

Contestation with the Bio-Power in Normalizing Process: The Life Experiences of Families with Autistic Children

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ABSTRACT

This study aimed to study the striving for normalcy of families with autistic individuals by using Foucault's postmodern framework of disability and the bio-medical model of autism. The methodology was a qualitative study that emphasized a participatory approach and in-depth interviews that focused on the intersubjectivity of meanings of autism. The findings indicated that the mainstream explanation of autism was based on a bio-medical model, viewing autism as an impairment to be corrected by medical intervention. Families hoped that medical treatment would provide normalization processes resulting in their children being able to study in an inclusive educational system. Many families had experienced dealing with abuse of authority, stigmatization, and discrimination. Some families had suffered from, and were willing to comply with, the requirements of professional authorities for a while, before refusing further intervention. This study argued that the biomedical model does not provide the absolute answer to caring for the autistic individuals and their families. This study recommended a more humanistic approach throughout the therapeutic process and social understanding to create an inclusive society by accepting the identity of autistic individuals and giving them the opportunity to present themselves as they are, even though their deficit cannot be corrected.

Keywords: autistic, biomedical model, bio-power, contestation

บทคัดย่อ

การศึกษานี้มีวัตถุประสงค์เพื่อศึกษาการดิ้นรนสู่ความเป็นปกติ ในประสบการณ์ชีวิตของครอบครัวออทิสติกโดยใช้กรอบแนวคิดความพิการหลังสมัยใหม่ของฟูโก้ วิวิธวิทยาเป็นการศึกษาเชิงคุณภาพใช้การสังเกตแบบมีส่วนร่วม และการสัมภาษณ์เชิงลึกที่เน้นประสบการณ์ร่วมกัน ผลการศึกษพบว่า ในกระแสหลักให้ความหมายของออทิสติกตามคำอธิบายทางการแพทย์ โดยมองออทิสติก

เป็นเรื่องของความบกพร่องที่ต้องแก้ไขให้ใกล้เคียงกับภาวะปกติมากที่สุด กระบวนการทำให้เป็นปกติจึงเป็นความหวังของครอบครัวที่ต่างดิ้นรนเพื่อให้ลูกได้รับการรักษาและเรียนร่วมกับเด็กปกติ หลายครอบครัวต้องเผชิญกับอำนาจ การตีตราและการกีดกัน บางครอบครัวยอมทนทุกข์และให้ความร่วมมือในการรักษาและท้ายที่สุดก็เลือกที่จะปฏิเสธกับการรักษา รูปแบบทางการแพทย์จึงไม่ได้เป็นคำตอบเบ็ดเสร็จสำหรับการดูแลออทิสติกและครอบครัวเสมอไป การศึกษานี้เสนอให้คำนึงถึง

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ความเป็นมนุษย์ในกระบวนการรักษาและในระดับสังคมเพื่อสร้างเสริมการอยู่ร่วมกันในสังคม ด้วยการยอมรับและเข้าใจความเป็นตัวตนของบุคคลออทิสติก แม้จะไม่สามารถแก้ไขความบกพร่องก็ตาม

คำสำคัญ: ออทิสติก รูปแบบทางการแพทย์ อำนาจทางการแพทย์ การต่อต้านขีดขึ้น

INTRODUCTION

Given the mainstream meaning through the medical model, autism is defined as “being disability” categorized in the group of Pervasive Development Disorders in the Diagnosis and Statistical Manual (DSM-IV TR). “Autism disability” means that a person has restriction in routine activities or social activities as a result of impairments in social interaction development, language, and communication impairments, as well as behavioral and emotional impairments (Development of Quality of Life for Disabled Persons Act, B.E. 2550). The cause of these impairments was determined to be from genetic factors and a neurological deficit (Gurney et al., 2003; Limprasert, 2008; Silverman & Brosco, 2007; Wing & Potter, 2002; Yeargin-Allsopp et al., 2003). These diagnosis criteria have been used and accepted worldwide through the explanation of a medical model. Since the medical concept has a strong influence in categorization—such as normality/abnormality, abled/disabled—it then becomes a mainstream part of discourse that influences other perspectives, including being reflected in remedies and systems of education.

Based on the postmodern perspective, bio-power is described as the ability to “foster life or disallow it to the point of death” (Foucault, 1990, p. 138). Foucault divides bio-power into “two basic forms; the first is described as “a disciplinary power or an anatomo-politics of the human body, the purpose of which is the subjugation and administration of the bodies”. The second is seen as “regulatory controls or a bio-politics of the

population, the aim of which is the ‘calculated management of life’” (Foucault, 1990). This can be understood as the power over the body, operating through individuation—tailoring to individuals in isolation of the collective population.

