

Understanding Participatory Culture for Teenagers with Autism Spectrum Disorder

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Abstract. Culture said to be one of the most powerful forces in our world. Society 5.0 is where human achieve a forward-looking society whose members have mutual respect for each other, a society that balances between cyberspace and physical space. Unfortunately, not all young people can use social media platforms because some conditions, such as disability. Disability is when a person has some limitation such as impairment whether in mental, sensory, or mobility functions to implement a task compared to another person without disability. Autism spectrum disorder is one of the disabilities that encounter limitless complications every day. In a social understanding of disability, they are unnecessarily isolated and excluded from full participation in society. However, the experience this young people have with popular culture and mainstream new media will be different. This research tries to understand how people with disability especially for people with Autism Spectrum Disorder express themselves through participatory culture. This research uses qualitative method and conduct interview and FGD for data collection. The result of this research expected to give understanding about participatory culture from standpoint of teenagers with autism spectrum disorder.

Keywords: Participatory Culture; Autism Spectrum Disorder; Disability; Popular Culture; Social Media

1 Introduction

The culture of engaging on digital media platforms like Facebook, Instagram, Twitter, YouTube, and much more has developed rapidly. This culture to be called later as Participatory Culture. There is an expanding in a number of society trying to engage in using these social media tools to express themselves [1]. Culture here means the texts and practices that the primary function is to manifest, to contribute or to be the occasion for the production of meaning [2]. Most of the consumers of popular culture are teenagers. Based on previous research, when they become fans for Korean Pop Artist, they do not only use the popular culture, but they also produce new artefacts too. Those teenagers use all aspects of participatory culture from affiliation, expression, collaboration, and circulation and they are doing them personally or collectively [3]. So, how does participatory culture apply on teenagers with autism spectrum disorder? As the participatory culture expanded and media

grew they did not take into consideration of those individuals who have disability¹. Not everyone has access to these opportunities, especially those who are with disabilities.

Person with autism disorder encounter a lot of difficulties every day. Their problem of socializing in a public sphere becomes their greatest disadvantage [4]. The challenge in peer communication, disadvantage in using and accepting nonverbal communication, and constrained impersonation of other's actions include in the social interaction problems. For that reason, they have a tough time in develop relationship with others and may not seem eager to do so. Yet, they are incompetent to identify people's feelings and actions and may express little or no facial expressions in reaction to others. Nowadays as example, there are therapies and schools that provide learning facilities for teenagers with autism spectrum disorder. One of the school is London School Beyond Academy chaired by Mrs. Prita Kemal Gani. London School Beyond Academy is focused on helping teenagers with autism spectrum disorder, that including communication disorder, social interaction disorder, behavior disorder. Despite the increasing presence of Augmentative and Alternative Communication (AAC)⁴ apps, a large number of individuals with communication needs are still not learning how to communicate with others [5]. When we talk about participatory culture, first we need to examine what we know so far about culture. Williams mentioned that culture can be used to refer to 'a general process of intellectual, spiritual and aesthetic development'. A second use of the word 'culture' might be to suggest 'a particular way of life, whether of a people, a period or a group'. The third use of culture refer to 'the works and practices of intellectual and especially artistic activity'.

The improvement of technology does not influence people without disabilities. Technology is seen to have fundamental values built into it, and those values actively operate to disable some people the person that we later call people with disabilities. Despite the advancement of technology, those who have already had technology can still be trained on how to use the technology with little problem. However, people with disabilities must first skillful enough to access the technology and learn how to use it from the beginning. As technology and social media develop, they provide main stream users and their ability to utilize the tools, but do not consider that those with disabilities do not fit the stereotypical main stream users [6].

The meaning of Participatory culture is a culture that assists many to communicate themselves and embrace other individual's ideas, but they do lack the inclusion of those who are disabled. For teenagers, when they can participate in a larger community and speak their ideas, they feel that they're connected to others, especially with the new technology and new media that allow them to do that. But speaking of the advantage of technology and the access to technology, we first must know that it's first created for those who are not disabled. And for that reason, technology needs to take into account and created from the ground up to solely suit those who are disabled. People with disabilities are not seeking a professional or disability-specific social media service, but rather wish to use the same popular social media tools used by the broader online community [5]. Digital social networking tools like a blog offer a number of important advantages for people on the autism spectrum:

- a. The accessibility or lower threshold for telling self-narratives
- b. Enabling interaction or the importance of community formation
- c. The comfortable mediation of the interface [7]

People with disabilities as users have used the internet, social and mobile media to find, create and adapt new spaces and styles of participation in media [8]. The limitation of people with disabilities from new media and present participatory cultures is particularly troubling given the potential of these spaces to stimulate engaged, active citizens of the world [9].

