Cloud explorer for popular keywords on Autism on Indonesian Twitter



It is not surprising that the particular terms *berkebutuhan khusus* and *anak berkebutuhan khusus* (special needs and special needs children) are the most frequent terms used when tweeting about Autism-related issues and addressing Autistic people and children. As explained previously in the data collection part of this chapter, terms such as ‘autist’ and ‘Autistic’ – terms that align with identity first language (IFL) and which have been associated with the neurodiversity movement (Runswick-Cole, 2014;

Shakes & Cashin, 2020) – were used in the first period of data collection for this thesis. However, using these words resulted in fewer returns compared to the second period of data collection which, with the added keyword of *berkebutuhan khusus* (special needs), generated more tweets. While this term is considered as a disability euphemism (Gernsbacher et al., 2016), in Indonesia it can be widely found in daily conversations and in formal use²³. As discussed previously in chapter 5, the term is often used to address people (and children) with disability, including Autistics. The term is still used largely in education area, including in the government legal documents for national education, for example *Undang-undang Republik Indonesia No. 20 tahun 2003 tentang Sistem Pendidikan Nasional*²⁴ (trans. *Law Number 20/2003 on National Education*) (Suharto et al., 2016).

From my personal discussion with the Commissioner of the Indonesian Medical Doctors' Council, Leila Mona Ganiem, she notes that the term special needs is still used in the 2003 Law on the National Education System (personal communication, 2020). Regarding this issue, she agrees that it is necessary to have agreement and use the correct term in the country's regulations, a term that is more specific in addressing people with Autism and considered fair to the related community (personal communication, 2020). The language used to describe people with disability reflects contemporary understandings of the place of people with disability within a given social context.

- **Stigma and discrimination toward Autistic**

As discussed previously in chapter 5, Autistic persons likely experience stigma and discrimination toward their condition, and this is no exception to Indonesia. In some tweets, Autistic people are still largely described as a victim or a victimised group, and

²³ As a parent of Autistic son, I noticed most of my peer parents prefer to use the term 'special needs' because it is a common term in Indonesia to refer Autistic. In a WhatsApp group discussion with other parents of Autistics, some state that they prefer the term because it is broader and more inclusive as it also represents those with comorbid conditions, e.g. Autistic with ADHD, dyspraxia, dyslexia and other learning difficulties.

²⁴ In the legal document, the term "special education" refers to a specialised education program provided for learners who have difficulties in following a standardised learning process due to physical, emotional, mental or social deficiencies, and also for those with proven intelligence or who are especially gifted (Act of the Republic of Indonesia on National Education System, 2003).

they are also seen as a part of a vulnerable group – being discriminated against or bullied. As one tweet stated:

... Mayoritas masyarakat Indonesia masih diskriminatif kok. Penyandang Autisme dan gangguan neurodevelopmental disorder lain juga didiskriminasi. Bully > diskriminasi terhadap yang lemah. Pokoknya, di negeri ini pemikiran orang harus yang umum aja.

... The majority of Indonesian people are still discriminative. People with Autism and other neurodevelopmental disorders are also discriminated against. Bully > means discrimination against the weak. In this country, obviously, people should think in a mainstream way.

This tweet seems to criticise the discrimination and bullying faced by disabled people in Indonesia, including Autistics, and ends with a satirical statement that having a “mainstream” way of thinking is much more acceptable. Other tweets also appear to include stereotyping and stigma in addressing Autistic people. For example, being Autistic is perceived as also being a person with bad behaviour, possessing a weird attitude or being categorised as abnormal and mad, as seen in the following tweets:

#infojabar Sebagian Masyarakat Indonesia Masih Menganggap Pengidap Autisme Sama dengan Orang Gila <http://dlvr.it/Q4n68x>

#infojabar Some Indonesians Still Consider Persons with Autism are Similar to Mad People <http://dlvr.it/Q4n68x>

@askmenfess Pernah ga ya tmn satu kelas gw fisiknya normal tp otaknya rada2 gitu itu termasuk berkebutuhan khusus ga? Trs anak sekelas pada mandang rendah soalnya dia sampe pernah nyolong :(

@askmenfess Have you ever had a friend like mine, he has a normal physical condition, but his brain is not normal, is he included in the special needs category? My classmates looked down on him, he once stole things :(

Gw liat seorang teman seperti orang yang Autistic dan idiotic, everyday my timeline full of his garbage.

I saw a friend who behaves like an Autistic and idiotic person, every day my timeline is full of his garbage.

In the last tweet, the Autistic person is viewed as “idiotic” who likes to tweet regarding nonsense issues. However, as discussed in the previous chapter, this kind of misuse of the word Autism and Autistic has often been criticised by the public, including Twitter

users. They share messages to the public as a part of an Autism awareness campaign, stating that misusing the word Autism as a joke and as negative labelling is wrong. I view this as a support to the neurodiversity movement – albeit using the term. By sharing such messages, they show their support in appreciating differences and countering the stigma of Autism as ‘anti social’ and Autistic as a person who exhibits bad behaviours.

In the second period of collecting the data from Twitter, a particular discussion emerged related to the Walk for Autism event. The event was held in Jakarta on April 2018 to celebrate Autism awareness month. However, recently there has been an increasing political tension relating to the Indonesian 2019 presidential election, and a heated debate has emerged regarding this event. A group of Autistic people was reported as being “victimised” for getting mocked by a group opposed to the current president; the group was being scoffed at for carrying a poster quoting Joko Widodo’s tweet about providing support for Autistics in Indonesia (Wicaksono, 2018). This incident incited a large response from Twitter users. Most protesters particularly come from the parents of Autistic children – who tweeted angrily to protest about the incident – and also from groups and individuals who are both the proponents and opponents of Joko Widodo. This will bring us to the next finding about parents as the majority voice when discussing about Autism on Indonesian Twitter.

- **The dominant voice: parental organisations and the news media**

By using the metadata values feature on DiscoverText, I filter the tweets to discover the ‘top users’ or most active users who posted tweets about Autism on Indonesian Twitter. As shown in Figure 4, Autism organisations are the top users, followed by news media, personal account and health industry (e.g. health facilities and therapy centres). The findings in this chapter indicate that news media still has a large influence on Twitter, as shown by the fact that 36% of tweets are in the form of news sharing as opposed to other type of messages (see Figure 5).

Figure 4. Most active users in Autism-related conversations on Indonesian Twitter

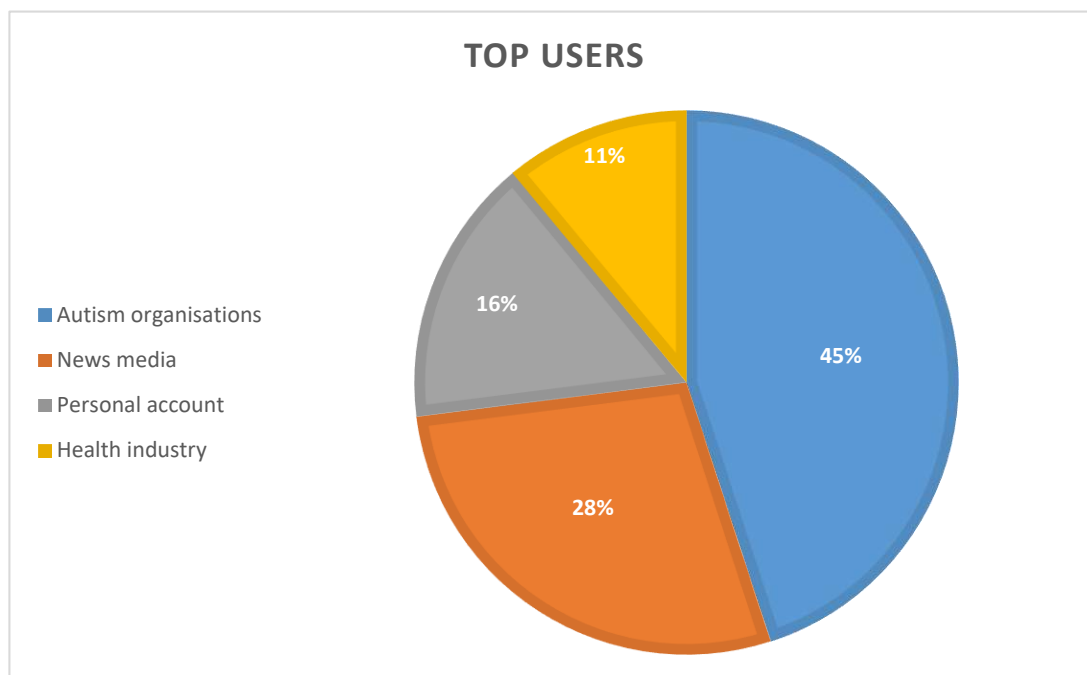
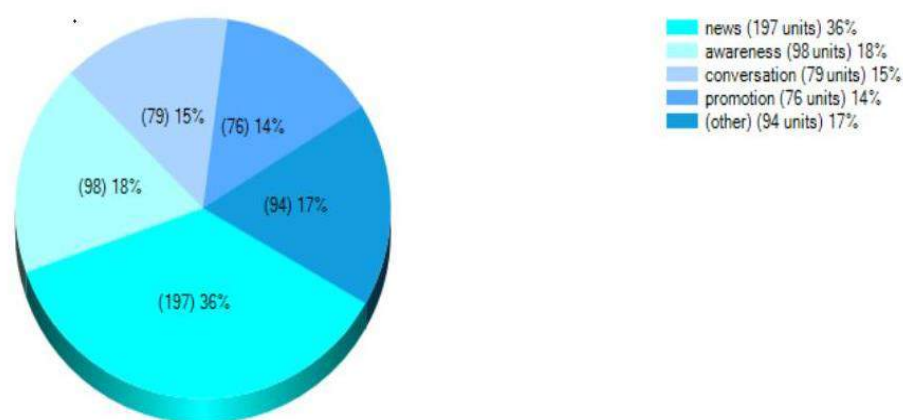


Figure 5. Type of Autism messages discussed on Indonesian Twitter



As discussed in chapter 5, parents-based Autism organisations have been actively campaigning in online platforms – starting from using websites and Yahoo mailing list – and currently using newer forms of online communication tools such as blogs, Facebook, Twitter and Instagram. YAI, for example, has joined the microblogging platform since 2009 and also has other Twitter account @PeduliAutisme (trans. care for Autism) and @walk4Autism_ID which served for their campaign purpose. These accounts, along with other parental Autism organisations and initiatives such as MPATI (@yayasan_mpati), Yayasan Biru Indonesia (@birukuindonesia) and others,

actively post tweets particularly in commemorating Autism Awareness Month. Time wise, there was a significant increasing in tweet amounts in April.

News media account is in the second position of top user category after Autism parent-based organisation (see Figure 4). In Indonesia, there is a tendency for mainstream topics in social media to follow the frames from traditional media, including retweeting/sharing/discussing content from mainstream media (Lim, 2011). From the data findings, news coverage about the events in Autism awareness month is the most popular topic being tweeted. As a result, trending topics on Twitter are largely event-driven and propelled by mainstream media. Meanwhile, issues about infrastructure and support for Autistics is the second most popular in the news category (see Table 11).

Table 11. Topics of Autism tweets on Indonesian Twitter in the news category

No	Issues	Amount
1	Event	67
2	Infrastructure and access	26
3	Medical and science	19
4	Personal and/or family story	16
5	Others	15
6	Supercrip/Inspiration	11
7	Education	8
8	Celebrity story	5

A previous study by Lim (2011) states that social media usage, including Twitter, largely comes from a particular socio-economic group – the urban elite group – making the majority of the content on Twitter reflect urban lifestyles topics and issues driven by mainstream media. This is also reflected in my findings, where the largest amount of tweets came from Indonesian news media accounts. The tweets reflected the stories and expressions of urban lifestyles, including as the most popular issue (art and/or cultural activity) and the least popular one (policy) (see Table 3).

As discussed before, the media largely focuses on children and uses the term ‘special needs children’ to refer to Autistics in their headlines, e.g. “Transjakarta Bus with Paintings by Special Needs Children”, “Thirty Scholarship Awarded for Special Needs Children in AutFest 2018 Event”, or “Commemorating Kartini’s Day, Special Needs Children Paint TransJakarta”. This overrepresentation as ‘children with special needs’ in news media shows the absent stories of Autistic adults in Indonesia, and suggests

that news about Autism is probably either framed to provide understandings of Autism as a condition that primarily affects those of childhood age or, as in this case, to infantilise Autism.

- **The minority voice: Autistic self-advocacy on Indonesian Twitter**

Besides the portrayal of Autistic person from non-Autistic point of views on Indonesian Twitter, the most interesting finding in this study perhaps are the tweets from Autistic persons themselves. Twitter users representing Autistic people, such as @anandasukarlan and @yarrayora, share stories and views from firsthand experience. For example, @anandasukarlan tweets about facts on being an Aspie to commemorate international disability day. He campaigns about #AspieIsAwesome and #AspiePower, promoting and raising awareness that being different should be viewed as a strength in someone's ability, not as a deficit. He posts articles and tweets about famous people who have Asperger's as inspirational stories, and shares his own experiences, including how his musical talent helps him to understand his emotions:

In case of Asperger's syndrome and other Autistic syndrome, I myself create music not to express my feelings or emotions, but to figure out my emotions. It is a common trait among Aspies that we sometimes don't understand what we feel. #aspiepower – @anandasukarlan

Another noticeable thread discussing neurodiversity issues is posted by @yarrayora, who mentions that she is an Autistic person. She tweets about the public's lack of understanding of neurodiversity and mental disabilities. One of her tweets explains that Autism is part of the neurodiversity spectrum by using the hashtag #keragamansaraf (neurodiversity in Bahasa):

Autism, ADHD, bipolar, dyslexia, dyscalculia, etc. are part of neurodiversity. Do not call us retarded or mad – @yarrayora.

Furthermore, @yarrayora also advocates on behalf of her identity as Autistic by communicating her disappointment to @AutismIndonesia – the Twitter account of YAI – due to their promotion of the Light it up blue (LIUB) campaign started by Autism Speaks²⁵. Autism Speaks is a US-based organisation which has been heavily

²⁵ The Light It Up Blue (#LIUB) campaign initiated by Autism Speaks has generated a large protest from Autistic self-advocates and communities. In April 2015, when the organisation urged followers to Light It Up Blue (#LIUB) for Autism Awareness Month, a counter-hashtag #WalkinRed emerged on

criticised by Autistic self-advocates for generating funds to undertake research and campaigns regarding preventing and curing Autism.

These examples show that Autistic adults in Indonesia, despite representing a minority group, can utilise the microblogging platform as an arena to provide a different discourse to that coming from news media. This reflects the progressive model and, although it is only represented in a small number of tweets, it should be pointed out as representing the minority voice, Autistic people themselves.

The expressions from Autistic accounts on Twitter show that the microblogging platform can serve as a channel for the minority group to share their voices. Through Twitter, they share their experiences as Autistic people and as multifaceted individuals, people with differences without focusing on the disability, something which reflects Clogston's cultural pluralism model. Their tweets provide diverse stories in which they can construct their own personal narratives and share it with the public. A tweet from @yarrayora protesting about the LIUB campaign, for example, also reflects the minority/civil rights model. This user represents the minority group who expresses her grievances to the other group, YAI, the Autism parental organisation. In this study, although the majority of tweets are largely representing the voices of Autism organisations and news media accounts on Twitter (see Figure 4), tweets from Autistic accounts such as @anandasukarlan and @yarrayora also represent the alternative voices, voices which can promote a fuller understanding of the concept of Autism to their audience.

7.4. Conclusion

In conclusion, the dominant frame in discussing Autism on Indonesian Twitter is still largely within the traditional model: medical, supercrip and social pathology or economic categories. Autistic persons in Indonesia are still mainly viewed within these three models, including portrayed as children – indicating the absence of Autistic adult in Indonesia. Despite this, the progressive model is presented in a number of tweets, particularly in art/cultural frames, charity frame and infrastructure/access frames –

Twitter – organised by #boycottAutismspeaks tweeters – to asked followers for Autism acceptance (Parsloe & Holton, 2018).

reflecting the conversations on Autistic rights for access and acknowledgement of Autism as a difference. The progressive model also appear in tweets from Autistic self-advocates who have started to voice their opinions against the majority voice and mark their presence as adult on the spectrum.

It is possible that the complexity surrounding the definition of Autism – as a broad spectrum with varying degrees related to the condition and the changing of diagnostic tools – also becomes a challenge to determine the Autism category. This complexity is also reflected in this study – shown by various degrees regarding the understanding of Autism on Indonesian Twitter. The findings indicate that viewers have different points of view – some view Autism as a disorder, others understand it as an illness, while some see it as a difference or categorise it as “special needs”. Defining Autism is difficult, as Autism itself is an “extraordinarily unstable category” – due to its broad spectrum and the vagueness of diagnostic category which resulted in an example of the ambiguity in defining (a category of) disability (Nadesan, 2005; Osteen, 2007).

The findings in this chapter offer an extension on studies in social media framing and disability – and framing in general –as previous studies suggest that media creators (eg. journalists and producers) could refer to the social media platform to listen and to include voices from Autistic people themselves in the news. However, there were also limitations regarding the findings in this chapter.

Firstly, the study is mainly focused on Twitter, whereas there are other popular platforms commonly used by people in Indonesia, including by Autistic people. Secondly, this study looked at a particularly limited timeframe of social media posts. Therefore, it would be useful to explore other popular social media platforms in Indonesia (e.g. Facebook, Instagram and YouTube) and to look for a longer period for the future study. A longitudinal study would be valuable to explore if there are any changes in the dominant frame on looking at Autism within social media context.

Despite some limitations, the findings of this chapter offers new insight into the public understanding of Autism on Indonesian Twitter. It suggests that the public understanding of Autism on this microblogging platform is largely influenced by the medical model of understanding disability. This follows the dominant constructions of Autism in the global context that historically, were pathological (O’Dell, et. al., 2016).

However, the findings of this chapter also suggest that social media can be a place for the alternative voice, particularly the Autistic self-advocates, to speak out on issues that extend beyond the medical model. This alternative voice can provide a different understanding about Autism, influenced by the global neurodiversity movement. Although not all of these alternative voices use the neurodiversity term, but they are living or performing it in a culturally specific way (e.g. @anandasukarlan's tweet "being different should be viewed as a strength in someone's ability, not as a deficit"). This alternative voice will be discussed further in chapter 9 before the conclusion chapter of this thesis.

However, as discussed throughout this thesis, parents' role can be important in the transformation process – from parental autism advocacy to Autistic self-advocacy – that is happening in Indonesia. Hence, in the following chapter I will discuss first about the majority voice – the parents' voice – to understand more about their roles in online autism advocacy in Indonesia.

Chapter 8. The Parents' Voices on the Internet

8.1. Introduction

As discussed in chapter 7, the voices of Autism in Indonesia are largely represented by non-Autistics, including parents and parent-based Autism organisations. These parental organisations – such as YAI and MPATI – have been actively campaigning and building networks among parents, therapists, health practitioners and educators in Autism advocacy since the beginning of the 2000s. This proliferation of network continues to be done through online media until recently. Parents of Autistic children can get benefits from online communication, particularly for reducing their social isolation, offering social support and representation, and also as a tool for socio-political articulation (Antunes & Dhoest, 2018). In the global context, several Autism parental movements have been heavily criticised due to their campaigns on ‘curing Autism’ or emphasising normalisation, ideas which are totally opposed to those of the Autism self-advocacy and neurodiversity movements (Hart, 2014). However, parents of children with disability often find their positions somewhat dilemmatic in perceiving their children’s disability. They are attracted to the social model of disability because it offers understanding that their child is not “less than”. However, these parents oftentimes have to refer to the medical model, particularly when dealing with medical specialists or educational services for their children (Livingstone & Blum-Ross, 2020). This reflects the condition in Indonesia, which will be discussed further in the next section.