Disability is constructed and given a definition through truth and knowledge within the context of scientific discourses. Medico-legal practices were controlling and made disabilities a common issue (Tremain, 2006). Therefore, the naming and framing of disabilities meant they were treated as objects in the knowledge and power contexts of biomedicine. Moreover, there was a reproduction of binary opposition discourse between ‘normality’ and ‘disability’ until it became the accepted thing. Disabled people then were marginalized. Society tended to ignore the capacity and capability of disabled people by linking their abilities to the image of impairments. As such, the disabled were devalued, and were portrayed as non-standard products, as damaged and flawed goods (Phillips, 1990)

Therefore, ‘normality’, not disability, was what society considered desirable and expected of people. Medical practices and the education system in turn were expected to help families to attain this expectation. Medical remedies emphasized correcting impairments and normalizing individuals, so that they would become as close to normal as possible. An inclusive education system supported the medical assertion of restoring capacities, improving the development, adapting proper behavior as well as training the autistic individuals to have social skills to study with non-disabled children.

This research study aimed at exploring the life experiences of the families with autistic children that were undergoing the process of normalization. A phenomenological approach was utilized to analyze the meanings and responses of the respondents through their subjective lens. These findings would contribute significant data in health care development planning, and educational

reformation.

Research methodology

This research study was qualitative and focused on participant observation and narrative interviews as the source of primary data. A sample of 23 autistic students in a special education school were involved in participant observation. Among these observed respondents, we applied purposive sampling and the snowball technique to conduct narrative interviews. The informants came from 14 families with autistic individuals aged between 12 and 17 years old. The families of the respondents were from the middle to lower socioeconomic strata of society, living in the urban and suburban areas of Lopburi and Singburi, where there were differences in educational levels and occupations.

This study gained ethical approval from the Human Research and Social Sciences Ethic Committee, Mahidol University. The informants volunteered to be part of the study and agreed to take part in the research by signing a consent form. They did this with the understanding that their personal information would be kept confidential. The researcher took both an etic and emic view of the research. The etic view was gained by searching for information and analysis of the perspective of the external person who looked into the life experience of the families. The etic view was also gained via interviews with teachers and school authorities who dealt directly with the respondents. The emic view was gained via objective participation in the life and world of the respondents. The use of intersubjectivity enabled the researcher to develop an understanding of meanings attached to the word “autism”, and learn about the lives of the respondents. The total time used to collect data in the field was 18 months.

Research findings

The majority of families who lived with autistic individuals subscribed to the mainstream medical paradigm of autism, which considered

autism as impairment in development, communication, and socialization, and that the impairment needed to be alleviated to approximate “normalcy” as much as possible. The normalization process, however, was an interplay of power, stigmatization, and exclusion that dominated both medical discourse and the cultural system.

Given meaning and striving for normalcy

In this study, autism had various different and fluid meanings. The image of autism still held in Thailand was attached to “Khun Poom”, the grandson of HM King Bhumibol Adulyadej who was autistic. There was also repetition from the media representing the positive aspects of autistic children as developmentally impaired but this impairment could be improved. A child with severe symptoms of autism would be called “mad” instead of “autistic”. This resulted in a lot of suffering for the families of such children. The following narratives have captured the subjective experiences of families with autistic individuals as they struggled with the intersubjective meanings attributed to autism as well as their obstacles towards normalcy for their autistic family members.

The story of Por. Por is a 17-year-old autistic adolescent. His father works in a state enterprise and his mother is a government officer. Their salaries are 100,000 baht per month (approximately US\$3,300). Por has received treatments continuously since he was three years old. However, his symptoms worsened. He went from being able to speak to only being able to make guttural sounds. He could not take care himself. Sometimes, he urinated and defecated in his trousers. He could not remain still and did not sleep well. When he was irritated and dissatisfied, he hurt people around him—he had bitten his mother three years ago. Por was treated with many medications and was prescribed conventional antipsychotic drugs for many years. He showed behavior such as drowsiness and being distracted as well as constantly salivating until teachers asked if he had

overdosed on drugs. He expressed his sexual desire by prostrating on the floor, smelling girl's shoes and masturbating until he had achieved ejaculation.