- a. Access not in terms of availability, affordability, or choice but in terms of an individual's ability to engage with a medium/technology and its content [10].
- b. A hegemonic user position is created by digital media technologies and their usage, and their position is not neutral but maintains an able-bodied norm and contributes to inequalities of access [10].

Recurring feature of the discussion of the impact of participatory digital media is the increased potential for marginalized audiences to actively engage with the media across the spectrum of commercial, public, community and alternative media. So what of the case of disability?⁸ What are the conditions of possibility for emerging new media areas for people with disabilities to provide more than disabling practices in the margins of digitization? As yet however there is no systematic theorization of participation and media as a concept from a disability perspective,⁸ that is why this research try to capture how the people with autism spectrum disorder participate in popular culture through social media.

2 Method

Paradigm used in this research is interpretive because it tries to recognize human behaviour, which is the explanation on how this phenomenon describes human action to reach a result. The interpretive paradigm encompasses broad range of orientations, each with its own historical roots. Nevertheless, researchers who adopt the interpretive paradigm believe that human action stands apart from the rest of the physical and biological world because of the reflective capacity of human beings [11].

This research use interview and focus group discussion to gather information, using informants from parents of the teenagers with autism spectrum disorder from LSBA (London School Beyond Academy). Another data collection will be from focus group discussion with the therapist and learning facilitators. Informants for this research are:

- a. Ignatius Haryanto – senior researcher and lecturer
- b. Samiaji Bintang – researcher and lecturer
- c. Hersinta – researcher
- d. Chrisdina Wempi – lecturer and head of LSBA
- e. Parents of teenagers with autism spectrum disorder

3 Results and Discussions

3.1 Participatory Culture for Teenagers with Autism Spectrum Disorder (ASD)

3.1.1 Autism Spectrum Disorder

The beginning of the childhood often become the period when Autism spectrum disorders (ASD) are neurodevelopmental disorders that are often identified [5]. Even though early discovery and identification of the developmental disorder is common, the exact causes of ASD are still unrevealed and multi-dimensional [12]. With the difficulties in socialization and communication, repetitive behaviors [5], and impairments in social interaction are the common characteristics of ASD. While these three impairments often occur in children diagnosed with ASD, they exist in changing stages, and not every teenage on the spectrum has the same challenges [5].

There are expansion of the number of adolescents and adults with autism spectrum disorder (ASD) in the world [13]. Sadly, the number of chances for these individuals to participate in their environment, as a result, they often experience poor outcomes in adulthood relative to their roles in the vocational, community, and other social sectors [13].

3.1.2 Digital Disability

The social model of disability differentiates between disability and impairment. It maintains that disability is the result of decision made by society and their impact on an individual with a specific impairment [10]. There are four stages of the digital disabilities, those are:

- a. First stage: an online platform will be accessible, but not highly distributed or used.
- b. Second stage: where a particular platform or service is highly popular but not accessible.
- c. Third stage: when one of these platforms that was previously inaccessible is then changed to become accessible and inclusive.
- d. Fourth stage: born accessible – with accessible design for people with disabilities applied from the foundation and then maintained as the platform becomes widely distributed.

Participatory culture is when society feel that they have low barriers to express their interest and their civic engagement, when they have strong support for creating and sharing one's creations, and some type of informal mentorship. A participatory culture is also one in which members believe their contributions matter, and care what other people think about what they have created [14].

