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THE APPLICATION OF SOCIAL MODEL FOR HANDLING COMMUNICATION OF CHILDREN WITH AUTISM IN THE FAMILY DOMAIN

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Abstract

Borrowing studies on disability discourse, there are two leading models of disability discourse, namely the medical model and the social model (LoBianco & Sheppard-Jones, 2008). Through these two models, the interaction of people with autistic children shows a different way. This study wants to show how the application of social models in handling the communication of children with autism. The case was taken in the life of Ry (14) - an autistic boy living in Malang, East Java. Research was carried out through participant observation, and interviews with the subject, namely Ry's parents. Data findings were analyzed using the concept of disability discourse. The result shows that the Ry family apply the social model more by following a typical child communication pattern but collaborated with social rules that allow both parties to feel comfortable communication. Ry's parents condition the other party that Ry has the potential to interact with-communication by giving detailed information about Ry's uniqueness.

PENDAHULUAN

Introduction

The concept of Autism is widely understood by the public. The important role of professional organizations and individuals who have authority in making definitions will determine people's understanding of autism. While an understanding of autism becomes important because it will affect the way people interact with people with autism and also influences how to handle autism. Internationally in the United States the limits or definition of autism refers to the Diagnostics and Statistics Manual of Mental Disorder (DSM) Most recently (2013) DSM-V has been published which melts all the terms related to autism into a single unit called Autistic Spectrum Disorder (ASD).

The problem is, with the ASD criteria, then what is autism being discussed as? If based on disability discourse, so far there are two conflicting dominant models in the disability discourse, namely the medical model and the social model. In accordance with the term, the Medical Model begins when doctors and scientists replace religious leaders as knowledge authorities in society (Humpage, 2007). So it is the medical professional who makes the diagnosis and "heals it." Medical experts will struggle with a biological perspective, including structural or functional deficiencies caused by physical, sensory, affective, or cognitive problems (Blustein, 2012). Disability is considered as a result of bodily and structural dysfunction, including the mind, and can be caused by illness, injury, or health conditions (Forhan, 2009). Care is aimed at individuals with disabilities directed at eradicating causes or correcting disorders (Bingham et al., 2013; Forhan, 2009). So what is

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considered not functioning, must be corrected, and will be left to the medical profession in rehabilitation programs.

In contrast, the social model is more popular among academics. The social model assumes that it is society that imposes disability on individuals with impairments (Bingham et al., 2013; Brandon & Pritchard, 2011; Coles, 2001; Indjov, 2007; Palmer & Harvey, 2012). Damage is considered a bodily disorder, such as restriction or damage to limbs (Forhan, 2009; Goodley, 2001). Disability is considered as a loss or restriction of activities caused by social organizations that do not take into account people who have disabilities and do not include them from community life (Goodley, 2001). Social models show that it is not a person's bodily functions that limit his abilities, but rather society (Barney, 2012; Roush & Sharby, 2011). Proponents of the social model argue that isolation and exclusion of individuals can be a product of community inability, unwillingness, or neglect in removing environmental barriers faced by people with disabilities or perceptions of individuals with impairments due to their inability to participate with community members (Forham, 2009; LoBianco & Sheppard-Jones, 2008; Palmer & Harley, 2012). The social model shows that building solutions should not be directed at individuals but rather at society. Thus, an increase for individuals with disabilities will require political action and social change rather than the physical changes in their bodies (Bingham et al., 2013). Damage is considered a form of diversity that offers a unique perspective that must be respected and celebrated (Roush & Sharby, 2011).

There are different definitions of disability between organizations. The first definition, according to WHO, the cause of disability is impaired function. The second definition, according to ICIDH, a disability is a condition caused by a combination of physical and social characteristics. Whereas in the third definition there is no inherent causality in the physical body. Full responsibility for the condition of "Disability" may be due to the nature of the community itself. In this view, the attitude of giving stigma is driven not by actual function, but by differences in perception of norms and failure to accommodate various physical expressions of humans.

In the end, from various definitions, disability discourse emerged into the dichotomy of two models, namely the medical model and the social model. These two models are very contradictory. More clearly can be seen in Table 1 that researchers quote from Justin Anthony Haegele & Samuel Hodge (2016) .