Hart (2014) argues in a study about Autism parents and the neurodiversity movement, parents have a critical role in opening the way, conceptually, for Autistic self-advocates nowadays. This is related with the second research question in this thesis: what are the parents’ role in supporting and assisting their children for self-advocacy movement in Indonesia? Referring back to the previous findings in chapter 6, the parents’ voice represents the majority voice in Autism discussion on Indonesian Twitter. Before moving further to explore the Autistic voice in Indonesia in the next chapter, in this chapter I will present the parents’ experiences on Autism advocacy and their perspectives about current, and future, Autistic self-advocacy in Indonesia. Throughout this chapter, my personal experience as a mother of Autistic teen in

Indonesia will take into account as it will reflect on the relevance of neurodiversity theory in my own experiences.

I will begin by describing the background of the four parents involved in this study. These parents were recruited from two online Indonesian parenting forums, a WhatsApp group of parents called *Komunitas Ortu ABK* (Parents Group with Special Needs Children) and a mailing list group for parents of Autistic children called Putra Kembara. Langan (2011) claims that parents of Autistic children do not speak with one voice; instead, their voices have always been diverse and sometimes opposed to each other as they have different backgrounds and interests. Taking that into account, three participants in this chapter were interviewed as parents who share their experiences as advocates in an online platform, assisting their children to use social media as a medium for social use. The fourth participant was interviewed as the expert, a parent who works as an academic and professional psychologist. Parents were selected based on two criteria – that they are actively using social media and that they have children who use social media. The objectives of the interviews are to explore parents' perspectives on Autism in Indonesia, in particular whether the use of social media can be beneficial to both contribute to Autism narratives and provide public understanding of Autism in Indonesia.

Regarding the recent phenomenon of the changing 'landscape' in the global Autism advocacy movement – where Autism self-advocacy movements have started to thrive on the internet – it is important to examine Indonesian parents' experiences and perspectives. The first part of this chapter will describe the participants' background, including their stories about experiences in social media use. This is followed by discussions about the benefits of social media, both for advocacy and for Autistics, as well as the participants' views on Autistic self-advocacy, and their role as translators for their Autistic children. Finally, the chapter looks at the acceptance of Autistic diversity and the challenges in social media use. I then draw some conclusions, including parents' views on the benefits of social media for advocacy, their efforts in conducting the translation process for the children, and how this can possibly contribute to the Autistic advocacy movement in Indonesia.

8.2. The parents

- **Daisy**

My first participant is Daisy, a mother of two children. Her youngest child, Jon, was diagnosed with Asperger's syndrome and ADHD (attention-deficit/hyperactivity disorder) and is currently in high school; soon he will enrol in university/college. Daisy regularly uses Facebook and joins several online parents groups on Facebook to get information and insights from other parents, such as Parents with Autistic Children, Parents with ADHD, and Christian Parents with Autistics. Since Jon received his diagnosis, Daisy has actively searched for any information available from social media, mailing lists and websites. She also has had several consultation sessions with Indonesian paediatricians who are well-known in working with Autistic children, including Melly Budhiman and Hardiono Poesponegoro.

As mentioned earlier in the introductory to this chapter, parents of children with disability commonly find themselves in contradictory positions to employ the language of social model and the medical model of disability (Livingstone & Blum-Ross, 2020). This is the experience of my participants – as I will discuss later in this chapter – as they perceive Autism as a difference, not as 'being less than'. On the other hand, they also refer to medical terms when discussing how they manage the effects of their child's disability.

Daisy joined Putrakembara – the pioneering online mailing list for parents with Autistic children – based on recommendations by her peer parents in a Facebook group. She also joined the WhatsApp group for parents started by the members of Putrakembara who prefer to have more interactive discussions through the mobile messaging app. Jon was very upset when he found out his mother joined the WhatsApp group as the group's name is *Komunitas Ortu ABK* (translates as 'parents with special needs children's community'):

He often borrows my mobile phone, because my phone is more sophisticated than his. When he found out about this WhatsApp group, he was furious. He told me, "Ma, I am not a special needs child". Once he deleted me from this group, and made me quite angry, because I had to make a request to be invited again to the group – Daisy.

Daisy's and Jon's situation reflects the problematic point experienced by parents as their children become mature and aware of their identities. Riany et. al (2019) find that an authoritarian parenting style is largely adopted by parents with Autistic children in Indonesia. It is possible that parents try harder to control their children's behaviour to avoid embarrassment caused by the social stigma (Riany, Cuskelly, & Meredith, 2019). This parenting style reflects in Daisy's story. According to Daisy, her son views himself as a "normal", non-Autistic person. Jon is a self-confident youngster and he does not regard himself as having "special needs". Until this moment he often says, "I am not Autistic, I am not". Daisy then reminds her son about his difficult behaviour, as he still experiences emotional tantrums. She told Jon, that "a normal person does not scream at midnight and does not beat his dad". When Jon has a tantrum, oftentimes the other family members – his parents and sister – have to hold his body to calm him down. Recently, according to Daisy's story, his father has started to become the object of Jon's anger when he gets into a tantrum.

Besides social media, Daisy also uses a mobile app called Life360 – a location-sharing app on iPhone – to check and track her son's location by tracking GPS signals from Jon's mobile phone. By using this app, Daisy is able to reduce her distress as Jon often wanders around the city to follow his object of interest – TransJakarta, the public bus system in Jakarta – and travel by himself alone following each route, sometimes until late at night. Jon also likes to spend his time using the family's computer in the living room which, according to Daisy, is difficult to control because he refuses to adhere to the time restriction given by Daisy.

- **Riri**

The second participant is Riri, a mother with 14-year-old son, Leo. Leo was diagnosed with mild Autism or PDD-NOS (pervasive developmental disorder – not otherwise specified) as, when he was 2–3 years old, he had communication problems and speech delay. Despite that, Leo shows no typical symptoms of an Autistic. According to Riri, he is an affectionate boy who likes to be hugged, can make eye contact, and shows no emotional tantrums. But, eventually, after spending a long time undergoing intervention processes, treatments and consultation sessions with paediatricians and psychologists, Riri and her husband have now acknowledged that their son is on the spectrum.

In 2008 when Leo was 4 years old, Riri decided to resign from her full-time job so she could focus on assisting her son. It was then that she started to blog (<https://mamanya.wordpress.com/>) about her parenting activities of her two sons, Leo and his older brother. Due to her issues with sleeping – which started to appear when her son was diagnosed – Riri decided to write a daily journal as a therapeutic way to ease her mind. She also subscribed to a number of online information sources about Autism such as Nakita, a parenting mailing list initiated by a popular Indonesian parenting tabloid. At that time, social media was only starting to gaining in popularity. As an active mailing list member, Riri could have access to consultations with some experts – psychologists and health practitioners – who guided her to have an early diagnosis for Leo.

Currently, Leo is enrolled as a student in junior high school, so now Riri is focusing her efforts to develop Leo's IEP (individualised education program) at school. She teaches Leo to socialise with peers and communities, and also handles puberty issues for teen Autistics. This may lead to the question of how or can a child assert their privacy or independence from their parent (Blum-Ross & Livingstone, 2017). However, as mentioned before, due to Indonesian traditional cultural beliefs that having Autistic children is a “cure” or Karma, parents tend to be more authoritarian in their childrearing process, particularly those who come from higher socio-economic groups (Riany et al., 2019). As in Riri's case, she makes extra efforts to guide her son for living independently and to share her stories about Leo's milestones in her blog – These practices can be viewed as a part of parent's effort to diminish the social stigma in Indonesia.

Riri admits that she still has “homework” to do to help her son find his future path; currently she is still exploring her son's interests. She follows other parents' success stories and accounts in social media, hoping to find further information about future education options for her son, and preparing for Leo to live independently in his adult years.

- **Vitri**

Vitri is the third participant in this study. She is also Fay's mother; Fay is also a participant in this study who represents Autistic (the interviews with Fay will be featured in the following chapter). Fay was diagnosed with Asperger's syndrome in

2006; at the time she was about to enter elementary school. In 2012, Fay got her diagnosis reconfirmed when she entered junior high school. At that time, Vitri found the internet very beneficial in providing essential information about Autism and Asperger's as she could get explanations about those issues from websites. As such, she felt more prepared when she took Fay to see a psychologist. When the interview for this study was conducted, Fay was about to turn 19 years old and had already started her first semester at university majoring in English language. Vitri actively uses social media; she has accounts on Facebook and Instagram, and also joins a WhatsApp group for parents with special needs children.

In addition, Vitri has a group of friends consisting of parents with special needs children who often meet and introduce their sons and daughters to each other. Until now, these children – now adolescents – became a close circle of friends. They regularly spent past times together enjoying recreational activities, and also collaborating on Autism-related events, projects and exhibitions. Vitri encourages her daughter to make friends and have social interaction by using social media and mobile messaging platforms – such as Facebook and WhatsApp – while she provides guidance and support. She found some parents of Autistic children from Facebook who live outside Indonesia and initiated introductions for the children to become pen-pals, writing letters and sharing stories with each other. Acknowledging her daughter's interest in writing, Vitri encouraged Fay to enrol in a writing course.

- **Adriana**

The fourth participant is Adriana, a well-known psychologist, an academic, and also the mother of an Autistic son. Adriana has made many important contributions to the Autism field in Indonesia, including as a member of YAI and the director and founder of Mandiga, one of the first Autistic schools in Indonesia. Currently, she is the chairperson of ASEAN Autism Network, a network established in 2010 which comprises of Autism family support organisations from ASEAN (Association of Southeast Asian Nations) countries. In this study, while other participants were interviewed as 'lay experts' based on their experiences, Adriana was interviewed as an academic and professional expert in psychology who deals with some teen and adult Aspie clients.

One of her published writings on the topic of Autism is a practical guide for parenting an Autistic child called *Menjadi orang tua istimewa, panduan praktis mendidik anak autis* (*How to become a special parent, a practical guide educating Autistic children*) published in 2008. In it, Adriana wrote that her son was diagnosed with Autism in 1997, when information about the condition was still very rare in Indonesia. Previously she thought that Autism was a disorder that her son needed to be cured of (Ginanjar, 2008) but, after reading some Autistic autobiographies and articles written by Autistic adults, her perspective changed; she now understands that “Autism is a part of a person, and will be continued as part of their characters and views even until they becoming adults” (Ginanjar, 2008). In 2006, Adriana had the opportunity to meet and interview the late Donna Williams, an Australian Autistic self-advocate and artist who published a series of autobiographies and books about Autism. Her meeting with Williams made Adriana realise that focusing on developing Autistics’ potential is very important (Ginanjar, 2008).

8.3. Data Analysis

8.3.1. Social media for seeking information and support

All of the four participants interviewed for this study are actively using social media; generally for communicating with friends, seeking information about Autism and also for networking with other parents to get social support. For example, when Daisy suspected Jon had ADHD, she tried to look for more information related to that topic. A similar experience was also shared by Vitri who looked for information about Asperger’s before she went to the psychologist for a consult for her daughter. Riri currently uses social media and searches the internet to get more information about IEPs and inclusive education systems for special needs students. She regards the internet and social media as very beneficial because they give her an abundance of information that she needs; this is particularly the case from sites outside of Indonesia:

We can read and compare their education system with ours, and Indonesia’s situation is pretty much left behind. So if I meet Leo’s teacher or his schoolmaster, I can give input to them. In Indonesia, there are many schools who claim to be inclusive, including Leo’s school. The school doesn’t quite understand handling these special needs kids. They think by admitting the special needs students, they

already fulfilled the government's requirement²⁶. But, as a matter of fact, we need specific expertise, skills and training for teaching special needs students. Sadly, in Indonesia, we still need many improvements – Riri.

However, getting information from social media also has its downsides – Daisy mentions the lack of information credibility and the massive issue of information abundance. She also admits to having stressful feelings occasionally, particularly after reading some “success stories” of Autistics from social media:

People often share their personal experiences with their kids, which may not be suitable for my son's condition; for example, about a gluten-free diet. And I also tend to experience information overload. Sometimes I also have this tendency to compare my son with others. For example, other parents have successfully encouraged their children's talent in art and they become great artists. Then I ask myself, am I doing enough for my son? – Daisy.

There are also parents who speak as parents with particular academic or professional expertise, such as Adriana. Adriana's use of social media is more to support her jobs as a lecturer and psychologist, to find credible information sources that she can use either for writing articles or as a source to help her clients. She regularly uses Facebook to connect with her friends and colleagues, while also relying on websites to search for academic journals and to learn the latest intervention methods for persons with special needs, a term that she interchangeably uses with “Autistics” and “person with Autism”. She claims that websites and online resources are beneficial for sharing early information to her clients, particularly for adult clients who are on the spectrum but do not know much about their condition yet. According to her experience, the internet and social media can be beneficial to help the adult client assess themselves:

When these clients come to me and ask 'Why am I different?' I ask them to read some information about Autism and Asperger's and also ask them to fill in an online checklist. It is more like a self-diagnosis kind of thing – Adriana.

²⁶ In 2009, the Ministry of Education released a regulation which stated that it is a compulsory for each district (*Kabupaten*) in Indonesia to have at least one elementary school and one junior high school for implementing inclusive education. Inclusive education is a system of education that provides opportunities for all students – including those who are identified in Special Educational Needs/Special Needs category (Kemendikbud, 2019)

From Adriana's story, it can be seen that the internet and social media have the benefits for Autistic adult to find information about themselves – which possibly can lead to further understanding about their conditions. This part will be discussed further in the next chapter (chapter 9) about Autistic presence in Indonesia.

8.3.2. "Sharenting" in social media as a form of parental advocacy

Furthermore, Daisy and Riri use social media as a form of parent advocacy on behalf of their children. Daisy personally views parents' advocacy – either online or offline – as part of the parents' role to educate society about their children's disabilities. She is aware that not all Autistics have the same abilities to voice out their stories:

Although some (Autistics) use social media, they probably have difficulties to speak out, or are still at a young age; like my son or yours. So it is difficult to voice out their opinions even though they can use the technology. So this is part of our duty to help them – Daisy.

For participants like Riri and Daisy, using social media to share stories about their parenting experiences helps them to understand the process they undergo in childrearing. Previously, Daisy created a blog that was intentionally made to share stories about her son, but she rarely updated it as she is more active on Facebook. Her postings about ADHD and Autism on Facebook seem to incite positive responses from friends and colleagues. For example, she got some private messages from her ex-students who asked questions related to their children's conditions and diagnoses. Daisy views this as a positive impact as she can help people and encourage them to search for further information on treatments and early diagnosis.

In using social media, Riri has a similar story to Daisy as her advocacy activity started from her interest in writing a personal journal about her family life:

My friends and relatives love those stories I created – those light and funny stories about my sons. I usually send those stories via email to families and friends – in the form of comic style with photos. They love it and suggest that I document it. When I was no longer working, I started to make a blog to document my sons' stories – Riri.

What started as an activity to release her thoughts and keep a record of Leo's development, it later became a popular information source as her blog attracted more

readers. People who google search Autism and the parenting story find her blog, introduce themselves and leave comments. In 2010, her blog reached more than 6000 readers and featured in some Indonesian printed media, including in *Nakita*, a popular parenting tabloid. Riri also regularly uses Twitter to follow current news and trending topics, Facebook and Instagram, with the latter mostly being used to upload pictures. Although Riri mainly receives positive feedback from her friends in social media, she has also been questioned by another parent about her constant sharing of stories about her son in that space. To her surprise, one day that same person asked for further information about Autistic children as he works as a personal sports trainer and he had just got a new student – who is Autistic – in his class. Through her activities in sharing her son’s stories via an online platform, Riri believes she has made some useful contributions to help people understand more about Autism.

For parents like Daisy and Riri, social media acts as a platform to release their thoughts and, also incidentally, acts as a tool for advocacy on behalf of parents with “special needs” children – both use the term “special needs” interchangeably with “Autistic” during their interviews. Advocacy movements are defined as “organisations that seek to speak for people who identify with a label, such as Autism; that includes parents, professionals or other individuals who share a sense of social justice with the individuals labelled” (Bertilsdotter Rosqvist, Brownlow, & O' Dell, 2015). For Daisy and Riri, social media has become a mediated tool to spread awareness and to help other people understand Autism. Both regard their sharing in the public sphere – in social media and traditional media – as useful and helpful in terms of increasing understanding for the general audience. Their main focus in using social media is to have mutual support from peers.

For me, luckily I frequently use social media and share to the public that my son is on the spectrum. At least I can make people understand my son’s condition. I am not ashamed of him, and I proudly share some of his activities, such as his musical activities. Jon plays angklung (a traditional musical instrument). At least they can see Autistic people have their abilities. Every person is gifted with talents from God, although their talent is probably different than a typical person. Theirs are very unique – Daisy.

My sharing in social media about Leo can help people to understand more about Autism. Social media can have positive impacts by opening people’s minds who previously do not understand Autism.

People can be more aware and understand that being different is not always bad. Autistic people are different; it seems that they cannot speak, but they have their own way of thinking – Riri.

Daisy's and Riri's experiences of "sharenting" (sharing images and information about children online) – a term mentioned by Blum-Ross and Livingstone (2017) – has many benefits for parents, particularly for expressing their experience, building network among parents and accessing references for advice and support (Blum-Ross & Livingstone, 2017). Social media and sharenting practices also facilitate parents of children with disabilities to learn about negotiating for health and education services for their children, and building their "networked empowerment" (Ammari & Schoenebeck, 2015; Borgos-Rodriguez, et.al., 2019).

By sharing their personal experiences in caring and supporting their children, parents become a part of an expert network alongside others such as educators, therapists, and activists or self-advocates. "Parenting experts" is the new category mainly emerging in social media; they offer advice for their peer parents who often face the double challenges of "maximising opportunities while minimising risks in the digital age" (Livingstone & Blum-Ross, 2020). Langan (2011) states that parents are regarded as experts because of their personal experience, while other parents can be regarded as lay experts, the ones who are doing more extensive personal research and study through the internet.

8.3.3. Courtesy stigma among parents of Autistic children

On the contrary, Daisy also experiences negative responses from her social media network of friends. When she updates her status and daily activities relating to her work on Facebook, she sometimes receives personal comments from relatives in her family criticising her as a mother who has too much ambition, too much focus on her academic career. For example, she was criticised for devoting too many hours doing her teaching job and attending conferences abroad while she should have devoted her time to assist her son. In our interview, Daisy and I discussed the stigma surrounding a mother's role in Indonesia – particularly for those with Autistic children. It seems that 'courtesy stigma' has been presented long ago among parents of Autistic children globally, and Indonesia is not an exception. Popular references from news media and early academic work – such as Leo Kanner's publication *Autistic disturbances of*

affective contact (1943) – refer to cold-hearted parents as one of the factors contributing to the Autistic condition. Kanner, for example, mentions briefly that “there are really few warm-hearted fathers and mothers” in the group of parents of Autistic children he worked with for his research (Murray, 2012). In addition, Kanner firstly coined the term “the refrigerator mother”, although he claimed later that parents were supposedly not to be blamed for the children’s condition (Murray, 2012).

Goffman (1990) refers to the notion of courtesy stigma, or stigma by association – as previously mentioned in chapter 5 – as the stigma surrounding people directly connected to individuals with disabilities, such as family members (Gray, 2002; Phillips et al., 2012). Particularly for parents of Autistic children, courtesy stigma is often presented in the form of a “discreditable” position because of its nature as an “invisible disability” (Gray, 1993). In Gray’s study of parents of Autistic children, mothers perceived themselves as being particularly stigmatised, as they are the ones who are most commonly given the responsibility of childcare (Gray, 1993). This stigma often causes difficulties for parents, as they feel the blame from others such as public and extended family (Borgos-Rodriguez, et.al.,2019). As a consequence, parents recognise the need to control their children behaviour in public, while also trying to find ways to “normalise” their children’s experience – for example, by publicly disclosing their child’s disability-related identity (Borgos-Rodriguez, et.al., 2019).