His parents did not believe in the spiritual path to cure his autism. They have been faithful to medical science and tried to follow the autistic treatment program. This choice was based on recommendations from the medical professionals who believed that if the autistic child could be trained before the age of five, the child would have more chance to be close to normal. This knowledge had influenced the parents in trying to search for treatments and education for the child. Thus, they took him to be treated at child psychiatry clinics in private and public hospitals. They often faced the questions *"Why didn't you do it? Why was your son getting worse?"* Furthermore, they could not go to a general hospital because their son would not remain still and made a lot of noise. They endured the blame of professionals and the discrimination of others.

Still, Por's parents took him to get treatment all the time. Every morning, his father would take him to a special school. In the evening, his mother would pick him up and take him to the Special Education Center for one and half hours of training and then they went home. During the semester break, they hired a teacher to train him at home during the day time. To date, no one has offered to specifically train him even though his parents can afford it. He was excluded from the behavioral treatment program due to the severity of his autism. However, his parents always blamed themselves for Por's lack of improvement.

At present, they are condemned and insulted due to Por's autism. People stare and whisper, describing his autism as "madness". The meaning of the term 'madness' is further emphasized by the recommendation of physicians that Por get treatment in an adult psychiatric hospital. Por's parents are very sad and distressed despite their best care. His father has coronary heart disease and had surgery 4-5 years ago. He said *"I could not die; I have a*

responsibility to take care of my autistic son". His mother plans to early retire to care for her son after he graduates from the special school. His father seemed to be disappointed and finally he said *"What shall we do, we have to accept the truth. We think we do our best, his mother puts her best efforts into taking care of him"*. Their expectations are for a rehabilitation program and public understanding for severe autism.

"Madness" is a traumatizing word. Nobody wants to be associated with "madness". In the life experience of Por's family, their suffering reflected society's perception of autism. In a society that defines human value by the ideation of sameness, those who are different or deviate from the normal standard would become abnormal. Por and other severely non-verbal autistic people were definitely devalued human beings according to their levels of difference or deviation. Por was tagged with the labels of autism and madness, accordingly. He and his family have been struggling with the meaning attributed to "madness". They have tried to push their son to be "normal" as much as possible to escape the stigma of "madness".

Contestation with the Bio-Power in normalizing process

'Normality', not disability, was considered as worthy of desire. Every family needed their children to be perfect physically and mentally. None of them wanted their children to be impaired and seen as a valueless person and social burden. To have normal children was an important indicator of a family's success. Also, the successes of children in learning, having careers and being respected were considered the success of the parents. Therefore, the success of children increased the self esteem and self actualization of the parents according to Maslow's Hierarchy of Needs (Wilson & Kneisl, 1996, p. 70). The families of the children with autism were willing to make all efforts and utilized all resources in the normalizing process. The following is an example.

The story of Notte. Notte was a thirteen year old autistic boy. His father was a physician and his mother was a nurse. They combined salaries amounted to 500,000 baht per month (approximately US\$ 16,700). Notte was diagnosed with autism and received all kinds of treatments available at that time from the famous specialists of child psychiatry departments e.g. pharmacotherapy to control undesired behaviors, speech therapy, sensory integration, behavior therapy, and hemoencephalograms (HEG). The traditional treatment of acupuncture was also used.

His mother shared that *“I had to do everything for my child though I was so stressed. As he was almost 4-5 years old at that time I really wanted the “graph shoot” (a positive increase in the graph that mapped Notte’s progress). I called the nurse to check for available time to train my son extra. I had to be patient. I had to surrender everything to have my boy being trained, no matter how much I had to pay.”* She spent a lot of money hiring the teacher from a foundation who worked in a famous private hospital. In school, she hired a special teacher to take care of him on a one-to-one basis. Every evening after school, she prepared extra exercises for her child to do. Notte trained hard, even during the semester breaks when he had to prepare himself for the next term. When he could not do the exercises or felt bored, he would twist his personal rope to release stress. However, he was not allowed to stop doing the exercise until all the exercises were finished. His life was being programmed to his mother’s will and her hope that *“Notte had to be in inclusive education. If he was in the special school, his development would regress just like other autistic children”*.

In the case of Notte’s family, it was obvious that the power of medical knowledge and negative representation of special education worked together in the process of normalization. Medical knowledge stated that if the autistic children had been diagnosed and received treatment as early as possible it would help the children have a better

prognosis and a high possibility of being normal (Noipayak, 2009). This was the medical text that relied on treatment and capacity restoration. This knowledge had unconsciously influenced the family’s thoughts. The family tried to search for treatments and therapists, though they had to face both the medical process and the commercial education system.