The different medical models and social models in viewing disabilities from various aspects. Medical models see disability as a malfunction of the body; structure. Flaws or abnormalities. While the social model sees disability as a community construction that is imposed on the existence of disruption; difference. Handling or treatment of disability according to medical models obtained from the diagnosis of medical experts. As for the social model, disability requires treatment based on experience and self-reference (individuals) that feel different. The target of interventions in managing disabilities according to medical mode is to "fix" the disability as far as possible; "Normalization" of individuals who experience disabilities. While the medical model does not target the individual they will be. Instead, they make social or political changes in an effort to reduce environmental barriers and increase the level of understanding. The outcome or intervention of the medical model is that normalized organ function is deformed; become functioning in society. Whereas the social output models are self advocacy, environmental change and understanding social inclusion.

Meanwhile, those who intervene in the medical model are professionals, while for social models those parties can be individuals, advocates, or anyone who positively influences arrangements between individuals and society. So that differences also appear in seeing and perceiving disabilities. The medical model has a perception of disability that is due to individual mistakes, but for the social model it is precisely seeing individuals as unique. The handling of the medical model keeps society the same, while the social model creates the effect of creating a more inclusive society. Finally, the perception of disability thus according to the medical model is regarded as negative. Whereas the medical model sees being defective as neither negative nor positive.

That is the background of this research. Based on the description of the model in disability discourse, it is interesting to observe how parents have their own limitations regarding the autistic state of their child. As in the case of Ry. Ry has verbal communication skills, and is able to attend public schools. Based on Kusumastuti's research (2018), Ry's mother defines autism as a different process. Ry's mother did not agree with the concept that children with autism must be normalized, but rather understood and fulfilled their special needs. Ry's mother's definition seems to fit the social model in the disability discourse. This research also reveals how social models are applied in Ry's interactions and communication by their families.

KAJIAN PUSTAKA

Social Model Discourse

The social model sees disability not as a matter of bodily function, but rather society is what limits the person with disability. The social model of disability is a reaction to the dominance of the medical model. The social model identifies systemic obstacles, negative attitudes and exclusion by society (intentionally or unintentionally) as the main contributing factors in "deactivating" people. While physical, sensory, intellectual, or psychological variations can cause functional limitations or individual disorders do not have to cause disability, unless society fails to consider individual differences.

The social model can be traced to the 1960s; certain terms emerged from England in 1980. In 1983, academic Mike Oliver coined the phrase "social model disability" in reference to the development of this ideology. Oliver's idea focused on an individual model (in the medical model) versus a social model, as a differentiator between disorder and disability by UPIAS. (Oliver, 1990).

The social model basically sees the community constructing an individual to be "visible" disabled, focuses on changes needed in society from various aspects (1) Attitudes, for example, have more positive attitudes and behaviors, or do not underestimate the potential quality of their lives - individuals with disruption. (2) Social support, for example helping with matters related to obstacles; resources, financial assistance or positive discrimination to defeat them, provide a friend to explain the work culture for autistic employees, (3) Information, for example using a suitable format (for example using braille) or language simplicity, or scope (e.g. giving an explanation about disabled problems in others), (4) Physical structures, for example in the form of buildings with tilted access and elevators, or (5) Flexible working hours for people with sleep disorders, for example or for people who experience anxiety panic attacks during rush hours traffic.

The social model shows that giving solutions should not be directed at individuals but rather at society. Some active communities have rejected "treatments", for example, maintaining a unique culture or maintaining a unique set of abilities. People who are diagnosed on the autism spectrum may argue against efforts to change them to be more like other people. Instead, they argue for accepting diversity and accommodation for different needs and goals (Seidel, 2004). Some people diagnosed with mental disorders argue that they are just different and not always appropriate. The biopsychosocial model is a holistic effort by practitioners to overcome disability / disease.

However, one criticism of the social model is that it fails to overcome interference as an observable attribute of individuals which is an important aspect of their life experiences (Palmer & Harley, 2012). As Palmer and Harley (2012) explain, by separating impairment and disability, the model does not fully take into account the life experiences of people with disabilities. These critics ask for more comprehensive and inclusive models or social theories. Critics of this social model have met with strong defenses from social support models. They reject this criticism on the grounds that while the potential for interference is not limited, or restrictions are not imposed because of their disability concept (Palmer & Harley, 2012). Instead, these people point to the gap between people with and without disturbances and interpret these differences as social disabilities (Palmer & Harley, 2012). The second criticism of the social model is that this model does not take into account differences between individuals with disabilities. The social model ignores different forms of intersectionality from discriminatory countries (Fitzgerald, 2006), such as racism, sexism, homonegativism, etc.