In Daisy’s case, the courtesy stigma is not only perceived by herself, but also by her daughter who once expressed her disappointment of having an Autistic brother, “Why did God give me this Autistic brother?” Those experiences motivate Daisy to be more open about her son’s Autism, and she also encourages her daughter to do the same. In 2013, Daisy was interviewed by *National Geographic Indonesia* magazine for an article about Autism in Indonesia titled *Dunia sunyi para pencari jati diri (The lonely world of the soul-seeker)*. In that article, she shares her experience as a parent, including the courtesy stigma experienced by members of the family, and how she manages it. She states that she choose to accept Jon’s condition and tries to do the best she can do, including by taking the role of an advocate for her son.

However, despite parents taking a greater role in Autism advocacy by using social media, they also recognise the potential of social media to be utilised by their children.

In the following section, I will address the benefits of social media for Autistics from the parent's perspectives.

8.3.4. Social media to support social interaction and personal interest for Autistics

Some participants like Daisy, Riri and Vitri state that their children are regularly using social media. However, as they have differences in age range and skills, their use of social media is different to each other, and still requires assistance from their parents. For example, Jon and Leo use social media mainly for social interaction and pursuing their personal interests. Jon has been using social media since 2010 – firstly Facebook, then Instagram and YouTube – under his mother's surveillance. For security and safety reasons, Daisy keeps her son's password so she can check his activities in social media. According to her, Jon still needs assistance as, until now, he shows "childish" behaviour despite being 18 years old. As a result, Daisy feels she needs to monitor her son's online activities:

We put the computer in our library room upstairs. I often go there and watch what he browsed. Mainly it is related to YouTube videos about transportation, such as trains, railway, and buses. Jon loves to watch TransJakarta YouTube account and people recording TransJakarta buses. Sometimes it exposes violent content, such as an incident where people recording the event about a thief who got beaten on the bus. I told him not to watch that kind of thing because it was so violent. After watching the video, he told me, 'Mum if I saw a thief, I would beat him'. His response made me quite concerned. – Daisy.

Jon is more of a visual person, and he likes searching for visual content in social media, particularly YouTube videos and Instagram pictures. He regularly uses Indonesian and English language in his daily activities, but mainly uses English to express himself in social media, e.g. writing captions and comments. Daisy says that Jon has "elevator friends" on YouTube – friends who have a specific interest in elevators, most of whom come from outside of Indonesia. They often have conversations and discussions about that particular object. Daisy suspects most of her son's friends are also on the spectrum as she finds there is a distinct communication style that they use in their conversations. Jon also likes to upload videos on YouTube, previously about elevator and also his current interest, the TransJakarta bus.

According to Daisy, her son uses social media largely for searching and discussing his personal interests, particularly about technical things related to bus routes and transportation. Occasionally, however, Jon also uses social media for interacting and communicating with his friends, including with the girl he likes. One of Daisy's concerns is relating to her son's difficulties with controlling his anger, because it has led to a negative expression in social media; he wrote offensive (swear) words in his social media comments. This behaviour shocked his teacher and mother, who prompted a direct warning to him.

In Riri's case, Leo regularly accesses his Instagram account. He sometimes uploads photos and pictures on it, and occasionally asks his mom to assist him for writing the photo's captions. Riri regards this activity as part of Leo's learning process for socialising – by sharing activities with his circle of friends in social media. Sometimes Leo asks his mother to take pictures of his drawings he created and put it on Instagram. Until recently, Riri protected her son's account by keeping it private for safety reasons – so it is only limited to a circle of closed network: relatives, classmates, and teachers. Leo also likes to watch YouTube, particularly watching videos of people playing games. “He likes to watch how people playing games, but when I asked him, ‘do you want to play that (game)?’ he answered, ‘no’”.

Riri also utilises social media to support her sons' interests and hobbies. For example, she once created a Tumblr account, which she no longer uses, for uploading and finding pictures and videos about insects for both of her sons. This was a time when Leo and his older brother developed a particular interest in observing insects, but they grew out of it. In addition to this, Riri created a YouTube account for uploading videos of Leo's activities from his therapy days. The reason behind uploading those videos is similar to her blog – for documentation purposes. For example, Leo was regularly doing running practice for his preparation to join the 2018 ASEAN Autism Games – which was held in Jakarta – so Riri made some documentaries about these activities and uploaded it on YouTube.

Compared to the other two participants, Vitri has a different story as her daughter, Fay, is older and can use social media independently. Fay regularly updates her status on Facebook and Instagram – mostly about her daily life activities and her personal

interests. Vitri said that Fay is very eager to share her stories and for people to read, so she decided to make a blog for Fay's writing outlet:

First, I made a blog for her. I told her, people can read her stories via her blog. To make it more unique, I suggested she made a profile mentioning that she is Autistic – Vitri.

Vitri saw Fay's interest in writing stories as an opportunity to open up more understanding about Autistic people. It is worth noting that Vivi's frames Fay's writing abilities as her "asset". She does not view Fay as incapable, instead she focuses on Fay's "special" skill ability to match the opportunity for being an Autistic writer. To achieve that goal, she decided to prepare Fay for writing professionally by enrolling her in a private writing course. Vitri expected her daughter to learn about writing techniques extensively and publish her own stories, something which she later achieved. By suggesting her daughter disclose her identity as Autistic in her blog, Vitri also aims to reach a larger audience by offering a unique selling point – in a form of authentic story about the lived experience of an Autistic youngster.

When Fay published her first books, Vitri taught her daughter to use social media to promote them. At present, she is putting forward another 'challenge' to her daughter – writing a non-fiction article in Kompasiana. Fay uses her Blogspot account to share her fiction articles – which she edits by herself – and Kompasiana for writing non-fiction articles, with Vitri and the tutor's assistance in editing. She also uses Facebook and Instagram to promote her books. Vitri also helps Fay to guide her in learning the differences between writing fiction and non-fiction articles. For example, to write a non-fiction article, Vitri would ask Fay to do some research by compiling facts and data and learning how to do interviews. According to Vitri, it requires some time to change Fay's style from writing fiction to non-fiction.

According to Adriana's perspective as a psychologist, many Autistic people spend most of their time online accessing social media and websites. They mainly use these platforms for social interaction and searching for their particular interest. Most Autistics she knows have difficulties in direct communication or social interaction. As such, CMC can be beneficial – in this case by using social media and mobile apps as mediated platforms:

I noticed from their stories – some of them love to write – they try to find friends from the websites. I also have clients who like to draw and have an interest in design, so they tried to search online for people who have similar design interests to have discussions. Some of them want to have a girlfriend or boyfriend; but are having difficulties in finding one, so they tried to use dating apps – Adriana.

Despite the fact that CMC does not require face-to-face communication, some Autistics still face difficulties in interacting through the mediated platform. Adriana gave an example of WhatsApp messenger, a platform which is largely used by people on the spectrum, at least among her clients. She pointed out that some Autistic students often get rejected when they try to get along with their peers in an offline environment, for example when having conversations and trying to fit with their friends. According to Adriana's observations, Autistic students in high school face a high risk of being bullied online²⁷. For example, when nobody responds to their postings or messages in WhatsApp or other social media such as Facebook, it can cause disappointment which can trigger a more stressful situation. In this case, social media can also be the cause of their grief.

However, she discovered that joining online communities – particularly special interest ones – proves to be beneficial for Autistics. Some of her clients have joined online communities with particular interest/hobbies, and it turns out that these can serve as a training ground for Autistics to develop social interaction, as it is much easier for them to start a conversation following the same topic. Adriana gives an example of a client who has developed a particular interest in aviation. Her client joins the aviation online community to engage with other people – those who have an interest in aviation industry-related topics, including aircraft pilots and workers in the aviation industry. This client feels more comfortable and accepted in that community because most of the members are adult and mature, and the topics in the conversation are 'safe', as they are specific and within his scope of interest. Adriana describes that her client does not need to do small talk or follow the usual steps of the social interaction process that might be perplexing for him because the conversations are directly focused on niche topics. Another client of hers also found Quora – a question

²⁷ In Indonesia, WhatsApp is commonly used as a communication platform between students and teachers, e.g. to coordinate activities and to consult regarding assignments after school hours.

and answer forum – useful in developing conversations and interaction. Apart from having regular conversations, the client also discovers more about his condition from Quora’s discussions.

From the interviews, it can be concluded that these parents offer their support so that Autistics can advocate for themselves in a social media realm, be it either for interacting with their friends, doing their hobbies, and/or sharing stories to others. According to Adriana, CMC can reduce some boundaries which exist in face-to-face communication such as offering opportunities to be more “direct” in conversations, albeit at the risk of receiving negative responses from their peers online. Mazurek (2013) argues that social media can compensate for some of the social difficulties experienced by Autistics. One of the advantages of social media is to facilitate Autistic people’s communication in a more comfortable format, such as eliminating small talk (Mazurek, 2013).

8.3.5. Parental mediation in Autistics’ social media use

Daisy’s and Riri’s stories in the previous section reflect a form of parental mediation they do in their children’s internet activities. Parental mediation can be seen in various forms; either enabling (e.g. shared internet activities by parents and children) or restrictive (e.g. setting rules and controls regarding children’s internet use) – with mothers mostly performing the restrictive aspects of parental mediation (Zhang & Livingstone, 2019). Scholars in previous studies on internet use among Indonesian families (Rahayu & Lim, 2016; Sekarasih, 2016) also found similar parental mediation forms in Indonesian context, ranging from restrictive to enabling. Enabling methods, for example, can be seen in a form of active mediation where parents discuss media content with their children, and co-viewing, where parents and children access the media together (Rahayu & Lim, 2016).

Parents with younger children, like Riri, opt to apply restrictive parental mediation – both in time and content restriction – by setting time limits to use the internet and also limiting access to certain contents. Riri also limits her son’s access to peer-to-peer interaction in social media for security reason. This depicts a form of internet parental mediation called interaction restriction (Livingstone & Helsper, 2008). For parent with adolescents like Daisy and Vitri, they give greater independence for their son and

daughter to use the internet and social media for exploring their hobbies and interests, and also for developing social interactions with their peers and friends. However, as in Daisy's case, she still applies a restrictive strategy, particularly to keep her son's password and periodically monitoring his activities on social media. She does this to ensure that Jon accesses appropriate content and manages his behaviour when interacting in social media.

Hence, the parents in this study also recognise the need to train and assist their children – and patients in Adriana's case – to acquire the skills, including technological and social capital, required in using the technology. Technology, including the digital ones, such as internet access and mobile computers were owned and used by parents as a form of "capital investment" in their child's learning process for their benefits in the future (Alper, 2017). In making decision to adopt technology for their children, parents were influenced by several aspects, such as their cultural values and personal goals, as well as their perceptions whether their child is mature enough to handle the responsibility of technology (Alper, 2017).

Consequently, the success of this technology adoption is also due to the parents' efforts in training their children to use social media 'appropriately' and learn digital literacy skills. The paradox of social media use for Autistic leaves the parents in this study weighing about the digital risks and benefits. This resonates with the findings from Livingstone and Blum-Ross (2020) among parents of children with Autism in the UK, where parents "often gravitated toward digital learning opportunities, focussing on the idea of a digital future as both welcome and worrisome" (p. 125).

As a result, in this study, some of the parents apply a mix strategy of restrictive and enabling parental mediation. Parents assist their children to use social media for interacting with their peers and for creating contents. However, they also monitor their children's activities for security and safety reasons to prevent the risks of negative impacts from the internet. In that case, digital technologies bring a complex task for parents with Autistic children: how to maximise the affordances of the internet and social media to build relationships and to use it to fit the children's particular strength and needs; while it also brings some concerning issues such as how to access credible information and whom to trust online (Livingstone & Blum-Ross, 2020).

Further, to prepare their children for using social media independently, including in doing CMC, sharing contents and possibly being a self-advocate one day just like Fay, parents facilitate training and assistance – that can be described as a “translation process” (Hart, 2014). The term translation process was coined by Brendan Hart (2014) and refers to the processes that parents do to make the practice of everyday life be more inclusive for their children; this will be discussed in the following section.

8.3.6. The role of parents as the translators for Autistic children

Autistic people (neurodiverse) have difficulties in understanding what non-Autistic (neurotypical) people are doing, feeling or thinking – and likewise. Consequently, artificial platforms must be constructed to mediate the communication process for Autistics (Hacking, 2009b). According to Hacking (2009), this is “human communication that does not depend on body language or eye contact”. Taking the example of the internet, this can act as an artificial platform to mediate the communication process. In Oliver Sacks’ book (1995), Autistic advocate Temple Grandin describes her experience as similar to being “an anthropologist on Mars”, like being an alien in the human world (Sacks, 1995). Hence, since the start of the parental advocacy movement in 1960s and 1970s globally, parents have taken on roles as translators, focusing in behavioural therapies and everyday parenting activities (Hart, 2014). By doing so, parents are encouraging advocacy by carrying out a practice of ‘normalisation’. While normalisation might seem to be the opposite of a neurodiversity approach, and also opposed to the critical disability approach, if we look from the parents’ point of view – including my personal point of view as a parent – I tend to agree with Ian Hacking’s (2007) argument that “normalisation is not where the action is”. “Normalisation” can be viewed as a critical process to the concept of “looping” and “making up people” (Hacking, 2007). That said, normalisation here refers to a translation process by parents, which is considered important to achieve the stage of ‘making up people’ and the ‘looping effect’. Making up people refers to creating new categories of kinds of people – a label, a classification of people made by institutions based on experts’ knowledge through research and validation processes (Hacking, 2007). For example, the definition of Autism as a ‘spectrum of neurodevelopmental disorders’ is the medical term that has been developed from continuous scientific research by academics in medicine, psychiatry and psychology areas since the 1940s.

A looping effect means that people will “evolve in their own ways so that the classifications and descriptions have to be constantly revised” (Tsou, 2007, p. 330), despite the already developed classification of people.

In my thesis, I view the parents’ efforts to help and assist their children learning to use social media as a part of their critical role as the natural translators (Wing, 1973; Hart, 2014). Parents are aware that Autism is not simply a pathological problem but a problem of alterity, where their children have differences in sensory, perceptual experience and linguistic expression (Hart, 2014). As such, in the process of understanding their kids, parents of Autistic children have a critical role as their translators and advocates so as to include them in daily life activities (Hart, 2014).

The three case studies presented in this chapter illustrate the translators’ role – Daisy acknowledges the need to assist and supervise efforts for her son when using social media, Riri creates social media accounts for her son to use as a training platform for his social interaction, and Vitri facilitates her daughter’s interest in writing and supports her in advocating for herself through her own stories. As stated by Hacking (2009), stories delivered in the form of autobiographies and blog journals created by Autistics – as well as also novels with Autistic characters – provide guidance to understand the language of Autistic life (Hacking, 2009b).

As already mentioned in chapter 2’s discussion of the critical concepts in this study, normalisation is considered important to the looping process as it can drive Autistic people to reclaim their identities (Hacking, 2007; Hart, 2014). The practice of normalisation, in Hacking’s view, is important to the concept of looping as it will provide support for Autistics to reclaim their identity (Hacking, 2007). In my view, and through examining parents’ role in this study, I tend to agree with Brendan Hart’s argument that efforts of normalisation²⁸, to some extent, can be seen as a positive contribution, as “a dialectical process of radical acceptance of the children’s differences” (Hart, 2014) (p. 293). Parents learn to communicate in their children’s language, to appreciate their differences, and to advocate on their behalf in daily life

²⁸ Continuing the argument regarding normalisation, Eyal (2010) states that Wolfensberger argues the goal of normalisation as “an existence as close to the normal as possible” (p. 117). Referring back to the broad spectrum of Autism, the goals can be various – e.g. from living independently, living in a group home, to living in a facility with medical staff (Eyal, 2010).

(Hart, 2014; Tsou, 2007). These efforts can be considered as “celebratory acts” that partly show parents’ support for the Autism community, despite some powerful parental organisations still using counterproductive efforts such as using fear and pity as charity strategies (Kapp, 2020).

The critical question lies in the extent to what parents will do when holding the role of the translators. To a certain level, it is possible that the translator’s role will no longer be exclusive to parents, once their children can do the translation for themselves. For example, with the use of the internet, Autistics can learn to ‘translate’ their languages and are able to use social media as a mediated platform. As discussed in chapter 5 and 6, some Autistic adults in Indonesia, such as Oscar Dompas, Ananda Sukarlan, Yarra and also Lala (with her Autism Indonesian Youth blog) have started to make their presence on social media – thus claiming their own voice and advocate on their behalf. Their stories will be discussed in the next chapter.

8.3.7. The acceptance of Autistic diversity and the challenges in social media use

All participants admit that there is still a lack of Autistic self-advocacy presence in Indonesia – most Autistic self-advocates they find in social media are non-Indonesians. Daisy agrees that parents are still dominating the Autistic advocacy force in Indonesia as there are not many Autistics in the movement. She hopes that the presence of Autistic self-advocates in Indonesia will help parents and others to understand Autistic perspectives. Through a Facebook group, Daisy found some non-Indonesian Autistic voices. Daisy recalls that they openly introduced themselves as people on the spectrum, such as “I’m 16 years old, I have Asperger’s” and “I’m not ashamed of what I am”. In Indonesia, Daisy only recognises two Autistics as self-advocates – Ananda Sukarlan and Oscar Dompas – whom she knew from her colleagues. Despite the fact that the Autism spectrum is broad, Daisy feels that the existence of Autistic self-advocates would be beneficial in giving more thorough explanations, particularly for the mainstream audience, to understand “what’s inside the Autistics’ minds”. She really hopes that, in the future, Autistic children who are also part of the digital generation will be able to share more about themselves:

It will be useful if we – as parents – encourage our children to share more about themselves. We can tell them that you have the duty and

the responsibility to inform other people about who you are, what you want and what you feel. I also tell my son the same thing – You can write what you feel (on the internet), but please do not swear or use offensive language to other people – Daisy.

The same opinion came from Riri, who likes to follow several Autistic self-advocates' social media accounts, all from outside Indonesia. One of them is Sarah Stubbs who provides a Q&A (question and answer) session in her social media account. Riri views it as a good example to open people's minds about understanding Autistic people, and she likes to share these accounts via her social media. Riri recalls that some participants, despite being non-speaking, possess excellent writing skills and publish their own books.

They have their own way of thinking and have difficulties in expressing it (orally). Reading their blogs or social media accounts made me realise that we cannot understate them. They may like to do certain behaviours – like stimming – but they have their own thinking, their own soul. Don't assume because they are like that (showing some particular behaviours) then they can't understand things and other people – Riri.

In regards to their verbal/oral communication difficulties, Riri believes that technology such as the AAC (augmented and alternative communication) tool can support and be used as a more practical way to help them in communicating what they want. Sometimes she feels confused about parents who push their children to undergo therapies for a long time rather than accepting and supporting their children's unique ways of communication.

Similar to Daisy and Riri, Vitri also tries to search for blogs written by Autistics, but rarely finds them, particularly in an Indonesian context:

Most of the Autism-theme blog writers are parents. If there is any Autistic blog, they are not from Indonesia – Vitri.

Vitri believes that Fay's stories will help other people – particularly in Indonesia – to understand Autism. Dawn Prince-Hughes, an American anthropologist and Autistic advocate, stresses the importance of Autistic writings to provide references for Autistic individuals as there is a perceived need among Autistic individuals for further research on their experience (Davidson, 2008b). This reinforces Fay's experience, as her book

generated positive comments and responses from her peers, particularly her second book. They told her that the book represents what they feel. Vitri therefore asked Fay to write more about her experiences as a person on the spectrum; however, Fay refused as she feels her freedom to write is somehow being limited. Vitri also tried to motivate Fay to create a vlog (video blog) – as an audio-visual format can sometimes be more attractive – but her daughter is still reluctant because she is not confident enough to present herself in this manner, plus that making a vlog would require more complicated technique skills. Currently, Vitri has suggested that Fay write both fiction and non-fiction – mostly on the topic of Autism – interchangeably. Both mother and daughter work together to make a monthly plan for Fay’s blog articles. For example, Fay will write fiction one month, and next month’s topic will be about event coverage, or about Fay and her friends’ experiences:

The concept and ideas come from me and she will put it into her writing. In the beginning, I edited her writing but her current posts were edited by her tutor. We use Kompasiana for Fay to write non-fiction articles. Currently, with her writing skills, Fay can have an internship job as a content writer in an NGO called Plan Indonesia – Vitri.