The story of Joy. In another example, Joy’s family was under similar circumstances of medical discourses as Nott’s and Por’s families. Joy’s family was middle class. Her parents work in a private factory and their salaries are 30,000 baht per month (approximately US\$ 1,000). They struggled with the treatment process for 8 years after Joy was diagnosed with autism. They tried to be good parents who surrendered to the power of knowledge. Joy’s mother stated that *“Many places provided treatment for autistic children, but it seemed that the therapists do not care, and understand children. They are not friendly. No matter how the children cried, they are forced to do as the therapists prescribe. It really hurts me. But I have to allow them to train my child as they have more expertise than us.”* She added: *“I used to be blamed by the speech specialist. Our daughter had not progressed in speech so they blamed us saying that we did not train her at home. Finally, they told us that our daughter is retarded. They said it in the neutral tone but hidden in it was blame. This made me feel even more stressed. I tried to think back and forth in my head, and decided I do not want my child to go to the therapy. I attempted to do as the therapists asked and was blamed for eight years. After that, I could not stand still anymore. I had already stopped training for four years. Nothing is better.”*

The contestation of power here becomes negotiation with power’s techniques, similar to the experiences of Joy’s and Por’s families. They suffered blame or surrendered to an inequality of power. After that they would be ignored and refused the treatment.

The families of Por, Notte and Joy struggled

to find the most effective treatments for their children. Notte could study in the mainstream school, while Por studied in a special school and Joy stayed at home. The treatment results did not produce their expected outcomes. Both Por and Joy could not speak. Por's behavior had regressed and was he stigmatized as a person with 'madness'. Both families who were faithful to medicine had been disappointed and had lost hope. The medical model, as a disease cure framework, seemed to be meaningless to these families. This reflected only that the medical model does not provide proper care for autism.

DISCUSSION

Bio-Power and stigmatization in normalization

The life experiences of families who have children with autism clearly display the bio-power of medical knowledge and public understanding in the process of normalization over the body of autistic individuals. Parents expect their autistic child to achieve a level of normality rather than be labeled as 'autistic' or be thought of as suffering from 'madness'. From the post-modern perspective, this naming of things is about language, which in turn is about the use of power that is invisible but exists everywhere. Power is not an object that can be given from one to another, but it exists only through the exercise of power (Foucault, 1981). Power is pervasive and penetrates into the self, prompting one to constantly check oneself (self-surveillance), until it becomes an integral part of one's identity, i.e., one's *doing* has become one's *being* (Valentine, 2006). In the daily life of a family with an autistic child, the power of knowledge has penetrated into their identity. They have surrendered to the power of knowledge that treats their children as a "docile body". For example, in Note's family, his mother has medical knowledge and uses it to control the treatment and lifestyle of her son all the time, as if he were a programmed robot. Moreover, she takes pride in subjecting herself to the medical discourse

and the education system. On the other hand, Joy's parents were initially willing to subscribe to the medical discourse but when the treatment result was not to their expectation, they chose to disregard the naming of autism and turned instead to positively accept their child as she is.

Medical knowledge claims that autistic children should be treated and be able to speak before the age of five, otherwise their opportunities to speak decrease over time (Noipayak, 2009). Such power of medical knowledge has been disseminated to parents with autistic children and drives them to seek treatment and inclusive education. When the families take their children to the treatment process, they often meet with the exercise of power from the medical and therapeutic authorities at every level. This exercise of power comes in the form of blaming the family and domination through knowledge. Based on Foucault's perspective, power is not exercised in terms of violence but it is the exercise of unequal power (Foucault, 2006).

In terms of the autistic discourse practice, the specialists often are in a higher position than the clients. The specialists have authorized power as they are knowledgeable and this is an example of what Foucault pointed out when he said that "Power is all on one side". This means that the knowledge power has created a state of docility in the clients. They have to accept the medical orders which are considered a necessity of the treatment. This exercise of power claims that power is over everything or the assertion of omnipotence (Foucault, 2006). Moreover, the power relationship is created from the knowledge pattern and becomes power of knowledge that governs the docile body. The bodies of families with autistic children are situated in the medical discourse unavoidably.