METODOLOGI

The study was conducted with a descriptive qualitative method. Qualitative research is basically understanding and understanding what happens to an individual, a society, or other objects (Denzin & Lincoln, 2009). While what is meant by descriptive is to build a whole framework for researchers to follow throughout the study. Initially the formation and identification of a theoretical orientation that can be carried out are determined before making research questions. Qualitative data analysis was done descriptively based on recognition of the subject through interviews, observations by researchers, and also based on documentation collected from subject uploads about the communication of children with autism.

The subject chosen was Ry's mother, Nh. The reason why the mother was chosen was because Ry's mother spent most of her time actively involved in Ry's autistic treatment intervention. While the father works in a private company owned by foreigners. And Ry's sibling is still 10 years old so he hasn't been able to tell much about what happened. Ms. Nh is a highly educated woman who graduated from the Faculty of Animal Husbandry, Bogor Agricultural University. At the time of the research, Nh was also an extracurricular teacher at an Extraordinary School (SLB). Teaching handicraft skills for students with special abilities. She also devotes herself to many social activities, such as freelance teaching children with special needs from disadvantaged families, moving a reading garden in a village, also initiating an alms-oxygen movement in the city of Malang for victims of natural disasters, and routinely organizing the "Sedan Friday" movement, which is distributing packaged rice in the morning for middle and lower class workers in certain areas in Malang City. But the main thing here is that Nh is fully involved, totally, and intervening herself in dealing with the disruption of the interaction-communication of children with autism. Based on this background, choosing Nh as the subject is very appropriate.

Interviews were conducted by researchers with Nh in a relaxed and profound atmosphere, the familiarity of the researchers with Nh was very helpful. Where researchers and Nh are both members of a support group community for ABK parents. Several times the researchers also had with Nh initiated the festival in commemoration of World Autism Care Day in Malang. This condition made it possible to conducted this research with in-depth interviews. In addition, data collection was also carried out by participant observation. Where researchers follow the guidelines made by the subject to observes while doing direct experience to interact and communicate with Ry. The third data collection is through searching documentation which is by observing and taking some subject status uploads on social media (microblog and facebook). All data collected is then processed based on the categories, then shown to the subject for approval. The data is then analyzed by comparing it with the results of previous studies and reading with a theoretical study.

TEMUAN DAN DISKUSI

The Window of Social Models.

The subject in an interview with researchers once said that autism is not a disease. The subject gave the term Ry autistic behavior as behavior that was in accordance with the standard operational procedure standard SOP special for Ry. Some examples, Ry likes or is obsessed with cards of Automated Teller Machines (ATM) and cellphones. To the extent that Ry likes to snatch these two objects from others when he saw them. In professional terms, it is called obsessive or ritualistic. But the subject will tell others that it's Ry's hobby.

> "*I call the difference in Ry as SOP or some kind of Ry's rule*", explained the subject.

Like Ry's obsession with a football player's jersey. He will wear it whenever and wherever. Even when invited to marry, Ry will choose to wear the jersey. Well, the subject analogizes it like a housewife with negligee. That for them (Ry and housewives) the pride costume is a matter of comfort, not a matter of oddity.

> *I" would say a term like that to ordinary people, ma'am. For example, my parents-in-law, our neighbour hostess of rented house who lacked understanding. For friends, I often refer to it as an obsession,"* explained the subject.

For the subject, the children's behavior does not have to be changed. Only need rules. Ask for permission. If you can, if you can't. Borrow or ask. When and where for how long.

> *"Because I can't force it to be normal,"* said the Subject.

Understanding about it was obtained by the subject based on in-depth experience. The subject tells at the beginning of Ry therapy, the trainers at the therapy site claimed that such behavior was abnormal. Then it must be eliminated by behavioral intervention, of course the subject and family become stressed because seeing the difficulties in front of their eyes in changing Ry's behavior so far. They become often worried and afraid if Ry makes mistakes in the social environment. The other side of their efforts to make Ry "normal" seems painful for Ry. The response is defiant, angry, and rebellious.

One time later the subject met a psychologist and a teacher in another place who gave her insight that Ry's behavior should not be considered as abnormal behavior. But something different. Behavior therapy is designed not to eliminate the behavior, but rather provides a rule about how it is appropriate to do it. For example, related to property rights. Ry must ask for permission to have a card or cellphone or what his obsession is if the card belongs to someone else. And must return if indeed it was not given. Ry was taught a rule so that his hobbies were channeled but did not damage social rules.

The subject's decision in handling this problem was more stable when it turned out, she had the opportunity to attend training in other intervention methods, namely the Treatment and Education of Autistic and Communication related handicapped Children (TEACCH) method developed in Western Australia. This method supports the assumption that autistic behavior is a difference, not an abnormality.