Vitri admits that Autism is a broad spectrum but, as a parent of an Autistic person, she does not care much about label or terms. She agrees that a label was once useful for medical or diagnostic purposes – e.g. getting treatments and interventions – but that, for her now, the most important thing is that her daughter and other Autistics can gain their independence in life. When I told Vitri about the debate surrounding the use of HF and LF terms, she said that Fay and her peers (in Vitri’s term, “special needs youth”) do not seem to have that kind of objection toward the use of the terms:

Some of Fay friends understand their conditions and they can explain their limitations. Most of them are youth above 16 years old; one of them currently is taking a master’s degree program at a university – Vitri.

In terms of Autistic self-advocacy, Adriana is not aware of any Autistic in Indonesia who conducts online self-advocacy activities, except Fay. But she acknowledges that some Autistic youngsters would be able to act as self-advocates by sharing their experiences with the public. Adriana mentioned Rudi – who is also in the same circle of friends as Fay – who often gets invited to share his experiences as an Autistic person.

Rudi is a very friendly and warm person; he was also one of the ‘stars’ to represent Indonesian Autistics in an important event – when YAI visited Istana Negara (the Presidential Palace) to meet the president, Joko Widodo. According to Adriana, Rudi’s parents are members of YAI, so they were already very open about their son’s condition from the start. Adriana remembers that Rudi was once involved in a live painting exhibition in Jakarta and did a great performance. According to Adriana, the other Autistics that she knows haven’t reached self-advocacy level yet, although there are others who like to blog but do not exactly share their narratives as Fay does. However, in terms of Autistics who have self-awareness or openly claim their identities as a neurodiverse, she states that she has never met one in Indonesia:

If they are in that condition probably they will not come to me asking for a consultation. This means that I never have a client who admits “I am joining a community to meet other people on the Autism spectrum and having conversations about that”; never – Adriana.

Nevertheless, Adriana tells me about another Autistic youngster, Omar, who is starting to ‘come out’ as Autistic. Omar currently is going to a state university in Yogyakarta and undertaking an undergraduate program. Omar’s mother was taking care of her son’s development, starting from his nonverbal condition until he can be admitted in a state university. When he was in high school, Omar openly told his friends in his religious community – he joined a *pengajian*, a Muslim prayer group – that he was Autistic. And when he entered university life, from day one his mother was disclosing Omar’s condition to the campus staff and students – so he can get the support to adjust to campus life. Even on some occasions, Omar was already “coming out” to the public. What Omar did can be considered as a form of self-advocacy, as it involves some self-disclosure to reach better mutual understanding. Autistic professor Stephen M. Shore wrote a guide for developing self-advocacy skills for Autistic students. He suggests that self-advocacy and disclosure are important skills to achieve a fulfilling and productive life. For example, by disclosing themselves to others that they have autism and explaining why an accommodation will be helpful (Shore, 2006).

The stories from all parents indicate that they support the idea and the efforts that are being made for Autistic people to be able to advocate on behalf of themselves. They provide support – including technical and social skills – to assist their sons and daughter in using social media, either for developing social interaction or

communicating their stories to the public. The parents in this study also state their acceptance and respect towards Autistic diversity, and focus their goals on achieving independent living for their children, as well as to make the ‘outside world’ more inclusive for Autistics. This resonates with the global parental activism movement in the recent decade, the one that Langan (2011) coined as the third wave of parental activism in Autism. This is one which indicates a global change from the medical model of Autism to an acceptance of Autistic diversity, and which dates from the early 2000s (Langan, 2011). Furthermore, this change possibly indicates an expanding popularity of Autism awareness and public recognition of Autistic presence in Indonesia, although it requires some collaborations such as with major parental organisations like YAI.

However, there are also challenges found among Autistics relating to social media use. According to Adriana, ‘high-functioning’ people on the spectrum who acquire not only technical skills but also the social skills – e.g. understanding the social rules and norms online – are likely to experience the positive impacts of using social media. They can present themselves to a wider audience, as some Autistics she has met have excellent writing skills compared to their speaking ability. On the contrary, she takes notes on the lack of social skills or awareness among Autistics as those can lead to negative risks from social media. From her experience, she often finds Autistic people – including Aspies – to be quite naïve, thus running the risk of being targeted in online (and also offline) fraud and bullying. Some of her clients have ended up being blackmailed and/or dogged by internet friends and online sellers. Generally, according to her, the parents often exert some controls by monitoring their sons’ and daughters’ online activities, including keeping their social media passwords. There are also cases when mothers would have to restrict their children from using social media as the situation worsened and began to show signs of bullying²⁹. Unfortunately, their children sometimes are not aware or do not recognise the situation nor why it can lead to bullying or other negative impacts on social media. According to Adriana, the degree

²⁹ Roy and Lewthwaite (2016) argue that technology can cause ‘social divide’ for disability. Peer surveillance in social media can caused powerful normative social pressures; for example, disability, as a different way of being, can be exposed to negative public scrutiny (Roy & Lewthwaite, 2016).

of social media impact and whether it can be beneficial for Autistics will largely depend not only on their ages but also on their most important aspect, their abilities:

In my view, for those who are very high-functioning, social media can have great benefits although probably it still has its shortcomings. But for those who still need guidance, it seems that parents need to guide and supervise them. Parents should paying attention to what they are doing with social media, and whether the conversations will lead to positive or negative impacts for their children – Adriana.

Those challenges mentioned by Adriana were also highlighted in a 2010 study by Burke et al. Although CMC in the form of social media can be beneficial – in terms of initiating contact with potential friends – it also possess some challenges. For example, when maintaining online contact, some Autistics find difficulties in three main areas – knowing who to trust, knowing how much to disclose, and understanding CMC-specific social norms (Burke et al., 2010). Furthermore, these problems possibly arise due to “characteristics of their cognitive processes and past experiences, including naiveté, inflexible perceptions of others’ intentions, and difficulty understanding how others perceive their actions” (Burke et al., 2010, p. 4). Addressing these challenges, specific training relating to social skills in CMC can be suggested, e.g. by using virtual peers and virtual scenarios (Burke et al., 2010).

8.4. Conclusion

In this chapter, a number of things can be concluded. Firstly, that parents are actively using social media to search for information about Autism, to find online support, and as a tool for their children to learn social skills and communicate their stories. Some parents also use social media as an outlet, whether it is to document their children’s milestones or to share stories from their children. Some activities which first started as personal documentation/journal project and personal sharing, later became a form of advocacy for their Autistic children, a way to provide understanding about Autism for a wider audience.

Secondly, parents identify advocacy as part of their parenting role. The goals of their advocacy are mainly to spread understanding and knowledge about people with Autism in Indonesia. Parents are still speaking on behalf of their children by utilising

social media – except in Fay’s case – where the mother assists her daughter to create her own content in social media so she can provide her narrative to the audience through her writings.

Thirdly, in this study, all parents are positioning themselves as allies to Autistics; they state their opinions in order to support their children and other Autistics in Indonesia to tell their own narratives. They believe it is better if Autistic people can share their stories from a first person account so other people can engage and have a deeper understanding of them. I view this as the parents’ support to the neurodiversity movement – to share the understanding of Autism as a difference to a wider audience in Indonesia. As such, they encourage their children to do so as they can see the benefits of it. However, they are also aware that their sons and daughters have to be prepared for the risks and negative impacts of online communication and social media use, which will bring us to the fourth point in this chapter.

In the fourth point, it can be concluded that parents are still holding the role as translators. They have their hopes and fears relating with digital media use for their children. Parents of children with disability see digital media as a potential tool for social and economic inclusion in the future, but they also have concern for its risk (Livingstone & Blum-Ross, 2020). As such, parents provide the necessary support and infrastructure to engage their children in their use of social media. They believe that the benefits of social media and online interest-based groups can act as training platforms to facilitate Autistics to engage in discussions and social interaction. However, they still feel the need to provide guidance and training for their children. Consequently, parents still exert some control to a certain degree around their children’s use of social media, depending on their skills and level of independency. For children who are still needing support and guidance, parents monitor and survey activities online in order to protect their children’s identities for security reasons. For Autistic who already possess the skills to interact and communicate via social media, parent provide any necessary extra training, such as writing practice, in order to facilitate personal interest and self-advocacy skills. In this case, the translation process can be seen as a form of practice to maximise their children’s functionality of technology.

In my final note for this chapter, the voices and narratives of Autism in Indonesia are still largely represented by parents, including in social media, as admitted by the parents themselves. The term ‘different ability’ and ‘special needs’ are also more familiar among parents compared to the term ‘neurodiversity’ due to the fact that the latter is more likely to be found in a non-Indonesian context when discussing Autism. This probably is the discourse of Autism – and disability in general – in an Indonesian national and institutional context. As discussed in chapter 6, government bodies, news media and several disability organisations prefer to use these terms in their documents, media coverage and campaign messages. While these terms do not specifically address Autistics, and the term ‘special needs’ has been criticised as a disability euphemism in some Western countries such as in the US (Gernsbacher, et al., 2016), it is a different case in Indonesia. As discussed in chapters 5 and 7, some parents and people with disabilities still prefer to use this term due to audience’s tacit knowledge and the inclusivity of the term for parents of children with multiple disabilities.

The next chapter will continue the discussion about the minority voice – the Autistic personhood that is beginning to emerge in social media. It will also address the main question for this thesis: how the internet and online communication by Autistics can empower Autistic self-advocacy and give understanding about the diversity of Autistic presence in Indonesia.

Chapter 9. Autistic presence, voice and personhood in Indonesia

9.1. Introduction

As discussed in chapter 7, the findings of a minority voice – the Indonesian Autistic people who utilise Twitter – indicate a different framing in viewing and understanding Autism. This chapter will continue to explore more about Autistics' points of view regarding their identities and their practice in using social media. Sara O'Neil (2008) emphasises the importance of listening to Autistics for gaining an in-depth understanding of the disorder. Despite the fact that Autism is linked with communication difficulties, Autistic individuals have learned to communicate through means other than traditional speech and face-to-face interaction, including communicating their voices through online platforms (Neil, 2008). Online communication has its particular affordances as it does not require face to face communication and has the possibility for asynchronous ways of interacting (Alper, 2014). For young people with Autism, this can be beneficial as it can relieve some pressures they usually encounter in a 'typical' form of communication (Alper, 2014).

This chapter is intended to include various voices from Autistics in Indonesia in order to provide an understanding about the use of social media as an outlet for Autistics' voice and presence. As such, this chapter will focus on the stories of five participants in this study who self-identify themselves as people on the spectrum: Ananda Sukarlan, who identifies himself as an Aspie; Yarra Yora, who identifies herself as Autistic and who posts tweets about neurodiversity; Lala Stellune (previously known as admin Lala from her blog Indonesian Autism Youth, or PAI, back in 2014); Ireisha, who published article about her experience as an Autistic in *Magdalene* (Anindya, 2017), an Indonesian-based online publication focusing on women and gender issues; and Fay. All five participants are active users of social media, which can be seen in the following table in the next section.

This chapter will illustrate how Autistic persons in Indonesia use social media to create their presence and voices. The first following part will tell the story about the background and the situation of each participant in engaging with online self-advocacy. I will begin by outlining the background and the situation of each participant, with a particular focus on how they engage with online self-advocacy

issues in Indonesia. Further analysis in this chapter will discuss the social media use of the participants, and whether social media can provide different narratives of Autism. Participant’s views about Autism and how it is perceived in Indonesia will also be addressed in the discussion part, before moving to about a discussion of the neurodiversity culture on the internet. The final part of the discussion will address on how media and popular culture can influence participants’ understanding about Autism as a socially constructed identity.

9.2. The participants

The five participants interviewed for this chapter have various background and different age range, although all of them have been diagnosed with Autism or Asperger syndrome³⁰. Most of them were recruited from the internet – based from their blog postings or tweets about Autism and advocacy. In addition, I also recruited one participant from the parents of Autistic children community. The purpose of choosing an informant from a different source is to acquire more diverse points of view. Their information details can be seen in the following table.

Table 12. Participants data

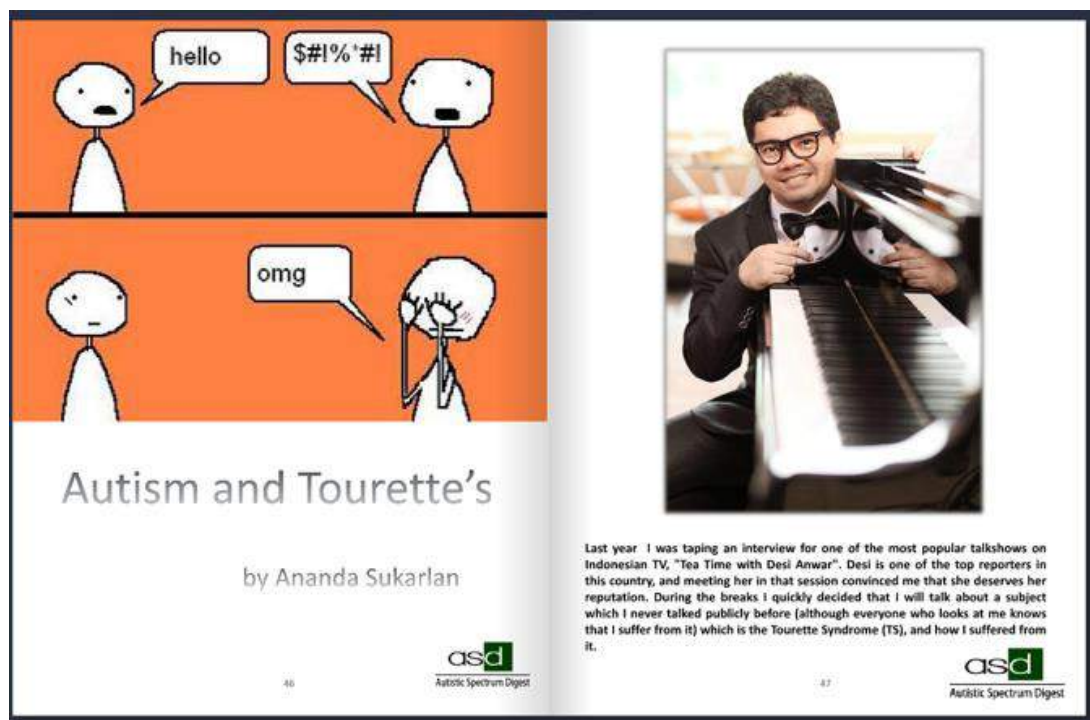
Name	Age, sex	Occupation	How they are discovered for this study	Social media frequently used
Ananda Sukarlan	51, male	Musician	from Twitter search	Twitter, Facebook, Instagram, YouTube, Blog
Lala Stellune	20s, female	Student (undergraduate), digital artist	from Indonesian Autism Youth (PAI) blog	Twitter, Tumblr, YouTube, Blog
Yarra Yora	20s, female	Digital artist	from Twitter search	Twitter, Tumblr
Ireisha	21, female	Writer	from <i>Magdalene’s</i> article	Twitter, Facebook, Tumblr
Fay	19, female	Student (undergraduate)	from community of parents with Autistic children	Blog, Facebook, Instagram, YouTube

³⁰ It is worth noting that the majority of respondents in this study are Autistic women. This is not usually the case in autism research, as the ratio of boys/males are higher among Autistics. It is assumed that female on the other side of the spectrum – who often possess higher verbal communication skills and social empathy – can “easily camouflage their social deficits” (Goldman, 2013).

- **Ananda Sukarlan**

Ananda is an Aspie who works as a musician; he is an internationally recognised pianist and composer in classical music. He currently lives in Spain but regularly travels to Indonesia for his work, conducting musical performances and collaborating in various art and music projects. His diagnosis was not made until he was 28 years old and only because he was living in Europe – according to him, at that time Autism diagnosis was not yet familiar in Indonesia. In 2014, he was named as one of the most influential people in the Indonesian art scene by *Tempo*, a national news magazine. Ananda is also acknowledged for his numerous music compositions, including a piano composition called *Lonely child* which is dedicated to children with disabilities (Sukarlan, 2010; Simanjuntak, 2017). He talks openly about his experience of being bullied at school because of his “awkward” condition in numerous media, including in *Autism spectrum digest* magazine in 2014 (Figure 6).

Figure 6. Ananda featured in Autism spectrum digest magazine, 2014



Prior to that article, in 2013 – in a media-first for Indonesia – Ananda was interviewed on a national television talk show *Tea time with Desi Anwar*, where he first publicly talked about being an Aspie and having Tourette syndrome (Sukarlan, 2014b). After his ‘coming out’ on the television show, Ananda shared further postings about

Asperger's syndrome on his Facebook account and on his personal blog under the pseudonym Andy Starblogger (Sukarlan, 2014a). Currently, he is actively using social media for advocacy and to raise awareness about Asperger's and Autism so that Indonesian people are more aware of the issues. Using hashtag #AspieIsAwesome, he tweets about facts on being an Asperger person, and has also posted YouTube videos about his experience as a person on the spectrum. Currently, he also writes articles for *Deutsche Welle*, a German-based international broadcaster, about the benefits of being an Asperger's and Autistic (*Asperger's Syndrome, Langkah Terbaru Evolusi Manusia?* trans. Asperger's syndrome, the next stage of the human evolution?) (Sukarlan, 2019).

Ananda shares his personal experiences with the public about being an individual on the spectrum and, as such, contributes a great deal to the Autistic self-advocacy movement in Indonesia. In his blog, he wrote that being an Aspie often causes extreme loneliness, which leads him to express his creativity in music, "When the feeling of loneliness happens, it usually indicates that I should write music. My best music is written when I am feeling horribly lonely" (Sukarlan, 2010). He also later participated in a YouTube video campaign which aimed to encourage people with Autism and other neurological differences to both face up to bullying and advocate for change. In the video, which was made on behalf of the Indonesian music education organisation Kita Anak Negeri (2014), Ananda states that the differences, the uniqueness that Autistic people have, should not discourage them nor be perceived as deficits:

If anyone bullied us, it was not because of what we said, or we did. It is not because of our passion, although sometimes our passion in certain areas can make us to be overly focused. For example, like my passion with music, which probably can make other people feel uncomfortable. But the problem (that triggers bullying) does not come from us, it comes from them, the people who bullied us. They feel insecure for their weaknesses, so they bullied us – Ananda in Bakti musisi untuk Indonesia (Negeri, 2014).

His statement above, to my interpretation, is reflecting his view about ableism – although he did not mention the term. Ableism, as stated by Goodley and Davis (2012) is "where the presence of the disabled body is unsettling for non-disabled people who are often in denial about their own vulnerability" (p. 18). In his statement above, Ananda rejects the notion of disability and Autism as a deficit and a 'problem'. Instead,

he addresses the problem of bullying toward Autistic comes from the bully themselves, who view Autistic and Aspie person as an object of discomfort. Furthermore, regarding his role as an advocate for Asperger's and Autism issues in social media, Ananda states (in our interview) that it has some positive impacts for the public:

People became more aware about the issues, and I got positive responses from them. A person who read my tweet contacted me and currently we are working for a book project about Asperger's. The benefits of doing advocacy in social media, actually, is not for me, but more for other people. For me, well, I'd rather say "I have this (condition)" – Ananda.