According to some informants, nowadays we communicate no longer in a one-way form but in a two-way form and the audience is no longer seen as a passive entity but they are also active. Active in the sense of selecting what they want to consume and then later they might be able to give a new meaning, yes, to what they consume and then also maybe they can also interpret something else that the message maker might not think of like that. It is possible to choose the boundaries between consumers and producers, and there actually has many opportunities for what has been a sort of separation between consumer and producer boundaries. When the boundary is gone, everyone can be involved. Everyone can speak their voices from anywhere. Disability participatory cultures just like any other participatory cultures shifting from forums, blogging and support groups to social networking and crowd-funding [8].

Participatory culture is being co-created every day, by vloggers, marketers, artists, audiences, lawyers, designers, critics, educators," and others, then the barriers to technological and cultural access, including barriers of disability, must be addressed so that such co-creation does not occur without input – or against the interests – or less powerful populations [10]. Through online spaces, communities can form, creative work can be shared, individuals can oscillate between creating and consuming content, and media industries can engage with (or take advantage of) the increased interaction among audiences. When we talk about Participatory Culture, it's actually very general, in many ways it can happen. Jenkins sees it more in the context of popular culture. The focus right now is participatory culture has the possibility to be able to interact with an audience, it's very broad, so then I think for us to talk about the media, we talk about for example empowering certain groups (whose voices have not been heard) through the media. After all, if a so-called participatory culture only eases the participation of those who are already benefited, then its progressive potential is unrealized, if not transformed into a regressive affirmation of existing power structures [10].

People with disabilities utilize many of the same social media tools that popular among others, and by adjusting and using these media technologies they claim the existence of alternate user positions and kinds of use. This behavior recalls the ideals participatory culture, as the community encourages artistic self-expression, sharing, and mutual education. Disability at the site of use was strikingly similar to the uses followed by audiences without disability, in these ways. Access and participation depend upon each other [7]. Just as access empowers participation, so does increased participation by diverse people in various contexts and practices ultimately make possible growth of access. It values collaboration, openness, sharing, community building, and transformative uses of cultural artifacts. From the study of disability and digital media it is clear that those who would support participatory cultures must also come to value and prioritize coalitional politics, inclusive forms of social interaction, and the contributions of often-invisible users. Participatory forms of access are possible, but they require the hard work of interdependence and collaboration. Accessibility is achieved through ongoing conversations about individuals' and groups' needs, and accommodations are available for all (not tied to disability status) and include unusual features such as a "quiet room" as well as interpretive services, wheelchair seating, and other conventional forms of physical and communicative accommodation. Accessibility is used to talk about equalizing access on the basis of disability but is extended to be relevant to class, race, and other differences as well. This is not simply universal design but is participatory in that it is collaborative, ongoing, and responsive to a community of people who both need and create accessible conditions. In these processes, "disability becomes less about a single person's experience and more about a collective need to address the public."

Collaborative culture requires creating forms of cultural accessibility that value differences in standpoints [15] to acknowledge variation. Can we build collaborative forms of participation that lead to new results, new possibilities, and new structures within which to increase access and enable cultural and civic participation? These are tall orders and complicated processes. Media access, disability, and participation are endlessly complicated phenomena, but they are exactly the problems through which it becomes possible to, into the world alternative ways of being and alternative ways of knowing. In this the possibility of beginning something new arises. However, to build more accessible futures, and to welcome the messy differences of bodies, cultures, and technologies [16]—these are the challenges and the rewards of unearthing the variations of ability and access. Participatory culture is a way to show and participate in a larger community where they believe their contributions matter, and feel some degree of connection with one another [6]. There are four forms of this participation, the first one is affiliation when they become the member in various forms of online media. the second form is expression when they produce some new creative forms like fan fiction, etc. the third form is collaborative problem solving, when they working together to complete tasks and develop new knowledge. And the last one is circulation, when they're not only produce but also distribute the new culture that they create. Participatory culture shifts from individual expression to community involvement. From the standpoint of disability, especially for people with autism spectrum disorder, almost all of the participants use social media. However, they only use for several purposes. Such as when they are browsing about things that they like. One of the informant said that her child is really interested in transportation especially about trains, so her child will use social media or internet to specifically looking for as many information about it. The other informant said that his child use internet to find any information about music because he really like all kind of music. And when they like something, they will repetitively talk about it or play the song all the time. But other than that, they don't use it as a media to communicate one another. Participatory culture

indeed is the ideal concept carried out by Jenkins, he puts it is that under ideal conditions. When all the internet access was good enough then everyone has the ability to read, visual, watch everything.