The description of the subject's views on Ry's autistic behavior in detail can also be read from documents that researchers took from the Subject's own microblog. Through the presentation of the Subject's narrative about autism and the autism behavior of her children shows the tendency of the Subject to apply a social model. This is evident from efforts to construct the surrounding environment to facilitate the characteristics of autistic children. Not the other way around where autistic children are asked to adjust the habits of "typical societies".

Interaction-Communication Intervention of Ry

One of the typical behaviors of people with autism is communication behavior or how to communicate it. Expressed in the DSM V American Psychiatric Association in the book Diagnostic And Statistical Manual of Mental Disorder Fifth Edition (2013: 50-51) a child is declared experiencing autistic disorder if he/ she shows a lack of communication and social interaction that is sedentary in various contexts. Activities that manifest at least 2 of the following behaviors:

1. Lack of social and emotional communication skills, for example, abnormal social approaches and failure to engage in two-way communication; failure to start or respond to social interactions;
2. Disruption of non verbal communication behavior used for social interaction, for example, integration of verbal and non verbal communication which is very severe; loss of eye contact and body language; lack of facial expressions and non verbal communication;
3. Lack of developing, maintaining, and understanding relationships, for example, difficulty adjusting behavior in various social contexts, difficulty in playing imaginatively or making friends, lack of peer attraction.

Indicators of communication and language behaviors that may be experienced by autistic children include flat expressions, not using language or body cues, rarely initiating communication, not imitating action or sound, having little or no speech, parroting words, strange intonation, appearing not to understand words, and use limited words (Sunu, 2012); one-way communication, able to speak but verbal communication is lacking, non-verbal communication is only in the form of touch, and body movements, lack of eye contact, have not been able to play with peers, are able to respond to communication during interactions but the response given is not in accordance with the topic of communication (Mahardani , 2016).

Ry's communication ability condition is verbal. Ry's communication characteristics like most autistic children, flat intonation. There is a tendency to repeat sentences. Especially if in the form of question sentences.

In contrast to research Sunu (2012) and Mahardani (2016) Ry often precisely starts a conversation when meeting with others. The style of conversation is always to ask the desired person. Usually the question is addressed by Ry to someone he suspects or sees from carrying things that Ry is obsessed with. These items are for example ATM Cards, Credit Cards and Mobile Phones. Ry's questions will be developed so that he feels satisfied with the answers of the person being questioned.

As explained by Subject - and researchers also saw for themselves and even experienced what happened when they came to the home of NH-WR, Ry's parents - that Ry has some obsession with objects. For example, old cellphone, and various bank cards. At that time the researcher was asked by Ry,

"Mrs. Frida has a cellphone?"
"What's the brand?"
"What year was it made?"
"From which country?"
"Can Ry see? Can I borrow it? '

Or Ry will also "interrogate" about
the ATM card,

"Mrs. Frida, is the ATM card still
valid?"
"Have a card from BRI bank?"
"What date is up?"
"What other ATM cards do you
have?"
Etc.....

Regard to Ry's communication characteristics, the subject asked his guests to be ready to be questioned by Ry. And if it is possible not to show the items that are Ry's obsession in front of Ry by telling that not having them. So Ry has no material to ask anymore.

Typically, if someone agrees to give him an old cellphone or bank card, Ry will try to catch up every time he sends a message via WA to the person who promised him.

"I told the person who promised to give something to Rayhan, so that he was prepared to receive messages repeatedly from Rayhan until the goods were given." Said the Subject. (July 9, 2019)

For example, see Ry's chatting with someone who promised Ry an old cellphone.

Ry : Send it when?
Someone : Haven't boxed. May be tomorrow.
Ry : Hopefully not miss. Nokia, take photographed. Right now
Someone : I can't. I'm on the way.
Ry. : If arrived, take photo.
Someone : Yes. 30 minute after
Ry. : Where are you now? Dewi photograped nokia at 08.00 p.m. Sister Dewi what day you send it

Source: Screenshot from the subject's cellphone.

> "If you don't want to be chased by Ry, then don't promise anything. It's better, just give the thing directly, it's okay," add the subject.

According to the subject, promising Ry must be clear. Give certainty at each stage. For example in the delivery of goods, of course there are processes starting from packing, delivery at the security deposit box, and when the rod is estimated to reach Ry's house. Then Ry will be satisfied, and wait according to the message or certainty that has been delivered.