- **Lala Stellune**

Lala is an artist and a university student majoring in visual art. Her diagnosis came when she was in the 5th grade elementary school in the US, where she lived between the ages of 4–8. At that time, she was diagnosed with 'mild Autism' and had her symptoms treated in that country. Lala currently works as a freelance illustrator and enjoys certain pop culture forms such as fan-art drawing, cartoons and television series. Social and political activism are some of her other interests; these are reflected in her discussion threads on Twitter and these drove her to start the PAI blog (<https://pemudaAutismeindonesia.wordpress.com/>) in 2014. Lala is the writer and illustrator of the PAI blog; she makes drawings for articles published in the blog, depicting herself as an Autistic female (Figure 7). For example, in her drawing (Figure 7), Lala explains about the difficulties of talking (*berbicara*) and the difference of direct communication (pictured in the right panel, communication in the real world, trans. *dunia nyata*) and mediated communication using computer and the internet (pictured in the left panel):

Figure 7. Lala’s illustration in the PAI blog about the communication problems of Autistics

ARTIKEL, KOMIK

KOMUNIKASI

🕒 JUNI 19, 2014 🗨️ TINGGALKAN KOMENTAR



Source: <https://pemudaAutismeindonesia.wordpress.com/category/komik-2/>

In the PAI blog, Lala, who is now living in Indonesia, admits that she still experiences “Autistic problems”, and wants to share her stories and listen to other Autistics’ experience. As such, she invited other Autistics to join and contribute in the PAI blog, as the blog was intended to publish first-hand experience and stories about Autism. As an advocate, Lala speaks critically on some issues relating to Autism; this is particularly so in her final blog post where she speaks about her disillusionment about the Light it up blue (LIUB) campaign in April 2015. The campaign was initiated by Autism Speaks³¹, one of the largest Autism advocacy groups in the US, in order to

³¹ Autism Speaks is considered as a “neurotypically run organisation” (Parsloe & Holton, 2018). The organisation sets its mission to raise funds for research in causes and treatments for Autism, thus relies heavily on the biomedical model. It draws a number of criticisms from self-advocacy organizations in the US, such as the Autistic Self Advocacy Network (Parsloe & Holton, 2018).

spread the awareness of Autism by lighting up buildings in blue. At that time, YAI started the push to light up the capital city Jakarta's most well-known landmark, the Monas monument. In the blog, Lala expresses her disappointment with this campaign. She believes Autism Speaks does not have the right to represent Autistic people since they do not have any Autistic representatives in the group – they also view Autism as a disease and associate Autism with “something bad” (PAI, 2015). According to Lala, she was being interviewed by Radio Republik Indonesia (RRI), the state radio network of Indonesia, on the same day as the LIUB event in Jakarta, and she failed to persuade people to call off the action. At the end of her last post, she expresses her resentful feeling regarding both the campaign and Autism Speaks:

Indonesian people still do not understand completely about Autism. It is possible that Indonesian people could be 'educated' by organisation such as Autism Speaks, with the definition of Autism that has been manipulated by ableism, non-Autistic people who do not want to hear the voice of the Autistics. Therefore, Indonesia needs the right education about Autism from the Autistic people themselves. Autistic people, who experienced Autism throughout their lives, are certainly better in understanding Autism than non-Autistic people who have a relationship with an Autistic person (PAI, 2015).

In my interview with Lala via email, she told me why she had decided not to continue with the PAI project, despite the fact that the project had been online for a year. Her decision was made because she could not find any Autistic people in Indonesia who “seem to care about Autism advocacy”. To her knowledge, most Autistic advocacy groups in Indonesia were initiated by the parents, and she could not find any Indonesian Autistic self-advocacy group. She expressed her disappointment about this situation,

... Autistic people themselves don't really care (about self-advocacy). Even one said that they've been cured of Autism even though Autism is a lifelong condition – Lala.

Currently, Lala continues to work on her self-advocacy actions in social media. In 2018, she created a YouTube video series, *The Autistic codes*, as part of her self-advocacy about how comedy TV series portray Autistic characters. The video series was uploaded in celebration of 2018's Autism acceptance month, and at the end of the video she expresses her opinion about the importance of the first-hand experience to understand Autism:

Autistics are a variety of people, not just an empty shell filled with Autistic symptoms. It is Autistic people themselves who should express their experiences, not the non-Autistics around them (Stellune, 2018).

- **Yarra Yora**

Yarra lives in Indonesia and is “officially jobless” – as she told me in the interview – after finishing school. Yarra’s name appeared on my Twitter search when I collected data for chapter 6 by using the keyword *keragaman saraf* (neurodiversity) in DiscoverText. She uses social media to sell her services as a digital artist, drawing illustrations for comics and *anime*. Yarra regularly uses social media sites such as Twitter and Tumblr to voice her opinion about Autism issues and being Autistic. As shown in these following examples – from her tweet in the quote below and her Tumblr post (see Figure 8):

This is a thread about the public’s lack of understanding on neurodiversity and mental disability. Autism, ADHD, Bipolar, Dyslexia, Dyscalculia, and others are part of neurodiversity, so do not call us as retarded or mad (yarrayora, 2017).

Figure 8. Yarra’s post on neurodiversity



Source: Yarra’s Tumblr, 2016

Having been diagnosed as Autistic when she was in high school, Yarra finds the internet and social media as important resources to learn more about her condition. In my interviews with her through LINE, a platform chat messenger application, Yarra told me that social media serves as a resource to have her words to be heard by other

people as, in the offline world, “such spaces are reserved mainly for the parents and health practitioners”.

During our interview, Yarra also spoke about her critique towards the majority voices who dominate the Autism world – the parents and health practitioners. As explained in the previous chapter, she tweets about her discontentment with YAI for promoting LIUB – an Autism awareness campaign initiated by the US-based Autism organisation Autism Speaks. She gives an example about what often happens in Autism awareness events, where people on the spectrum tend to be “sitting pretty on display” while the parents and health practitioners take the lead. That said, she prefers to discuss Autism with online friends who are on the same spectrum rather than search for Autistic resources online. According to her, most online resources are dominated by Autism parent-based organisations or “mom bloggers who write woes about having Autistic children”. Furthermore, Yarra expresses her adverse feelings towards charity organisations founded by parents. In our interviews, she states that parents of Autistic children tend to think of Autism as a disease that needs to be cured:

Oftentimes an organization founded by the parents instead of the Autistics themselves are... less about helping Autistics and more about eradicating Autism. And also focuses on how the parents are suffering because their kids hate being hugged, or how they won't talk or whatever else they paint their kids as often times even parents with neurotypical kids don't even treat their children as their own person. Now imagine with Autistic kids who have trouble speaking out, it gets worse. – Yarra.

- **Ireisha**

Ireisha is an English literature graduate who works as a writer, editor and translator based in Jakarta, Indonesia. Her name appeared in my online search in an article titled *Coming out as Autistic* published in *Magdalene*, an online publication on Indonesian gender and cultural issues (Figure 9). The article, published in October 2017, is probably the first one discussing this particular issue about Autistics and self-identity in an Indonesian context, an idea described in its byline, “Though she doesn’t fit into the established image as an Autistic person, “normalcy” to her feels like an illusion” (Anindya, 2017). The article tells her story of being a person on the spectrum in

Indonesia, of having what she describes as “a complicated relationship with Autism” (see Figure 9).

Figure 9. Ireisha’s article on Magdalene



Source: Magdalene, 2017

Having been officially diagnosed with Autism when she was in her toddler years, she remembers that most of her childhood was spent on therapies such as Son-Rise therapy, a home-based program for Autistic children or adults. According to her experience, she is often viewed as “normal” by others and does not fit within the established image of Autistic in Indonesia – as Autistic is largely portrayed as ‘special need’ person who constantly need economic and medical support; or on the contrary, as being a savant.

When I invited her to be one of my participants in this study, she expressed her interest as she has a particular concern that disability and Autism issues have not yet had an in-depth discussion in an Indonesian academic setting. In one of our first conversations through mobile messenger’s platform LINE, Ireisha told me one of the reasons why she decided to write the article. She found out that it is easier to find people talking about diversity in the global setting, particularly in the Western context, whereas it is much harder to see people talking about neurodiversity in Indonesia:

To be honest, I sense a lack of ‘Autistic own voice’ in Autism discourse in Indonesia. I think the discourse in Indonesia tends to

focus on parents and also on the medical model of Autism, too –
Ireisha.

Moreover, she believes that the internet provides space for finding people with similar interest and to talk about Autism, rather than directly talking to people (particularly in Indonesia). For example, she knows several Indonesian people who are Autistic, or at least people who have a relation with Autism in Indonesia, but according to her, “It’s still difficult to talk about it directly. Some of them seem to think of Autism as illness or taboo”.

- **Fay**

Fay is the youngest participant in this study. She is a prolific 19-year-old teen writer who was diagnosed with Asperger’s when she was 12 years old. I came to know her through a seminar held by YAI in 2017, where her mother had a conversation with me about Autistic teens using social media. Fay had already published three books, all in Bahasa (although some are using English titles) titled *Lessons of a friendship* (2015), *My life, my dream* (2016) and *Keluargaku Jiwaku (My family, my soul)* (2019). The first one is her compilation of short stories with a specific theme about friendship, while the second book is a literary memoir based on her life as an Aspie teen. For Fay, blogs are a channel for her writing outlet, as she regularly writes in her two blogs, Blogspot and Kompasiana³². Fay’s aspiration is to be a prominent writer; as discussed in the previous chapter, her mother told me in a separate interview that by sharing Fay’s point of view as a person on the spectrum makes her articles more unique compared to other blogs. This particular point of view is stated in her blogs’ headings:

Nobody is perfect, including me. Being diagnosed with Autism does not mean I cannot create something. On the contrary, the ‘different’ world where I live gives me the freedom to observe the world around me and to write about it. My blog is my training place to write. One day, I will make my dream come true – to be a writer.

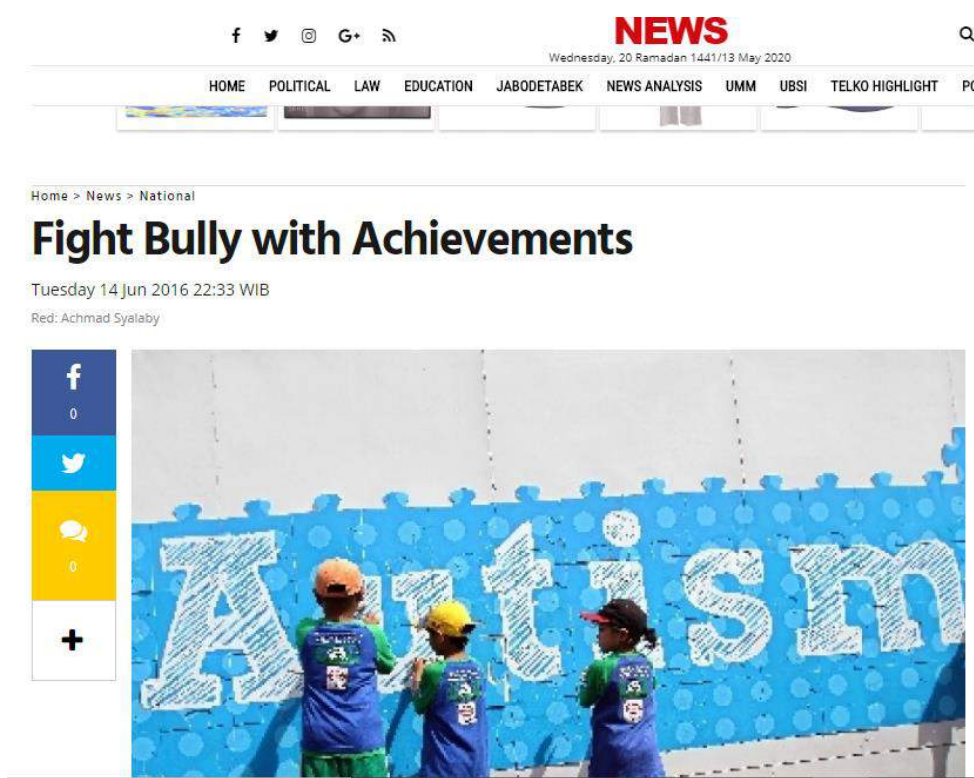
About her being an Aspie, she views her condition as something positive in her second book, quoted from her book as follows (Figure 10):

I view Asperger’s as my weakness, but apart from that I also have my strengths. I have no differences to other people, as they also have

³² Kompasiana is a curated citizen journalist blog platform which requires a more formal language writing style. The blog platform is owned and operated by *Kompas*, the national leading newspaper.

their weaknesses and strengths. Nobody is perfect. I know my weaknesses, and I will grow my strengths (Izzah, 2016) (back cover).

Figure 10. Fay's second book featured in Indonesian news media



Source: Republika.co.id (Syalaby, 2016)

Currently, Fay is studying at the Open University (Universitas Terbuka) and taking a major in English translation. Knowing Fay's interest in writing stories, her mother enrolled her in a private writing course 5 years ago so that Fay could learn creative writing skills with an experienced tutor. In her Kompasiana blog, she regularly writes about the topic of Autism in a journalistic reporting style – for example, Autism events in Indonesia, movie reviews about Autism, and interviews with other Autistic teens – while her articles in Blogspot are intended for daily journal and fiction stories. Fay started her blogging activities in 2012 in Blogspot, and her Kompasiana blog started in 2017. She independently edits her articles on Blogspot, but for Kompasiana she gets editing assistance from her mother and her writing tutor.

Fay also has a circle of close friends, other Autistic teens whose parents are also friends with each other. They regularly communicate through WhatsApp messenger on their mobile phones, having daily chats and making appointments to meet or going to the cinema together. Besides WhatsApp, Fay regularly uses Instagram and Facebook

messenger as communication tools. It is worth noting that Fay and her close friends often made collaborations through their creative projects. In her second book, for example, two of her friends provided the illustrations for her book cover and the colouring sheets inside the book.

9.3. Data Analysis

9.3.1. Social media as an ‘embedded media’

Social media is an ‘embedded media’ – a term that Philip Howard (2003) refers to people’s increasing reliance on the communication technology in their daily activities, such as socializing, getting in touch with family, advertising products or services, or spending time in their leisure activities (Thurlow, et.al., 2007). Historically, social media is defined as “a group of Internet-based applications that builds on the ideological and technological foundations of Web 2.0, which allows the creation and exchange of user generated content” (Kaplan & Haenlein, 2010, p. 61). Social media platforms are constantly developing in various forms, including the most popular social networking sites (Facebook), video-sharing (YouTube and Vimeo), blogging sites (Blogger and Tumblr), microblogging sites (Twitter) and mobile messaging platforms (WhatsApp and WeChat) (Arleen & Fritz, 2015; Miller et al., 2016).

According to all of the participants in this study, social media usage is part of their daily essential activities. For example, Ireisha uses various kinds of social media and online messaging platforms in her daily activities, such as Tumblr to find interesting posts, Twitter and Instagram for connecting with friends or looking for photographers, and also mobile messaging apps such as LINE and WhatsApp for more interactive communication. Once in a while she also opens the popular platform Facebook to connect with family and her university friends, as well as posting her writings and important moments³³. Another example is Fay who uses social media to seek references on writing tips and Autism reference. She likes to follow accounts about writing tutorials and tips on Instagram and Facebook. Fay also uses the internet to look up some references about Asperger’s and Autism through websites and Wikipedia. In

³³ According to a news article in the *Jakarta Post*, Facebook is the most popular social media site in Indonesia, with 130 million accounts in 2018 (Ajistyatama, 2018).

addition, participants also use social media as a creative outlet. Fay uses blogs to practise her writing skills, while Ireisha, Lala and Yarra post their creative projects – in the form of fan arts, drawings, essays, poems etc – to various social media platforms such as blog, Tumblr and Twitter.

Another participant, Ananda, stated that as well as personal use, he also utilises social media for professional use – to support his job as a musician and a social media influencer by promoting concerts and events, selling CDs, and advertising his activities as a brand ambassador. A social media influencer is categorised as an independent third party social media endorser; these are mostly prominent people, either celebrities or well-known personalities in their areas, who shape audience attitudes through blogs, tweets and the use of other social media (Freberg, et al., 2011). For that reason, Ananda has several social media accounts for personal use (Twitter) as well as those for professional use (Facebook and Instagram) which his staff have access to.

For people with disability, social media is viewed as an important medium, particularly in regard to communication, exchange and activism (Ellis & Kent, 2017). Particularly for people on the spectrum, written communication via social media can provide an interval in the communication process, particularly in order to reduce sociospatial and sensory anxieties that usually exist in direct or face-to-face interaction (Davidson & Henderson, 2010; Davidson & Orsini, 2013). In my study, all participants find that online media platforms can serve as comfortable mediated tools for facilitating social interactions and for communicating their views, as well as a convenient way to search for information sources. Twitter seems popular among participants – all participants regularly use Twitter, except Fay – while social networking sites (Facebook and Instagram) and mobile messaging apps (LINE and WhatsApp) are also well-liked by them. Besides that, three participants (Lala, Yarra and Ireisha) regularly use Tumblr for blogging and searching for topics within their interests.

Ananda finds social media, such as Twitter, a comfortable medium to express his thoughts. While others, such as Lala, said that social media helps her to facilitate daily social interactions with other people. She once wrote in her blog that she prefers typing rather than talking, as typing is a great technique for some people on the spectrum who can imagine words and their structure but have difficulties using their spoken words to explain. Using social media for communication and social interaction can lessen the

distractions for people with Asperger's syndrome and those who may have difficulties in non-verbal aspects of social communication such as interpreting gestures, facial expressions and maintaining eye contact (Penny & Standen, 2009). For example, Yarra admits that she finds it easier for her to talk through text rather than face-to-face. Others, like Ireisha, say that doing mediated social interaction through social media and mobile messaging apps is more straightforward compared to face-to-face communication channels as she does not have to worry about non-verbal cues:

I am often being alone, only accompanied with my mobile phone. Then I think about something, and I am tweeting my thoughts. I am expressing myself more on Twitter – Ananda.

I use social media every day. I mostly use Twitter now, though I occasionally use Tumblr. I think social interaction is the most important thing when using social media, because I don't or can't interact with people in real life often – Lala.

It is easier to talk via internet because there are fewer distractions. People tend to not appreciate it when I look at my feet when we are talking. It makes them think I'm not polite or not interested in chatting with them – Yarra.

I usually tend to over-worry when talking to people face to face because I am afraid that I interpret something (facial expression, gesture) wrongly or I miss something important – Ireisha.

Different preferences come from Fay who mentions Instagram and WhatsApp messenger as the most frequent platforms she uses in daily activities. It is important to note that in the first interview with Fay, she was accompanied by her mother who sometimes assisted her when she was having difficulties understanding or answering my questions. One of the reasons Fay uses social media is to search and browse for her special interests. She likes to use Instagram to browse her favourite things such as pets – particularly cats – and foods. She finds mobile messaging apps such as WhatsApp more useful for daily communication and social interaction; she has a particular WhatsApp group called Amazing things in which she holds the role as group administrator. All members are Autistic teens with a similar age range (18–20 years old) who first met each other at an Autism event and were introduced by their parents. Once in a while, Fay also uses Facebook Messenger to communicate with her online 'pen pals'; these are friends from outside Indonesia (from Germany and the US) with whom she exchanges messages online, but whom she has never met offline. These pen pals are also teens on the spectrum, and they were introduced by their mothers who

knew each other through Facebook groups. Fay's case resonates with a study in 2018 that indicates social networking sites are used by Autistic adults to pursue social connection (Ward, et al., 2018). In Yarra's case, for example, social media platforms serves as a conversation starter to share her experience with other friends on the spectrum:

I learn more about my own condition from a friend (online) in a spectrum rather than health professionals in Indonesia. She is from America and we did not even know each other was Autistic until we start blogging about it. I think the best way to say it is 'birds of a feather flock together'. We can sense from each other's behaviour that we are similar, and that's how we get along. And then we find out that other friends in that same circle are in the spectrum too – Yarra.