In postmodern society, disability is given multiple meanings. To have impairment is not necessarily unhealthy; disabled people are not actually ill. The truth about medical reality is questioned. The contestation of power here becomes a negotiation with power's techniques as in the

experiences of Joy's family. Though they had to accept suffering by being blamed or had surrendered to the power for a while, they were still ignored and refused the treatment finally. However, many families realized the necessity of the treatment due to their expectation of normalcy, such as in Notte's Family. They would negotiate with the powers by changing the form of the relationship to be more equal. They presented themselves as knowledgeable on the same level as the therapists in order to reduce overlapped power. However, many families cannot neutralize power. They were still looked down on and blamed as if the child's autism was their fault, such as with Por's family. The therapists refused to listen to the problems, and instead judged and suppressed the family using only the medical perspective. The families had to accept their suffering within the medical exercise of power. The families also had medical knowledge to provoke their minds all the time.

Consideration of the medical model of disability

"To be normal" in the series of medical explanations is based on the medical model of disability that considers disability as an individual deficiency. This model focuses on preventing, healing, and restoring the deficiency. According to this study, the families accepted that their children were deficient and needed to be healed. Meanwhile, the families confronted suffering from society and had to struggle to be free. From their experiences, taking care of autistic children was not based only on the medical model of disability; it must also be combined with social aspects. This meant the families still needed the experts to correct the impairment of their autistic children by arranging the therapeutic program and managing the social aspects of their lives.

Most research on autism in Thailand has tried to find methods of stress reduction for the families. All were in the framework of the medical model of disability, focusing on working individually not socially, i.e. giving consultation in

groups (Hongngam, 2003), promoting the self-efficacy of caretakers (Puttahraksa, 2005), and having many treatment modalities (Mongkholsirigul, 2003; Pheephimai, 2004; Pisek, 1999; Wongsalee, 2005). A considerable amount of the research was executed within the frame of the medical model of disability; however, there were some researchers who attempted to consider the problems which were caused by the experts, for example, problems in providing behavioral therapy. Those findings indicated that the therapists focused on changing the behaviors of children without considering the families. They did not understand the limitations of the parents in the roles of special teacher and caretaker. They were tired and stressed from nurturing their children with problematic behaviors all the time. Some families were in conflicts while other families were broken. It has been recommended that the therapists should be concerned with the family aspects combined with behavioral therapy (Harris, 1984). The family-centered practice existed only in principle, not in practice. In principle, the therapists must transfer the power in decision making and practice to the families. However, the therapists mainly used their own decision making instead. They did not respect the decision making of families (Dodd, Sagers, & Wildy, 2009).

Although the medical model of disability was necessary for taking care of autistic children, this study indicated that there was the exercise of power in medical discourse. The results from this study showed that there was inappropriately administrated psychotropic medication therapy. Some autistic individuals had received prolonged treatments of medication without concern for the long-term side effects. Behavioral therapy, which focused on the outcomes, overlooked the humanity of families and their children. If the children's symptoms did not meet the outcome standard, their families would be blamed for ignoring the practice. Family members would be blamed if a child over the age of five could not meet the desired outcome

of speech therapy. Many professionals refuse to train autistic individuals who are growing into adolescence, so that these individuals seem to be excluded from the treatment process. The families of autistic children have to contest with power, stigma, and discrimination throughout the treatment process. This study proposed that although knowledge and proficiency were important for the therapeutic process and rehabilitation for autism, there needed to be the development of humanizing health care services that included moral treatment, ethical drug administration, and respecting the personhood of autistic individuals and their families.

Having lived with autistic individuals, the researcher agrees with the recommendation of ‘Social construction of disablement interpretation’ (Smith, 2010). This model focuses on both the individual and social aspects of therapy and medical assistance for persons with autism. The concept believes that disability is an individual’s impairment and the negative social construction affected the identity of disabled persons. This study found that knowledge produced and reproduced the negative image of autism. In medical discourse, an autistic was viewed as a disabled and dependent person who needed to be treated. The socio-cultural discourse viewed persons with severe-functioning autism as individuals who could not control themselves or they were referred to as individuals who suffered from ‘madness’. These constructions of knowledge worked together until the image of autism became one of an individual who was incompetent and thus an image of a person who was devalued became a reality. The negative image of autism needs to be changed. The model then should focus on correcting the impairments of persons with autism while promoting the identity of the individual in a de-stigmatizing environment.

RECOMMENDATIONS

Applying the concept of ‘the Social construction of disablement interpretation’ is

necessary in caring for persons with autism. On the individual level, a sense of humaneness should pervade the therapeutic process with an understanding of the person’s feelings, accepting their identity, and giving them the opportunity to present themselves as they are, even though their autism could not be corrected. On a social level, the human value of autistic persons is concerned with reducing the exclusion of these persons from society.

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