The social model of disability distinguishes between disability and impairment [17]. It maintains that disability is the result of decision made by society and their impact on an individual with a specific impairment. Person with disabilities use the same social media tools like the others, and by adapting and using these media technologies they assert the existence of alternate user positions and kinds of use. This behavior recalls the ideals participatory culture, as the community encourages artistic self-expression, sharing, and mutual education. As shown in the interview with one of the parents of teenagers with autism spectrum disorder that these teenagers are more excited when they use social media and the other parent said their ability to use social media is more advance than their parents. New media platforms that they use are WhatsApp, Instagram, Twitter, Blogs, Facebook, Line, and YouTube. Other findings from the parents about their children are that they are more enthusiastic when using social, they are not interested in social media as media to communicate, for them social media is only for viewing, watching, listening to music, or for looking for information. Other facts are when they like something, they will play it repeatedly. They're utilizing the browsing feature for something he is interested in especially in the world of transportation. Nevertheless, even though these teenagers still need to be trained to be able to use social media properly. One of the cases that happened to one of the teenagers is they went to deep to social media without knowing the rules, and no one supervising when using social media. Because the anonymity in the world of internet, no one really knows if you are a person with disability or not. It can lead to a bigger problem. That is why, they still need to be supervised and mentored when accessing social media. The technology itself not providing enough accessibility for those who are disabled. Maybe some of the teenagers expressed their works in social media such as Instagram or blogs. One of the individual with autism said that she uses blogs for her writings. She rarely uses Instagram, but when she's using it, it's for looking for inspiration and make friends with her idols. Other individual with autism uses Instagram to promote his works. His father said that his son loves to draw and he's very excel in drawing, but only to put his drawings, not making friends in social media. Compared to what participatory culture characteristics such as affiliation, expression, collaborative problem solving, and circulation, perhaps only one to two forms that could be implemented in teenagers with autism spectrum disorder but not in such order.

So, could the participatory culture apply in the standpoint of people with autism spectrum disorder? Hersinta said that in the research that she did with several autistic individuals, they argued that social media and the internet provided an alternative space for expression, dialogue with autistic individuals outside of Indonesia, rather than offline spaces which were more dominated by majority power - parents of autistic individuals and health experts. One of the informants (from the research) mentioned that after using social media to share experiences from a disability perspective and conduct advocacy, many audience responses were positive about what he shared. For informants with this disability, social media actually becomes a kind of alternative platform to balance the voices and opinions of the mainstream media which tend to be more able-ism point of view. About how to help the people with disabilities to be heard of, actually there are two things that can be done. First there should be a mandatory side from the government. The regulation about disability which actually involves to include all aspects of the media aspects actually existed. It means that if it is encouraged, the obligation is to help disabled friends can participate or the media give their space to be involved either in production or voicing their aspirations, the second is voluntary

model, the term is yes, those who have initiatives that have innovations and then later they themselves must fight. The problem is when it is related to the market, it is difficult. When it comes to markets, everything is limited, because the sustainability depends on the market itself. From the point of view of teenagers with autism spectrum disorder and all of the informants, actually social media is giving opportunity for them to access information, because participation and access depend each other. Access as in terms of one person's ability to engage meaningfully with a medium/technology and its content. When the online media needs to develop collaborative problem solving as one of the form of participatory culture, it requires creating forms of various accessibility that value differences in and acknowledge standpoints to welcome dissimilarity.

4 Conclusions

The finding for this research show that participatory culture is not fully working from the point of view of teenagers with autism spectrum disorder. From all of the fourth forms of participatory culture, they only use social media to find information that related with their favorite things. They haven't try to participate in the community. Because participatory culture is not only about individual expression, but also about community participation. Participatory culture that proposed by Jenkins is in the normal state and it is not yet involving or including people with disability but expected to include one. Yet, that doesn't mean participatory culture cannot be fully applied for people with disabilities. The possibility remains open to realizing a participatory culture even though it does not necessarily fulfil all four elements from participatory culture. However, the efforts to build a culture of inclusion and friendliness for persons with disabilities must be continued to create more equal opportunities to everyone.

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