Computer-mediated communication (CMC) has a number of affordances which Joseph Walther (2007) refers as “hyperpersonal”. The hyperpersonal aspects in CMC describe how self-presentation can be conveniently ‘constructed’ in an online conversation. For example, online messages are editable and there is a potential of asynchronous communication which provides more time for online users to compose their messages advertently with fewer distractions (Walther, 1996, 2007). The aspect of potentially asynchronous communication in CMC is also highlighted by Yarra and Ireisha. They both admit that the internet gives them a more flexible timeframe to construct their responses, so this diminishes their anxieties to some extent. Written communication is their preferred mode of communication; as Yarra says, in oral communication it seems that she needs a “longer time from the brain to mouth. But with typing, I don't have to move my mouth, so it's faster”. Similarly, Fay acknowledged that she has a tendency to be more silent while faced with a direct/face-to-face conversation as she admits having difficulties in socialising and maintaining eye contact in face-to-face communication. As such, Fay is more articulate in communicating through the written form. Joyce Davidson, who analysed over 40 Autistic biographies, argues that the written word is preferred among Autistics for self-expression and communicative interaction due to their experiences of having repeated stress or ‘meltdown’ situations in processing environmental stimuli (Davidson, 2008b; Davidson, 2010). The aspect of time flexibility in online communication is also acknowledged as a benefit for Autistic adults with Asperger's, as communicating via

online platforms can provide “more control over the structure of conversations in terms of pace, topic and turn-taking” (Penny & Standen, 2009). However, there is an exception; as Ireisha and Fay confirm, if the conversation involves very close friends or relatives, they would prefer face-to-face communication over social media conversations.

In particular, the specific features in each social media platform seem to have impacts on how participants utilise it. For example, Ananda prefers Twitter to communicate and express his personal view because the microblogging platform provides more practicality in terms of limited characters and Twitter’s conversational streams style:

I never use Tumblr. I don't like Facebook. When you post on Facebook, people can comment with no reason. Each platform is different. I think Facebook is better intended for posting, and other users are not allowed to comment. The comment features made me dizzy. I always post on Twitter, and my blog posting also appears on Twitter. My most frequent activity is tweeting. After finding Twitter, I rarely doing blog. Posting in a blog requires longer writing. While tweeting is just a short writing, and you're done. Twitter is more personal – because you think, and directly write (tweet) – Ananda.

He also added that visual features in Instagram are more suitable for him to support his job as musician and a social media influencer. As one of the prominent people in the classical music industry, Ananda is recruited by some brands as their brand ambassador (or people who represent the brands) in social media. According to him, Instagram is ideal as a promotional tool as it emphasises the visual element and has captions for description. Besides Instagram, one of his blogs (anandasukarlan.com) is also created for professional use, as well as for “posting something fun and light, but not personal”.

Similarly, other participants also utilise social media for both work and professional use, such as Lala and Yarra who use Tumblr to offer their services as digital artists. For Lala, Yarra and Ireisha, Tumblr is also used for finding specific information and networking. According to them, Tumblr is suitable to their needs as the online platform is a mix of microblogging and social networking sites where users can post multimedia content in the form of a short blog. As an open platform, Tumblr has a particular infrastructure and interactive design that allows fan groups and subcultures to create

and distribute information, stories, memes, comments, analyses and other posts along with popular tags (Allesøe Christensen & Jensen, 2018; Natalie, 2018). The practicality offered by this platform also acts as an advantage for fandom communities, particularly provided by the ‘reblog’ features. Other features such as tag to search for particular topics and longer characters (compared to Twitter) also makes Tumblr more convenient to create and distribute information about Autism:

The ‘reblog’ features allow for people to easily share their thoughts, as well as adding their opinions. And the feature is pretty easy and it's a bit of microblogging, so you can share thoughts in a longer sentence (unlike Twitter) but it's not too long or complicated (compared to Blogspot/LiveJournal) – Ireisha.

In Tumblr, even though it's not the nicest place to be, it's easier to get info since it doesn't have character limit like Twitter. There are blogs focusing on supporting Autism and an entire tag trying to help people understand how our brain think – Yarra.

9.3.2. Being Autistic: how Autism is perceived in Indonesia

In Indonesia, Autism is identified under the category of mental disability according to the Ministry of Health (InfoDATIN, 2014). However, as previously mentioned in chapter 4, Autism is put in different categories by different government bodies. This vague definition of Autism was also reflected in most participants’ answers. Firstly, they claim that Autism is perceived differently among various social class groups in Indonesia. Secondly, they acknowledge that the term itself is a new one in Indonesia, as Autism public awareness in Indonesia was only started in the late 1990s. As explained by Ananda, when he grew up in Indonesia in the 1970s, his parents did not know about either Asperger’s syndrome or Autism. In his case, he feels grateful for not being able to receive the early diagnosis as the condition enforced him to learn “to live as a typical or normal person”. Often, in response to their children’s disabilities, parents impose certain levels of normalcy, expecting and training their children to be as ‘normal’ as possible. In Ananda’s case, since he was at a very young age, his parents made great efforts to train him to acquire better social interaction skills, and also basic daily living skills which required fine motor skills such as tying shoelaces. He remembers those skills that, probably regarded as simple tasks for other kids, were, for

him, challenging. He experienced that having non-physical disabilities like Autism and Asperger's in the 1970s and 1980s was considered outlandish. As he explained:

I imagine if my parents were still alive, they would think, 'There is no such thing as Autism, while you can be trained to overcome your problems by learning the skills.' For them, Autism would be an excuse for me to feel comfortable and resisting to learn. It was like, 'you are lazy, despite you can do that'. My father worked for the army, so for him, everything can be learned through strict training and discipline – Ananda.

Even in the current situation, most of the participants also believe that Indonesian people still have a limited understanding of what Autism is, particularly due to the diversity of socio-economical backgrounds in Indonesia which contribute to people's knowledge and understanding about Autism, as well as getting adequate access to health services. As outlined by Lala, Yarra and Ireisha, there is a different degree of understanding about Autism among Indonesian people. For example, people from the upper-middle class are more aware that Autism is a diagnosis and a lifelong condition due to greater access to information from the media and other sources:

There are possibilities that people from the lower social class group could not differentiate Autistics with mad people since Autism is probably still an unknown concept for them. Although in my experience, in middle to the upper-class group- such as the academic environment- nobody sees Autism as something to be bullied – Lala.

.. it is quite complicated – especially because Indonesia has a very diverse background. In capital cities, particularly among upper-middle class population, they are already aware of "Autism" as a diagnosis, so they tend to be more sensitive about Autism (for example, not to joke using Autism word), but they still have a rather limited view on what Autism is. Meanwhile, people in lower-class might not really know about Autism, or tend to think about Autism as simply "kid who misbehave" or "result of bad parenting", well those kind of things. And they don't really have the access to be given proper treatment, so there's that – Ireisha.

No matter what the country is, sadly Autism is still seen as an illness instead of a different way for our brain to work. Viewing Autism from a neurodiversity approach is still limited among certain groups (e.g. academics) and has not really reached the general public yet – Yarra.

Regardless of recent Autism awareness messages and news that emphasise Autism as a lifelong condition and therefore unable to be cured, according to some participants, Autism in Indonesia is largely viewed as an illness instead of disability. For example, after publishing her article about coming out as Autistic in 2017, Ireisha faced the question from her friend, “Are you cured though now?”, to which she has to explain that her condition is not an illness. According to her opinion, people tend to view Autism in a dichotomous way, either as something “very severe” or “horrible” – with a non-verbal condition and not able to meaningfully interact with others – or being a savant. Furthermore, Ireisha shares her personal experience, where a lot of people made comments to her such as “Don’t say that you are Autistic because it’s such a severe thing”.

This kind of dichotomy is also concerning for Yarra and Lala. Both express their concern about the impacts of using the terms ‘high-functioning’ (HF) and ‘low-functioning’ (LF) to classify Autistic people. They point out that Autistics do not prefer to use those terms as, in Yarra’s words, they make the spectrum sounds like a scale of ‘able’ and ‘disable’. Consequently, it can affect how people view Autistics, which can lead to other kinds of stigmatisation and limits their access. Jac den Houting, an Autistic activist, argues that such dichotomy tends to erase individual variations in ability, and also has the possibility to restrict access when receiving support (for those who are deemed ‘high functioning’) and to deny autonomy and agency (for those who deemed ‘low-functioning’) (Den Houting, 2019). Similar arguments were addressed by Lala and Yarra regarding their disagreements in using those terms, while Ireisha claims the terms have the tendency to be biased:

I do hear from other Autistics that people deemed ‘high-functioning’ get silenced because they haven’t felt ‘true Autism’, while people deemed ‘low-functioning’ also get silenced because they don’t understand themselves – Lala.

Although people tend to focus on ‘low-functioning’ spectrum, these people on the spectrum were mostly treated like they do not have their own autonomies. It’s even harder for them because they have trouble communicating, which is why I think it is important for communication styles outside of verbal ones to be used. For example, writing or signing, and pictures are also fine – Yarra.

It is important to have a sort of indicator to explain the point of spectrum so Autistic people can get better accommodation that suit

them, but the word low-functioning vs high-functioning is very loaded – Ireisha.

As a disability, Autism also posed another challenge as an invisible disability, particularly for those on the other side of the spectrum, such as Asperger's. Rosemarie Garland-Thomson argues that an invisible disability is similar to a homosexual identity, which is often difficult to disclose as there is a risk of affecting relationships – or surprising others – by announcing or revealing it (Garland-Thomson, 2017). This is clearly expressed by Ananda, who admits that having a mental disability like Asperger's is more invisible compared to a physical disability. Consequently, he does not like to declare his condition and is also opposed to the idea of 'coming out' when I asked him about how he publicly shared information on his condition in the media:

I thought, why I need to come out? It is no use for me. I can live 'normally'. Why do I have to tell other people 'Hey, I have Asperger Syndrome'?" With my Tourette Syndrome, yes, it is more visible – you can see from my movements, the tics. When people see that, they usually make comments, like 'Yes it is visible, you made that particular movements'. But I also got other comments, questioning me, 'Why does he seems so nervous?' or 'Is he having some kind of stress?' – Ananda.

Moreover, he remembers an incident when he was being pushed to talk about his Asperger's syndrome by the host of a television program who interviewed him. Ananda admits that at that time he was reluctant to do that because of his situation. He had been living away from the country for many years, thus he did not know the current situation in Indonesia. But the host eventually managed to encourage him to share his experience and that by doing so he would inspire a lot of people. According to his opinion, in Europe, where he currently lives, having Asperger's is not necessarily considered as deviant:

I view that as a common thing – not as something to hide but also no need to declare it in the public. Meaning, it is not something outlandish. Asperger Syndrome is a common thing. In Indonesia, I have not yet got the courage (to speak about my condition) until then – Ananda.

Moreover, according to Ananda, accepting differences in Indonesia is considered problematic, “Not only in this area (having an invisible or mental disability) but also in other issues such as religions, races, tribes and others. Initially, if people are different they will be perceived as being odd”. This explains why at first he was doubting himself about telling people publicly about having the condition as in Indonesia he sees people are still reluctant to disclose certain issues, including having disabilities and sexual preferences:

For example, about Autism, people here might say, ‘Is he mad or what?’ And Autism term being perceived in Indonesia as “Uh it is so autistic”, which means antisocial. Basically, it is not only Autism but also other issues like LGBT. People who are different, they will be seen as ‘not okay’ – Ananda.

However, a different experience came from Fay, who claims that disclosing her condition is not a problem since, according to her experience, other people will understand her condition. From her experience, people will understand and view her as – using her term – ‘normal’ after she explains about her Autism. It is probably worth noting that Fay’s background is different from the other participants. For example, Ananda spent his childhood in the 1970s where Autism was still a term found only in limited references such as academic papers and textbooks. But Fay grew up in an era where Autism awareness messages and campaigns were spreading throughout the country. Despite the fact that she feels that she is being accepted with her disability, Fay still feels different from typical or ‘normal’ people; she admits she is a very quiet person and has difficulties in understanding non-verbal communication such as jokes. According to Fay, in Indonesia there are people who view Asperger’s syndrome as not part of the Autism spectrum; nevertheless, she views Asperger’s as a disability and as a part of the spectrum.

Fay’s mother, who is also a member of YAI, actively encourages and supports her daughter to communicate her disability to the public. For example, in her blog post about an Autism awareness event in 2018, Fay wrote that Autism is not an illness that can be ‘cured’, “Autism is not a disease, and as a consequence, it cannot be cured. Autism is a special needs, and only therapies can help children with special needs to overcome their problems”. Interestingly, among all of my participants, Fay is the only

one who uses the term ‘special needs’ – a term largely used in Indonesian daily context to address children with disability, particularly Autistic children. It is also interesting to note that in her blog post, she emphasises therapy as the only way to help overcome the problems of special needs children. A different point of view came from Ireisha, who states her opinion about how most therapies are designed to ‘normalise’ behaviour for Autistic people. However, she is not opposed to therapy as long as it is beneficial to support the lives of people on the spectrum:

Yeah, some Autistic people can be very opposed to facilities. I guess mostly because some therapies are designed as a way to "normalise" behaviour instead of supporting Autistic people? But some therapies can be helpful, obviously, as long as the goal is to actually help Autistic people's life. I get the wariness on therapy, though – Ireisha.

Based on my study findings from Twitter – as mentioned in chapter 6 – Autism is largely portrayed as a condition that mostly affects children, as the Twitter conversations about Autism primarily refer to children. A similar situation was also found in a study by Riany et al (2016) about cultural beliefs and Autism in Indonesia. In that study, a number of participants who represent leaders within their communities still view Autism as a condition among children, as children who have difficulties with communicating and understanding instructions (Riany, et al., 2016). This issue is also pointed out by Yarra, who states that, in Indonesia, Autism is mainly considered as a “childish” illness, despite the fact that Autism is a lifelong condition. In her opinion, Autistic adults have difficulties in acknowledging their condition, “because there is a general preconception that Autism can only be detected at an earlier age”.

The fact that Autism is a broad spectrum with various conditions and ability levels – ranging from profound mental retardation to superior intelligence (Wing, 1997) – also makes it more difficult to understand for the general audience. Furthermore, as explained in chapter 5, there have been cases of misusing the term *autis* (autist in English) in Indonesia. The term was once popularly used for referring to people who are immersed deeply with their gadgets. This situation is addressed by all participants who express their concerns about the effect of misusing the term, something that can lead to stigmatising Autistics. As Lala said, “It is pretty sad how it trivialises Autism,

how it does not make Indonesians aware of Autism and how to accommodate them from all groups in Indonesia”.

9.3.3. Autism, cultural construction, and advocacy movements in Indonesia

For some participants, the cultural factor is viewed as one of the aspects that influences people’s views and understandings about Autism. Yarra addressed the impact of local culture, that there is a traditional belief surrounding Autistic children/people and people with mental disabilities. She gave an example; in Indonesia, a person who experiences mental breakdown is often regarded as possessed by ‘something’ such as an evil spirit. This is not to mention the stigma against the mental issue, which she views as not only being an issue in Indonesia. Lala also believes that Indonesian culture seems to “silence” Autism, as Indonesians are not used to expressing their opinion directly:

In Indonesia, people are very polite and do not demand eye contact. If they find a quality they don’t like, they do not express it. Instead, they would distance themselves, or at least that is what I’ve been seeing – Lala.

The stigma against mental issue is not something that is isolated in Indonesia only. And taking care of your ‘crazy’ relative is considered embarrassing because they are seen as a ‘burden’ – Yarra.

As previously mentioned in chapter 5, there have been cases found in Indonesia’s rural and remote areas where families keep their Autistic children bound in chains or locked in a room. These situations either happened due to people’s lack of knowledge about Autism, or due to inadequate financial support to provide treatments for their children (Wike, 2015). Tucker’s investigation of Autism families on Java island – the most populated island in Indonesia – indicates that Autism symptoms – such as ‘being in a world of one’s own’, crying or laughing with no apparent reason, wandering and sensory hypersensitivity – were labelled as crazy (*gila* in Bahasa) or severely disturbed behaviours by family and community members. A similar fact also reported by Melly Budhiman, the chairman of YAI. In 2008, she wrote about cases in West Java’s rural areas, where a number of children with symptoms of Autism were treated by shamans. She describes that due to inaccessibility to health information and services, the parents associated Autism symptoms with being possessed by spirit or supernatural powers (Budhiman, 2008).

As mentioned in chapter 6, public understanding of Autism in Indonesia is influenced largely by the medical model of understanding disability, thus suggesting that Autism in Indonesia is mainly constructed within the medical model. This medical model is presented heavily in the mainstream media and is also promoted in campaign messages by parent-based Autism organisations in Indonesia, at least in the past 10 years. Previous research on an Indonesian Autism advocacy organisation's campaign in 2007–2008 affirmed that one of the key factors in influencing people's behaviour toward Autism issues is the urgency level of the issue (Ulima & Dhani, 2012). As a consequence, the campaign's organisers (YAI and Putrakembara) focused on medical-based issues – such as the increasing Autism prevalence, and the importance of early detection and treatment – as their key messages for early period campaigns (Ulima & Dhani, 2012). Campaigns in that early period were mainly targeted to parents, families, health practitioners and educators, those who are expected to support the organisations in generating messages and increasing Autism awareness issue in Indonesia (Ulima & Dhani, 2012). At that time, those campaigns did not yet acknowledge the potential of Autistic self-advocacy.

This issue is also addressed by the participants of this study. Lala, for example, believes there are differences regarding the situation in Indonesia and those outside of the country, particularly related to Autism advocacy. She explains that, while a large number of Autistic self-advocacy movements can be found outside Indonesia, in that country all Autism advocacy groups were initiated by parents. Moreover, Lala believes Autistic people in Indonesia do not seem to care about self-advocacy as she has met some Autistics who believe that “they have been cured” from Autism. This is similar to Yarra's experiences, who states her adverse feelings toward parent Autism organisations as, based on her experience, parents with Autistic children “tend to think of their kids' Autism as a disease that needs to be cured”. Therefore, when responding to a local psychiatrist tweet about Autism awareness when commemorating the 2018 Autism awareness month, Yarra stated her standpoint clearly. Despite the fact that she appreciated the thread has been made to support Autistic people, she suggested using the term ‘acceptance’ instead of awareness for raising Autism issues. In her tweets, she believes that ‘acceptance’ is a more suitable term, which has been widely used by Autistic advocacy groups:

“The term awareness is used commonly by another group- a group whose focus is to make parents believe that Autism has to be cured, while they are making a profit out of it instead of helping Autistic people.” (Yarra’s tweet, 2018)

Regarding the issue on the difference between advocacy movements in Indonesia and other developed countries, Ireisha also sees a contradiction between the social versus medical models in accepting disability/differences. She perceives this contradiction stems from the fact that parents want to advocate and spread awareness regarding Autism to the mainstream audience. Ireisha believes it is a good intention from the parent Autism organisations to make people understand more about Autism; however, she also suggests for more inclusivity to involve Autistics’ points of view:

I think the discourse in Indonesia tends to focus on parents and also on the medical-model of Autism. However, unfortunately, they still hold the assumption that neurotypical is ‘more’ compared to Autism as if it is some sort of lesser thing. This is definitely the assumption that is generally spread in society, so it is somewhat.....inevitable. Which is why I think that parents should be open to Autistic's opinion, so they can find a new perspective of seeing Autism. Which is something that is lacking in the current discourse, although I think it's getting better and better – Ireisha.

Historically – as explained in chapter 4 – the global Autism movement was initiated by parents of Autistic children in the 1960s, putting forward the medical point of view in order to seek information and solutions to treat ‘the problems’ of Autism. In the last 10 years, however, a new wave of parental voices in the Autism movement has started to shift from the medical model to the social model, focusing on supporting and accepting Autistic diversity (Antunes & Dhoest, 2018; Langan, 2011). Evidently, I found that more Autism campaigns from Autism parental organisations in Indonesia have started to show similar situations, for example by conducting a number of collaborations with Autistic people, both teens and adults on the spectrum. These organisations invited Autistics to be involved in their events – as spokespeople and advocates. In MPATI’s 2018 event, for example, they started to raise the issue of Autistics living independently by choosing the theme “Be informed, be inspired, get a job”. Fay, who got invited to collaborate with MPATI’s events several times, had a chance to speak on behalf of Autistic youngsters in a public talk show held by the organisation. She also managed to join their internship program as a reporter on KBR

(Kantor Berita Radio), an independent national radio news agency. As Fay told me about her experiences:

Despite the challenges for people with Autism to be accepted in the workplace, I think there are many of them who already secured their jobs. For example, like me, I got the internship job. My friends and I also got the opportunities to exhibit our creations in a number of events held by Autism organizations – Fay.