The subject also gave a rule for Ry to ask only once for one question. The results of this intervention produced a new "rule" for Ry. She tried to make sure that he would not keep asking. Like when Ry was waiting for the routine of sharing rice packets on Friday. When Ry keeps asking, then in one question he changes it as follows,

> "Mama .. Rayhan wants to ask once ... Sharing the rice, what day and what time is it?"
>
> Ry's question is actually still two questions, the day and time.

In addition to asking questions, Ry's communication also tends to ask and report or be of a notification. As an example of the conversation with the subject below,

Ry. : Mama, I want a souvenir starbak's coffe from Jakarta.
Mama : Oh... Mama likes to buy in a local diner mas Re. Okey? This is Mama's fave since long time ago.
Ry. : Okeeeey
And bruuuuuuum ... we arrived.
Ry. : Mama... it's like starbak but not starbak.

Source: Subject's status upload, November 9, 2019.

Based on these examples, the subject focuses on the contents of Ry's conversation. The focus is Ry wants coffee. It turns out the way the subject succeeded in responding to the focus of Ry's conversation. So coffee is still being done and that makes Ry quite satisfied.

However, Ry could not yet understand the matter of time in a sequence of behavior. As can be followed by the subject's status on November 9, 2019 below,

Ry. : Mama .. please put this mansetI in Ry's arm. Ry wants to be a goalkeeper.
Mama : Whose shirt is it, mas?
Ry. : Brother's shirt
Mama : Why did you cut the sleeve?
Ry. : To make manset for golkeeper.
Mama : Mas Ry, told Mama if you want to make something, right? ... Don't cut any shirt without permission.
Ry. : Mama, allow Rehan cut Rayi's shirt.
Mama : The permission before cutting it mas.
Ry. : Ry have asked for it.
Mama : All right, but it's wrong. Before cutting. Not after.

Source:Subject's status upload, November 9, 2019.

The style of conversation above makes the subject modify in such a way with the aim of increasing Ry's understanding. In the next experience, Ry already seems to begin to understand.

Ry. :Mama, Rehan have trimmed my hair.
Mama : Who had your hair cut?
Ry. : Myself, Yeeey
Mama : What did you use?
Ry. : Scissors
Mama : Where?
Ry. : In bathroom
Mama : Where was the hair thrown away?
Ry. : Put in a plastic bag, dumped in the trashbin. Yeeah Rehan's smart (cheering himself)
Mama : Mas ... if you want to have your hair cut, tell Mama. We go to a barbershop.
Ry. : Mama, I want to have my hair cut.
Mama : Say it before you cut it, not after. Where did you get the idea cutting hair?
Ry. : Re wants to be like this footballer... (He showed a photo)
Mama : Later, after delivering rice, Re should go to the barbershop with Papa.
Ry. : Why?
Mama : You hair needs to be tidied.

Source: Subject's status upload, November 9, 2019.

The subject's experience in communicating with Ry shows that an autistic child can apply two-ways communication.

The social model that Ry's family uses to overcome Ry's interaction-communication character is while following Ry's style, the subject manages to make "rules" also for Ry to maximize the effectiveness of communication in interacting with others. The subject gives a detailed prologue to the people who will be communicating with Ry. Then she gives them two options. That is avoiding being chased by questions and fulfilling promises to Ry, or obeying Ry's communication style so that Ry is really finished with his curiosity or until Ry feels the question is finished. If it is a statement, Ry will ask for certainty that the other understands the statement and give him responds.

KESIMPULAN

People with autism communicate in a different way than most people. They repeat what they say and show a lack of empathy with what happens to their communicating partners.

Autistic people open the chat with questions, but they don't seem to like being asked. So if you start a conversation with an autistic person, you can start by describing something, so that autistic people have material to ask questions.

After asking a question, autistic people want an immediate answer; if they don't get it, they'll keep chasing the answer they want. So really, the questions being asked are more about confirmation or approval than they think. If the answer doesn't match what they think, autistic people will backtrack the question to get an answer that matches what they thought before. The debriefing continues until everything that is thought has been approved by the other person. Such a pattern can be continued by the interlocutor exploring as much as possible what is on the autistic person's mind, then offering a compromise of several appropriate responses and there is no need to postpone responses whose truth is not in line with what he is saying. autistic person thinks It is better to say 'I can't keep' or say 'none' than to make promises that are difficult for other people to keep for people with autism.

This still requires more detailed research and collecting as much experience as possible in communicating with autistic people who have different characteristics.

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