Such collaborations between a parent-based advocacy organisation and Autistic people in Indonesia show the opportunities of greater inclusivity – particularly in creating more active roles for Autistic self-advocacy and providing support for Autistic adults. As discussed in the previous chapter about parental voice on Autism advocacy in Indonesia, there seems that no conflict appears between the parents and Autistics – as the parents involved in this study stated their support for Autistic acceptance in Indonesia.

9.3.4. The neurodiversity culture in social media

A previous study by Goggin and Noonan (2007) indicates that blogs and forums have been used to promote alternative (disability) narratives, ones that are not always in compliance with the dominant model, including the social model (Trevisan, 2017). Some of my participants – Lala, Yarra and Ireisha – learned about neurodiversity, as an alternative narration to consider Autism beyond the dominant medical view, from online discussions and postings in blogs and other social media. While Ananda and Fay acknowledge that Autism is a disability that should be accepted and a difference that should be empowered within the people on the spectrum, they did not mention the term neurodiversity nor bring the topic in their advocacies through social media.

The discussion about neurodiversity issues emerged from social media, particularly from Tumblr. Lala, Yarra and Ireisha explain that the idea first appeared in social media platforms like Tumblr, blogs and Twitter when they were searching for information outside Autism topics. For example, Ireisha found the term neurodiversity when she was involved with her fandom activities of the TV show *Community's* Abed Nadir. The term appears in a large number of discussions and posts related to Abed Nadir's character in Tumblr and, according to her, she found a lot of Autistics were engaged in fandom activities. Yarra found the discussion surrounding neurodiversity

and Autism topics in a *manga*, a Japanese comic, in cartoon online forums, and also in Tumblr. Compared to other social media or online forums that have fandom-related activities, Tumblr – according to Ireisha – is a place where more “progressive” fans congregate and start discussion threads about their interests:

Well, it actually starts by fandom activities, actually. As I mentioned in that Magdalene article, I first find out about neurodiversity because I really like a TV show titled "Community", in which one of the characters (named Abed Nadir) has a very Asperger-like quality. I relate to that character a lot, so I like to search the contents of this character on the internet. Mostly Tumblr, and I end up finding out about neurodiversity because a lot of Autistic people actually share a lot of discussion or posts about him, so I find out about the idea of neurodiversity. – Ireisha.

As pointed out by Lala and Ireisha, the idea of neurodiversity originated from Western countries and became popular through the online platform in the 2000s. Ireisha recalls the neurodiversity term was firstly introduced by Autistic advocate Jim Sinclair when he made his presentation “Don’t mourn for us” in the 1990s. Sinclair’s presentation has been marked as one of the most consequential pieces on neurodiversity and Autism acceptance. Ireisha thinks the idea emerged due to self-awareness among Autistics, “that Autism is really a part of their own self and their own identity”. She also interprets the idea of neurodiversity as seeing Autistics not as a ‘bad thing’ but as a part of diversity and ‘wealth’ of neurological situations. For Yarra, however, she believes that, generally, people are still unfamiliar with the term neurodiversity, and that this is possibly still limited to certain groups such as academics.

As mentioned in chapter 2, online communities and blogs are significantly popular among Autistic people, and these platforms quickly become places for Autism culture and neurodiversity advocacy to spread globally (Masschelein & Van Goidsenhoven, 2016). However, as pointed out by Lala, neurodiversity is “a very Westernised concept of Autism” and, based on her experience, she has not yet seen any Autistics in Indonesia who find such value in their Autism. That is also the reason why she decided to drop her Autism self-advocacy project – the Indonesian Autism Youth – in 2015:

I have not seen yet any Autistics (that I know of) in Indonesia who finds value in their Autism. One even thinks that Autism is just part of their past. Mental health is not taken as seriously in Indonesia as it is in the West, as mental illness is associated with people on the

streets, let alone neurodevelopmental disorders like Autism. So, I just left behind the neurodiversity movement as I see it not suitable yet in Indonesia – Lala.

In order to establish a disability movement, Ward & Meyer (1999) suggest two key elements – self-help skills and group organising. The first is regarded as an important matter to gain one’s dependency, as people can manage to take care of themselves. The second refers to finding allies based on the ‘group identity’, that people with disabilities have the same social experiences as each other despite the fact that they have a similar or different type of disability (Ward & Meyer, 1999). I support this argument, as the participants in my thesis already possess self-help skills to take care of themselves, for example having jobs, going to college and speaking for themselves, so they can do their self-advocacy movements. However, it is worth noting that there is one participant who still needs more support; Fay still gets assistance from her mother and her tutor in order to communicate and to be able to narrate herself through her writings. There are also challenges faced by Autistics in finding allies to form a group identity; thus, initiating an Autism self-advocacy movement is difficult in Indonesia. As Lala explained:

I think it's important (for people to come out) so there is a sense of solidarity. Any form of Autistic advocacy is impossible if no Autistic person talks about their own experiences – Lala.

Historically, making connections with other peers – young people or adults on the spectrum – is not easy. There are possibly a number of reasons contributing to this, such as parents who do not openly inform children about their diagnosis, and also the critical advice for the ‘normalisation process’, for example integrating Autistics into mainstream education and exposing them to non-Autistic peers in this process (Waltz et al., 2015; Waltz, 2013). In addition, for those who get diagnosed as adults, the situation is probably more difficult as they may have experiences of previous wrongful diagnoses or social failure (Waltz et al., 2015). As in Ananda’s case, he previously did not feel the urgency to ‘come out’ and disclose his identity as he now “can live normally”. However, in the later stage, he admits that sharing his experiences publicly will help other people to understand more about having an invisible disability like Autism. On the other hand, he is not interested in following people, including those

related to Autism issues or advocacy. When he needs to search particular issues or news about Autism, he will go directly to the information source, such as websites and articles by typing certain keywords:

I only follow very few people (Autistic advocate) on Twitter. I do not follow people largely because I rarely see other people feeds. Frankly, until now I do not understand the point on following people on Twitter, because I'm not interested. Following people for me is just for courtesy – Ananda.

In the developed countries, more advancement in Autism diagnosis and treatments have been discovered, as well as more accessible information for the public. This situation is probably different compared to third world countries such as Indonesia, where public knowledge about Autism and access to health information and services are uneven. In Western countries such as the US and its European counterparts, Autistic people have become more educated and engaged in more self-discovery, seeking other peers to validate their condition (Ward & Meyer, 1999). In a more recent context, this information and these networks of community are to be found more quickly using the internet. In my study, this resonates with the cases of Lala, Yarra and Ireisha who found their peers via online discussion, and particularly through the influence of popular culture, which will be discussed in the following section.

9.3.5. The influence of media and popular culture

The importance of the role of the media – either in the form of news or entertainment content – for creating a fair representation of Autistic people was brought to my discussions by Lala and Ireisha. Indonesian movies and entertainment shows, according to Lala, are lacking “real-life acting” compared to movies and shows from Western countries. Lala said that popular culture content like television shows and movies – which portray genuine acting – can be beneficial for learning and observing people’s behaviour, including Autistic characters’ behaviours. In 2018, she created a 16-minute video on YouTube titled *Autistic codes* where she examines some characters in the US popular television comedy series associated with Autistic people. These include the popular Sheldon Cooper from *The big bang theory* and Sam Gardner, the main character from the Netflix series *Atypical*. She makes a critique on how these characters – albeit well-liked by the non-Autistic or general audience –

represent Autistic characters as ‘the other’ by making them as an object – emphasising their social awkwardness, their repetitiveness, and their intense interests for laughing materials. On the contrary, from my Twitter findings (as presented in chapter 6), *Atypical* was seen as a positive reference by the Indonesian audience as giving a better understanding about the Autistic character:

“In my opinion, this TV series (Atypical) is great. We can understand how the perspective of this world from an Autistic. How difficult it is for him to understand the world without being mocked at.” (Twitter user, 2017)

Contrary to the tweet above, as an Autistic, Lala believes *Atypical* and *The big bang theory* have created unfair representations for Autistic people. *The Michigan Daily*, a US-based newspaper, raised a similar concern on how TV comedies could make a better representation of Autism, as popular series like *Atypical* often use idiosyncrasies and quirks in their characters as laughing material (Anantharaman, 2018). For better examples, Lala points to two Autistic-coded characters in two different comedy series – Abed Nadir from the NBC series *Community* and HBO’s *Flight of the conchords* Jemaine Clemaine. According to her opinion, these roles portray good Autistic characters by making them active roles and subjects who are given the authority to have an opinion regarding their own actions. Despite the fact that these two TV series are unfamiliar to an Indonesian audience – compared to *The big bang theory* and *Atypical* which are more popular – Lala was trying to voice her opinion as an Autistic person, sharing her thoughts about how, ideally, Autistic characters should be portrayed in a comedy.

Indeed, Abed Nadir from *Community* is also considered to be a great influence for Ireisha. In her article published by *Magdalene*, she shares how she finally accepted her “condition” by relating herself to the cast. Although she has been diagnosed with Autism since elementary school, Ireisha previously doubted her diagnosis – particularly during her teenage years –because her condition seemed to not fit with the general portrayal of Autism. As she explained in her article in *Magdalene*:

“It took me a long time to accept Autism, as I finally found an image of Autism that finally reflected me. It was Community’s Abed Nadir, the undiagnosed-but-codified Asperger’s character that finally gave comfort in my late teenage years. The similarity struck me

dumbfounded, and then hopeful, as I finally found someone I could relate to.” (Ireisha, 2017)

In addition, according to Ireisha, popular and mainstream media tend to portray Autism in two different categories – either as savants or those who cannot interact and are helpless. Such kinds of portrayal made her confused, as she could not identify with these traits. As she told me in the interview:

Most media portrays Autism as either this brilliant people who's really really talented at math, science--and I'm not bad at them, but I'm not really good at them. Or it's usually the non-verbal who is usually shown in such a simplistic way, that they cannot interact with the world/communicate with others. They are also usually portrayed as very logical to the point unemotional/cold too, which is not who I am... – Ireisha.

From my observation of published articles and news footage in online Indonesian media during my fieldwork, many of these still used the word “suffering from Autism” (*menderita autis* in Indonesian) in describing Autistic condition. When I discussed this concern with Ireisha, she pointed to the medical perspective in viewing disability – how disability and Autism are still considered as an illness, as something ‘severe’ or ‘horrible’ in Indonesia – due to the media’s portrayal of disability:

Well, people tend to see as ‘suffering’- which also correlates somewhat to how people see it as illness, sometimes. That is kind of sad..... but I think it is not their fault because of that how it is represented in media. I myself used to doubt that I'm Autistic despite knowing that I actually have a diagnosis during my teenage years. It's just how it is presented and thus they have a limited view on Autism – Ireisha.

What Ireisha described above in the last sentence had been defined by Samantha Murray (2007) as the audience’s “tacit knowledge”. Tacit knowledge can be viewed as “internalized social statements” from the media and in everyday life about certain groups such as people with disability, ageing people and obese people (Rodan, 2014). Subsequently, the audience will draw on this tacit knowledge from media representations. Based on a report from the Indonesian Centre for Innovation Policy and Governance (CIPG) about the media and vulnerable groups in Indonesia (2013), the Indonesian media has the tendency to cover disability issues using a medical approach. Consequently, it is possible that the stereotyping and misleading

representations created by the media – such as “implying the uniqueness for being different” – could jeopardise the idea of creating equal rights for disability groups (Nugroho, et al., 2013). This is not only in the form of news, but also in entertainment content such as television shows which also have the possibility to portray disabled people in a more marginalised position. Gray (2008) argues that television entertainment can create a dichotomy on what is ‘normal’ or ‘abnormal’ by relying on particular stereotypes (Rodan, 2014). This was addressed previously by Lala on her critique of some popular TV series characters with Autism as, by emphasising their quirkiness, they were represented as ‘the others’, the abnormal ones.

Despite the concern of stereotyping and misrepresentations by the media, it is worth noting that some articles in Indonesian leading print media have played a significant role in providing early guidance for families with Autistic children. According to previous research by Tucker (2013), some news publications provided benefits by publishing early information for parents about the idea of Autism, its symptoms and treatments. Moreover, those articles used balanced and positive or neutral language in discussing Autism, compared to some US and European media which often use negative rhetoric in doing Autism coverage (Tucker, 2013b). However, to create more equal coverage for Autistic people, the media should consider providing more information through the socio-cultural model, not only through the biomedical path (Kim, 2012). The socio-cultural model emphasises more on the social contexts in which Autism is understood and viewed (Kim, 2012). As Ananda explained:

In Indonesia, there are many things still left undisclosed. Including Autism, people perceived it as crazy or antisocial. We still have problem to appreciate differences. As a culturally diverse nation, the Indonesian people have various religions, languages and ethnical backgrounds. One of the keys is to educate people about appreciating human diversity – Ananda.

In Indonesia, there has been a transition in perceiving disability – from medical model to social model – particularly since the ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2011 and the introduction of Law No. 8/2016 on People with Disabilities in 2016. This also affects the shifting in government’s policy from a medical- and charity-based approach to a rights-based approach; including policies related to disability rights for education, social justice and law protection, and also for health support and service (Millati, 2016). Although this

thesis will not delve into further debate between the medical and social model in Indonesia, it is worth to note that some scholars criticised the social model as it lacks the nuance, complexity, and socio-cultural consideration to view disability in the Global South (Millati, 2016; Ware & Schuelka, 2019). As such, it is important to consider the importance of socio-cultural, religious, and political contexts in understanding disability – including Autism – construction and conceptualisation in Indonesia.

9.4. Conclusion

Based on my interviews with all five participants, it could be concluded that the internet can be very enabling, particularly in terms of accommodating their social interaction, voicing out their opinions, and sharing their stories with the public. Social media such as Twitter, Tumblr, blog, Instagram and YouTube have become a CMC tool for their presence, an alternative platform for them to speak on behalf of their identities. These online platforms also become the medium to get information and, for some participants, it provides different understandings about neurodiversity culture. For them, communication is not always compatible with speech, as most of the participants preferred the written form as a more comfortable way of having conversations. As Neil (2008) states, “Communication is not synonymous with speech, or even with face-to-face encounters” (p. 791).

However, while all participants have similar views on understanding Autism as a difference, some of them construct and interpret their own identities in a more critical way, for example by reframing Autism as neurodiverse, thus challenging the conventional/medical views of Autism. This change of view has been facilitated by the internet and social media, starting from online discussions in fandom and fan art communities. Through social media, some participants have produced their own narrative and created alternative views in interpreting Autism, such as writing articles about their experiences or creating guidance about Autistic representations in the media.

Not all participants are familiar with the term neurodiversity. At the time when this thesis was written, neurodiversity is still not widely used in an Indonesian context when discussing Autism, either in the media or in advocacy movements. In Indonesia,

the medical approach is still widely used in the mainstream media, while the Autism advocacy movement is largely dominated by parent-based organisations. The neurodiversity view is predominantly only disseminated through online platforms and Autistic communities outside Indonesia. While social media and online resources provide essential references for most participants in understanding Autism, popular culture in the form of non-Indonesian television series also act as an influential reference that Autistics can relate to. However, while most of the Indonesian media still applies the medical model approach, currently different approaches such as the social model of disability have started to take place in campaign messages by Indonesian Autism organisations. Evidently, Autism parent-based organisations such as YAI and MPATI have started to campaign about Autism as a ‘different ability’ and have started to spread messages about the importance of accepting differences in Autism. This apparently follows the global Autism narrative in which Autism is increasingly recognised and appreciated as “a kind of human difference” (Grinker, 2007).

It is also worth noting that cultural representations of disability and traditional beliefs have large impacts on people’s understanding about Autism. In Indonesia, Autism is still related to karma and taboo; it is labelled as being odd or mad, or possessed by an evil spirit. These representations can lead to stigma and discrimination toward Autistic people, adding to the impact of Autism as a non-physical or ‘invisible disability’. As a final note, when discussing Autism online presence and self-advocacy in Indonesia, it is important to acknowledge that Autistic self-advocacy is still based on personal identity – not on a group identity where they can share the same social identities with each other. Up to the time of writing this thesis, there is no Autistic organisation in Indonesia – either online or offline – that exists without an associated parent-based Autism organisation. On the other hand, these parental associations – in their efforts to provide opportunities for Autistics to have a better quality of life in society – have currently started to be more inclusive, for example by conducting collaborations with Autistic youngsters and adults.

Chapter 10. Conclusion

This thesis investigates how the global Autism movement (or the neurodiversity movement), particularly from the internet, has influenced the understanding of Autism in Indonesia. Autism is a socially, culturally, and historically constructed category of disability. It is not only a medical label that marks a person's biological psychiatric condition, it also becomes an identity of being 'neurologically different', influenced largely by the global Autistic movement on the internet.

Taking a critical approach to disability as a framework, I addressed the questions raised in this thesis – how Autism is represented and understood in Indonesia, particularly through online platforms, and how social media can offer alternative ways of understanding Autism in Indonesia and become a catalyst for new forms of expression for Autistic adults. The framework of critical disability studies and critical Autism studies serve as the basis for analysing the discourse of Autism in Indonesia, particularly in viewing how cultural and social context define and regulate disability. Periodically, the notion of Autism has been changing, influenced by multiple stakeholders – the Autism activists, including Autistics, parents and other advocates, health practitioners, media and other institutions, and social actors who are involved in the process of defining and interpreting Autism.

This study offers something that has not been covered before in Indonesian studies about Autism – the voices of various stakeholders, from the public voice on Twitter represented largely by the news media and Autism organisations, to the voices of Autistics and parents. As far as I can determine, this is the first study in exploring the use of the internet and Autistics' presence in Indonesia, so I expect this thesis will provide a starting ground for offering further suggestions to continuing study in this area rather than a complete definitive study. This may be particularly so in regard to contributing to the discussions of how the online platform can influence the understanding of Autism, and how Autistic individuals come to think and talk about themselves in social media. Moreover, the discussions in this thesis will contribute to providing a reference about Autism advocacy movements in Indonesia.

This final chapter presents a review of the overall findings in the thesis and the contributions that my research makes to the existing knowledge. I also emphasise certain issues that emerged from my research – which may provide suggestions for further investigation in Indonesia or other countries where Autism has already taken place. To provide a review of the findings and implications of this study in this chapter, I will reflect on the thesis’ aims and objectives as outlined in Chapter 1, and discuss how it will contribute to future studies related to Autism in Indonesia.

10.1. Findings and implications

The idea of Autism is still contested and debated globally, as indicated by the dynamic changes in Autism conception, previously from the clinical category to a new form of political and social identity. The rapid development of internet usage has facilitated networking and relationship-forming opportunities for Autistics, thus contributing to the growing “Autistic culture” globally (Davidson, 2008a). As evidenced by my findings, this has also occurred in Indonesia – the internet and social media enables the Autistics in this study to have a shared space where they can exchange conversations comfortably. In particular, as discussed in chapter 9, the online platform has opened the way for some participants in this study to understand their Autism as part of their valuable, politicised identities. Those particular participants in this study view themselves beyond the medical definition of Autism that perceives them as ‘disabled’ by a mainstream or neurotypical culture. Instead, the Autism culture on the internet, in the form of the neurodiversity movement, provides them with a form of self-awareness as neurodiverse people.

My research also revealed that Autistic individuals make different choices in framing their Autism. Some view their Autism as identity, while others prefer to see it as a difference and a diagnosis that needs treatments and therapies. These choices are not fixed; they change over time and are influenced by aspects such as the cultural norms in society that are adopted by families and communities, and by alternative narratives from the media. In my thesis, I argue that experiences from peers can also influence how Autism is interpreted. These shared experiences are progressively distributed through online communities and self-advocacy groups, thus creating different

narratives about Autism. In this study, Autistic self-narratives distributed through online communities – although mainly non-Indonesian communities – play an important part in the informative stage of conceptualising and experiencing Autism – although not yet contribute to the transformative interpretations of Autism in Indonesia. As such, in the informative stage, Autistic self-narratives can provide information to Autistics in terms of giving insights about other peers, building networks, and conducting self-advocacy (McGeer, 2009) while, in the transformative stage, the self-narratives have more impact in creating a new framework about Autism as a form of life (McGeer, 2009).

However, the way Autism is interpreted in Indonesia is still largely related to traditional or medical approaches, as shown by the content analysis results and discussions on Twitter in chapter 7. While the internet and social media provide different understandings about Autism – both for Autistics and non-Autistics – by introducing the neurodiversity approach, most of the information and news about Autism is still dominated by accounts from mainstream news media, health-related services, and parent-based Autism organisations which focus on messages from a clinical perspective in viewing Autism. This in turn plays a critical part in influencing identity formation among Autistics. In a later stage, the awareness of having values in their personal identities – that being Autistic is part of human differences – can lead to how self-advocacy is formed. The findings in this thesis also indicate that Autistic online presence and self-advocacy are still based on personal identity, not on a group identity where they can share the same social identities. This reflects the argument from Waltz et al. (2015) that Autistics' identity formation is influenced by many aspects, including cultural norms propagated by families, schools and other institutions, and by socio-medical constructs such as diagnostic systems (Waltz et al., 2015).

In Indonesia, parental-based advocacy has opened up the way for Autism to be recognised and accepted, initially as an awareness of a disorder and, currently, as a difference that should be accepted. As discussed in chapter 8, this parent-based advocacy is still going strong in Indonesia, particularly for promoting a concept of

‘differ-ability’ or a different ability, and accommodating special abilities³⁴ by focusing on special talents of Autistic children and adults. In this context, disabilities can be seen as the gateway to special abilities, turning disability to an advantage (Siebers, 2016). In most Indonesian cases of Autism representation – and, indeed, other disability representation – this frame of ‘special abilities’ is largely used as a discourse, particularly to counter the stigma and exclusion from society towards people with disabilities.

In Indonesia, Autism has been represented over the years mostly by non-Autistic people, including parents who have first-hand experience in engaging with Autistic individuals. To date, there is still a lack of Autistic self-narratives in Indonesia, which has resulted in parents having a greater role in mediating the narratives of their Autistic children, thus creating a “mediated rhetoricity” (Lewiecki-Wilson, 2003; Osteen, 2010), a language used for the benefits of disabled people that is co-constructed by parents, caregivers and advocates. The findings from parent interviews in chapter 8 indicates that, in the context of providing narratives about Autism, this is primarily done by the parents as the ‘mediator’ or the ‘translator’. While a few minority voices from Autistic self-advocates are beginning to show their presence in social media, the conversation about Autism in Indonesia continues to be generally dominated by parents and health practitioners. As discussed in chapter 8, the role of parents as the translator can be viewed as part of their task to help facilitate their children to achieve a higher level of independence.

However, an important finding from this study is that a transformation process is possibly ongoing in Autism identity construction in Indonesia, indicated by the emergence of minority voices via an online Autistic presence. This Autistic presence reflects Hacking’s proposal of a “looping” effect (2006), an impact which emerges not only from the medical and professional literature but also from Autistic self-narratives, which influences individuals’ identity formation – to construct particular forms of disability identities (Hacking, 2007, 2009a; Waltz et al., 2015). Earlier in the year

³⁴ The term ‘differently abled’ is rarely found in Western academic literature and everyday use (Bilić, 2017). According to the Oxford Dictionary (2014), “*Differently abled was first proposed (in the 1980s) as an alternative to disabled, handicapped, etc. on the grounds that it gave a more positive message and so avoided discrimination towards people with disabilities. The term has gained little currency, however, and has been criticized as both over-euphemistic and condescending. The accepted term in general use is still ‘disabled’*” (Bilić, 2017).

2020, more voices of Autistic adults appeared in Indonesian social media as neurodiverse people began to share their experiences. This shows a possibility of a dynamic change in the social construction of Autism in Indonesia. The lived experience of Autistic individuals, in the form of shared self-narratives on the internet, can influence other Autistic peers to identify themselves and think of their Autism as a new form of embodiment, as a new way of being a person.

10.2. Future research directions

As a result of this thesis, further studies are needed in order to further emphasise the Autistic lived experience as an epistemological basis for acknowledging the need to understand Autistic adults in Indonesia. Historically in Indonesia, research into Autism was mainly conducted in the clinical and pedagogical areas, and was more targeted to parents and educators (Tucker, 2013b). As such, more studies from the perspectives of Autistic adults would be useful in providing an in-depth understanding of Autistic portrayals as individuals. Moreover, as discussed in chapters 8 and 9, some parent-based organisations and communities have started to be more inclusive in addressing and including Autistic adults in their online and offline campaigns³⁵. As such, it will be useful to conduct longitudinal studies about the social media content from Autism organisations and communities in Indonesia to provide a further description of how Autism is presented in online advocacy movement, both now and then.

However, as I stated previously in this thesis, cultural context plays an important role in how we interpret disability and Autism. Disability is visibly multifaceted in the global context (Goggin & Newell, 2000), thus, it is important to theorise disability as an “idea that must be framed and understood in context” (Grech & Soldatic, 2016). My findings indicate that, among Autistics involved in this study, neurodiversity is viewed as a Westernised concept of framing Autism, while, for other Autistics and parents, and also for the mainstream audience, it is also viewed as an unfamiliar term. However, they are living or performing the concept of neurodiversity in a culturally specific way, by understanding and accepting Autism as a difference that has to be

³⁵ A number of Indonesian Autism organisations and communities such as YAI, MPATI and ASD Career Pathways Indonesia – a new community who have recently started their campaign on Instagram – have, in just the past year, started to focus on the lived experiences of Autistic individuals and promote self-advocacy in their campaigns.

accommodated. As mentioned previously, the term differ-ability (*difabel*), or a different ability in framing Autism and disabilities, is more familiar in Indonesian disability advocacy campaigns than the concept of neurodiversity. This would make another compelling area for future research as, presumably, Indonesian culture views and constructs Autism and disabilities differently compared with Western countries.

When I gathered the data about Autism in Indonesia for this study, I also saw a growing trend of Autistic characters appearing in Indonesian entertainment media such as movies and fiction stories. Besides Autistic autobiographies, entertainment content can also be useful for creating awareness for a mainstream audience, both for viewing disability and Autism as a difference and, possibly, as a reference for learning Autistic characters' behaviours. However, popular culture in the forms of entertainment media about Autism should pay more attention to giving a fairer and more diverse portrayal of Autistic individuals. Therefore, it would be beneficial to conduct further research about media representation on Autism in order to explore the extent to which media can act as a reference for Autistic individuals. For example, by portraying Autistic characters in an active role rather than a passive object of observation.

10.3. Indications for practical contributions

Although in this thesis I have made the claim for the critical role of the internet as a medium to build new understanding and framing about Autism, it is important to remember the fact that Indonesia is a country with diverse cultures and large disparities in socio-economic status. The dispersed nature of Indonesia's geographical location also contributes to creating a gap in accessing health information and services between people in rural and urban areas. In this study, the findings I collected predominantly reflected the voices of those who live in urban areas and represent the middle-class, as this group has the most access to both the internet and to health services. These economic, cultural and infrastructure aspects in Indonesia have different impacts that will influence people's understanding and experience of disability, including Autism. It is highly possible that parents of Autistic children who have more resources are more able to provide help and assist their children to learn skills and abilities required for living, including accessing social media as a medium for communication.

During the process of developing a literature review for this thesis, I encountered difficulties in obtaining adequate data regarding the number of Autistic adults in Indonesia as most of the data and information about Autism focuses on children. As discussed in chapter 5, the only published study mentioning the prevalence of adult Autistics in Indonesia was conducted more than 25 years ago. Therefore, this clearly needs to be addressed in order for relevant government institutions, Autism organisations and communities to be able to work together to provide more comprehensive data on Autism. Having an extensive Autism prevalence data will provide a strong base for developing inclusive policies and planning for advocacy in order to obtain equal rights for Autistics.

Finally, to conclude this thesis, it is also important to reiterate my personal view as a parent of an Autistic teen living in Indonesia. One of the most valuable pieces of knowledge that I learned from conducting this study is a deeper understanding about Autistic adults in Indonesia, either those from a different side of the spectrum or those who require lower support. I view their existence as somewhat hidden and excluded from the mainstream representation of Autistics in Indonesia. Due to their highly independent status, they do not fit within the more common portrayal of Autistics in Indonesia which largely focuses on those who require higher support (see chapters 7 and 9). Consequently, an important point to be acknowledged by the mainstream audience in Indonesia is that Autism consists of a very broad spectrum. Referring to Orsini's idea of "interdependence", Autism should be understood as a wide range of conditions among the people within the spectrum, as well as both as a debilitating disability and a neurological difference (Orsini, 2012). For example, there are some who require assistance in their daily lives, but there are also some who need to be accommodated as neurodiverse. The difference between people on the spectrum should not be viewed as a gap between high-functioning and low-functioning – nor one labelled as more inferior compared to others – but rather as a difference that should be understood and accepted. As such, it can be suggested for placing the emphasis more on inclusivity in order to create equitable collaborations between parents and Autistics and develop a stronger advocacy movement in Indonesia.

To achieve that, Autism advocacy has to address the different voices in Autism. In a context of Autistic citizenship, it is important to understand the diversity of Autistic

presence and, as such, recognising their different needs to support and accommodate them (Orsini, 2012). This includes acknowledging the modes of communication suitable to their needs and their specific communication styles. For example, by using other means of communication – including using assistive communication tools to support their specific communication styles – rather than forcing them to adopt common or normative communication modes.

The emerging of online neurodiversity movement in Indonesia has shown that the internet greatly facilitates the specific communication modes among Autistics. The online neurodiversity movement provides a form of self-awareness for Autistics to view themselves beyond the medical definition. With the internet and social media as a comfortable mediation to voice their stories, Autistic can create a diverse narrative that represent themselves.

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APPENDICES

Appendix A: Participants Interviewed

Name	Sex/Identity	Occupation	Location
Ananda	Male/Autistic	Musician	Jakarta
Lala	Female/Autistic	Undergraduate student, digital artist	Online
Yarra	Female/Autistic	Digital artist	Online
Ireisha	Female/Autistic	Writer	Online
“Fay”	Female/Autistic	Undergraduate student	Jakarta
“Daisy”	Female/Parent	Lecturer	Tangerang
“Riri”	Female/Parent	Housewife	Depok
“Vivi”	Female/Parent	Lecturer	Jakarta
Adriana	Female/Parent	Psychologist, lecturer	Online

Appendix B: Questions Guide for Autistics

Personal information

1. Do you live in Indonesia or outside Indonesia?
Apakah Anda tinggal di Indonesia atau di luar Indonesia?
2. What is your occupation?
Apakah Pekerjaan Anda?
3. Since when did you know yourself as Autistic?
Sejak kapan Anda mengetahui Anda autistik?

The use of social media

1. How often do you use social media?
Seberapa sering Anda menggunakan media sosial?
2. What are the benefits in using social media? (eg: for getting information, entertainment, social interaction etc)
Apakah keuntungan dalam menggunakan media sosial (Cont: Untuk mendapatkan informasi, hiburan, dan interaksi social, dll.)
3. What social media do you use? Do you find particular social media is more fitting for certain purpose?
Media social apa yang Anda gunakan? Apakah Anda menganggap media sosial tertentu lebih cocok untuk tujuan yang dimaksud?
4. Most Autistic people find the internet to be much more comfortable tool to communicate, compared to face to face (direct) communication. Do you think using social media is a more comfortable way for interacting and communicating with others?
Kebanyakan orang autistik menganggap internet adalah alat yang jauh lebih nyaman untuk berkomunikasi, jika dibandingkan dengan tatap muka (komunikasi langsung). Menurut Anda apakah menggunakan media sosial adalah cara yang lebih nyaman untuk berinteraksi dan berkomunikasi dengan orang lain?
5. Do you think social media could be beneficial for providing more understanding and awareness about Autism in Indonesia? How far do you think it could be beneficial in that matters?
Apakah menurut Anda media sosial dapat memberi lebih banyak pemahaman dan kesadaran tentang Autisme di Indonesia? Sejauh mana menurut Anda manfaatnya dalam hal itu?

Views on Autism and Autism advocacy

1. What do you think about Autism in Indonesia; how do you view yourself as Autistic, and how people view Autism?
Apa pendapat Anda tentang Autisme di Indonesia; bagaimana Anda memandang diri sendiri sebagai autistik, dan bagaimana orang memandang Autisme?
2. Do you think it is different with the condition outside Indonesia (where we can see a lot of Autism advocacy movement online and offline)? If yes, why do you think it is different?

- Menurut Anda apakah kondisinya berbeda di luar Indonesia (dimana kita dapat melihat banyak gerakan advokasi Autisme online dan offline)? Jika ya, mengapa menurut Anda itu berbeda?*
3. What aspects do you think has influenced how people understand Autism in Indonesia?
Menurut Anda aspek apa yang mempengaruhi bagaimana orang memandang Autisme di Indonesia?
 4. How do you view treatment and therapy for Autism?
Bagaimana Anda memandang penanganan dan terapi untuk Autisme?
 5. Do you often read or see Autistic people 'coming out' in Indonesia (communicating their identity in public, for example in social media or other means)?
Apakah Anda sering membaca atau menyaksikan orang autistik 'mengaku' di Indonesia? (mengkomunikasikan identitas mereka secara publik, contohnya di media sosial atau lainnya?)
 6. What is your opinion about Autism advocacy and Autistic self-advocacy in Indonesia?
Apakah pendapat Anda tentang advokasi Autisme dan advokasi-diri orang autistik di Indonesia?
 7. What do you think about the terms 'high-functioning' and 'low-functioning' for labelling Autistic?
Apakah pendapat Anda tentang istilah 'high-functioning' dan 'low-functioning' dalam menamai autistik?
 8. What do you think about media portrayals of Autism and Autistic in Indonesia?
Bagaimana menurut Anda penggambaran media terhadap Autisme dan autistik di Indonesia?
 9. Do you think there is a stigma for Autistic in Indonesia?
Menurut Anda apakah ada stigma bagi orang autistik di Indonesia?

About the internet and neurodiversity

1. What do you know about neurodiversity?
Apakah yang Anda ketahui tentang neurodiversity?
2. What are the difference of neurodiverse and neurotypical?
Apakah perbedaan neurodiverse dan neurotypical?
3. How do you find the idea of neurodiversity?
Apakah pendapat Anda tentang neurodiversity?
4. Can you explain about the neurodiversity culture on the internet?
Dapatkah Anda menjelaskan tentang budaya neurodiversity di Internet?
5. From the medical point of view, Autism is seen as a pathology condition, which needs “therapy” and “treatment”- is it contrary with the neurodiversity view?
Dalam kacamata medis, Autisme dipandang sebagai kondisi patologi, yang membuthkan “terapi” dan “penanganan” – apakah itu bertolak belakang dengan pandangan neurodiversity?
6. Do you find peers or Autistic advocates from the online community?
Apakah Anda menemukan rekan atau advokat autistik dari komunitas online?

Appendix C: Questions Guide for Parents

Personal information

1. What is your occupation?
Apa pekerjaan Anda?
2. Can you tell me about the background of your child?
Bisakah Anda menceritakan sedikit tentang kondisi anak Anda?

The use of social media for parental advocacy

1. What drives you to use the internet and social media? How long have you been using it and what kind of social media?

Sudah berapa lama Anda menggunakan media sosial? Media sosial apa saja yang digunakan? Apa yang mendorong Anda untuk menggunakan internet dan media sosial?

2. Do you use the internet and social media to find and share information about Autism? Can you tell me about this?

Apakah Anda menggunakan internet dan media sosial untuk mencari dan berbagi informasi tentang Autisme? Bisa Anda bercerita tentang hal ini?

3. Can you tell me about your positive or negative experiences when you use social media to share information about Autism, to express your opinions and to find information about Autism?

Bisakah Anda memberi tahu saya tentang pengalaman positif atau negatif Anda saat Anda menggunakan media sosial untuk berbagi informasi tentang Autisme, mengungkapkan opini Anda dan mencari informasi tentang Autisme?

4. What benefits do you get in using internet technology and social media for communication tools? In your opinion, is there a risk for you in using social media?

Apa keuntungan yang Anda dapatkan dalam menggunakan teknologi internet dan media sosial untuk sarana komunikasi? Menurut Anda, apakah ada risiko bagi Anda dalam menggunakan media sosial?

5. Do you use social media to tell your story as parent of Autistic to others? Can you tell me about this?

Apakah Anda menggunakan media sosial untuk menceritakan kisah Anda sebagai orangtua dari anak autistik kepada orang lain? Bisakah Anda bercerita tentang hal ini?

The use of social media for Autistics

1. Does your son/daughter use social media to find information or share information? Can you tell me about this?

Apakah anak Anda menggunakan media sosial untuk mencari informasi atau berbagi informasi? Bisakah Anda bercerita tentang hal ini?

2. Is there any benefits and risks for Autistics to use the internet and social media? What is your opinion about this issue?

Apakah ada keuntungan dan resiko tertentu bagi anak/orang autistik dalam menggunakan internet dan media sosial? Bagaimana pendapat anda tentang hal ini?

Views about the potential of internet use for Autism advocacy

1. Do you follow certain accounts of Autistic advocate on the internet?

Apakah Anda mengikuti akun orang Autistic di internet?

2. What do you think about Autistics who use the Internet and social media to advocate themselves (for example: promoting Autism as a way of life, or expressing their opinions about giving people Autism rights)?

Bagaimana pendapat Anda tentang orang autistik yang menggunakan Internet dan media sosial untuk melakukan advokasi diri (misalnya: mempromosikan Autisme sebagai perbedaan cara hidup, atau mengungkapkan pendapat Anda tentang memberi hak kepada orang-orang dengan Autisme)?

2. In your opinion, can social media be beneficial to provide a greater understanding and awareness of Autism in Indonesia? If yes, to what extent it can be beneficial?

Menurut Anda, apakah media sosial bisa bermanfaat untuk memberi pemahaman dan kesadaran yang lebih baik tentang Autisme di Indonesia? Seberapa jauh manfaatnya dalam hal ini?

Appendix D: Metadata from Twitter

Table D.1 The most frequent hashtag used related with Autism

Top values for: hashtag:	
Meta value	Total
walk4autism	33
walkforautism	29
walkforautismJKT	22
autismawareness	10
jakartawalk	9
autismawarenessmonth	8
walk4autism2018	6
walkforautism2018	6
WorldAutismAwarenessDay	6
haripeduliautissedunia	5

Table D.2 The most frequent users who tweet about Autism in the first period (Nov 2017-Jan 2018)

Meta value	Total
@birukuindonesia	10
@yarrayora (per)	6
@WeGotLove_RP (fanbase community)	3
@CordBloodDay (health mnfct/org)	2
@globalautism	2
@MAIJakarta (therapy support)	2
@ParentingINA (media)	2
@pu_jp96 (per)	2
@UniqkidsAutisma	2
@waluyo_iyo (per)	2

Table D.3 The most frequent users who tweet about Autism in the second period (Mar-May 2018)

Top values for: username:	
Meta value	Total
Autism_Indonesia	30
90.4 Cosmopolitan FM	9
Uniqkids Autisma	5
Galeri Antara	4
POPMAMA	4
🌟☆GilaAgama☆🌟	3
Dwi Astarini	3
kumparan	3
newsmerahputih	3
Sapawarga Kota Sby	3

Table D.4 The most popular user's location

Top values for: user_location:		
Meta value	Total	View
Indonesia	52	
Jakarta, Indonesia	43	
jakarta	16	
Jakarta Capital Region	12	
Jakarta Pusat, DKI Jakarta	10	
Bekasi, Jawa Barat	7	
DKI Jakarta, Indonesia	7	
Surabaya	6	
Jl.Antara no.59 Jakarta Pusat	4	
Kota Surabaya, East Java	4	

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